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Authors
Wu, E
Barnes, DE
Ackerman, SL
et al.

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Eveline Wu\textsuperscript{ab}, Deborah E. Barnes\textsuperscript{cde}, Sara L. Ackerman\textsuperscript{f}, Jennifer Lee\textsuperscript{a}, Margaret Chesney\textsuperscript{a} & Wolf E. Mehling\textsuperscript{ag}

\textsuperscript{a} Osher Center for Integrative Medicine, University of California, San Francisco, CA, USA
\textsuperscript{b} Department of Counseling Psychology, California Institute of Integral Studies, San Francisco, CA, USA
\textsuperscript{c} Department of Psychiatry, University of California, San Francisco, CA, USA
\textsuperscript{d} Department of Epidemiology & Biostatistics, University of California, San Francisco, CA, USA
\textsuperscript{e} San Francisco Veterans Affairs Medical Center, San Francisco, CA, USA
\textsuperscript{f} Department of Social & Behavioral Sciences, University of California, San Francisco, CA, USA
\textsuperscript{g} Department of Family and Community Medicine, University of California, San Francisco, CA, USA

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Preventing Loss of Independence through Exercise (PLIE): qualitative analysis of a clinical trial in older adults with dementia

Eveline Wu\textsuperscript{a,b}, Deborah E. Barnes\textsuperscript{c,d,e}, Sara L. Ackerman\textsuperscript{f}, Jennifer Lee\textsuperscript{a}, Margaret Chesney\textsuperscript{a} and Wolf E. Mehling\textsuperscript{a,g}*

\textsuperscript{a}Osher Center for Integrative Medicine, University of California, San Francisco, CA, USA; \textsuperscript{b}Department of Counseling Psychology, California Institute of Integral Studies, San Francisco, CA, USA; \textsuperscript{c}Department of Psychiatry, University of California, San Francisco, CA, USA; \textsuperscript{d}Department of Epidemiology & Biostatistics, University of California, San Francisco, CA, USA; \textsuperscript{e}San Francisco Veterans Affairs Medical Center, San Francisco, CA, USA; \textsuperscript{f}Department of Social & Behavioral Sciences, University of California, San Francisco, CA, USA; \textsuperscript{g}Department of Family and Community Medicine, University of California, San Francisco, CA, USA

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Objectives: Preventing Loss of Independence through Exercise (PLIE) is a novel, integrative exercise program for individuals with dementia that combines elements of different conventional and complementary exercise modalities (e.g., tai-chi, yoga, Feldenkrais, and dance movement therapy) and focuses on training procedural memory for basic functional movements (e.g., sit-to-stand) while increasing mindful body awareness and facilitating social connection. This study presents analyses of qualitative data collected during a 36-week cross-over pilot clinical trial in 11 individuals.

Methods: Qualitative data included exercise instructors’ written notes, which were prepared after each class and also following biweekly telephone calls with caregivers and monthly home visits; three video-recorded classes; and written summaries prepared by research assistants following pre- and post-intervention quantitative assessments. Data were extracted for each study participant and placed onto a timeline for month of observation. Data were coded and analyzed to identify themes that were confirmed and refined through an iterative, collaborative process by the entire team including a qualitative researcher (SA) and the exercise instructors.

Results: Three overarching themes emerged: (1) Functional changes included increasing body awareness, movement memory and functional skill. (2) Emotional changes included greater acceptance of resting, sharing of personal stories and feelings, and positive attitude toward exercise. (3) Social changes included moe coherent social interactions and making friends.

Conclusions: These qualitative results suggest that the PLIE program may be associated with beneficial functional, emotional, and social changes for individuals with mild to moderate dementia. Further study of the PLIE program in individuals with dementia is warranted.

Keywords: Alzheimer’s disease; other dementias; general; qualitative methods

1. Introduction

A growing body of literature suggests that physical exercise has beneficial effects for physical (Pahor et al., 2014) and cognitive (Angevaren, Auferdemanke, Verhaar, Aleman, & Vanhees, 2008) functions in healthy older adults as well as in individuals with cognitive impairment (Heyn, Abreu, & Ottenbacher, 2004; Heyn, Johnson, & Kramer, 2008). In addition, several recent clinical trials (Pitkala et al., 2013; Rolland et al., 2007; Teri et al., 2003) and systematic reviews (Blankenshoof et al., 2010; Potter, Ellard, Rees, & Thorogood, 2011) have demonstrated beneficial effects of exercise in individuals with dementia. A recent meta-analysis identified 16 randomized, controlled trials of exercise interventions in 937 individuals with dementia, finding evidence that exercise improves the ability to perform basic activities of daily living, such as eating, dressing, bathing, using the toilet, and transferring from bed to chair (Forbes, Thiessen, Blake, Forbes, & Forbes, 2013). However, the effects on the cognitive function and quality of life in individuals with dementia were less consistent.

A small number of feasibility and the case studies of non-conventional exercise in people with dementia, such as yoga (Gallego, Alexey, Ma Clara, Lina, & Reyes, 2011), tai chi (Burgener, Yang, Gilbert, & Marsh-Yang, 2008; Yao, Giordani, & Alexander, 2008), Feldenkrais (Ann, 2006), and dance movement therapy (Nyström & Lauritzen, 2005), have suggested improvements in functional abilities, in emotion and/or in cognition. In addition, a few large-scale studies of tai chi in healthy older adults have found improvements in cognition measured by quantitative methods including Test B of the Trail Making Test, clock drawing, and Minimal Mental Status Examination (Chang, Nien, Tsai, & Etnier, 2010), better sleep quality (Irwin, Omlstead, & Motivala, 2008; Li et al., 2004), fewer falls (Li et al., 2005), and reduced fear of falling (Wolf, Barnhart, Ellison, & Coogler, 1997), and improved overall well-being, assessed by a set of interview questions (Kutner, Barnhart, Wolf, McNeely, & Xu, 1997).

There are several reasons to consider particular non-conventional exercise practices — often referred to as mind-body therapies (Mehling et al., 2011), mindful exercise (La Forge, 2005), somatic education (Batson & Schwartz, 2007; Hanna, 1988), and mindful movement (Payne & Crane-Godreau, 2013) — as potentially

*Corresponding author. Email: mehlingw@ocim.ucsf.edu

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beneficial for people with dementia, either alone or in combination with the conventional exercise. First, these practices use physical movement sequences that begin simply and progress in complexity, with the goal of learning new movement skills to help people with dementia maintain functional independence related to daily activities. Second, these practices are described as ‘a matter of looking at oneself from the “inside out,”’ where one is aware of feelings, movement and intentions, rather than looking objectively from the outside in. . . . focusing on an inner experiential body, not on a body as an objective entity or mechanical instrument’ (Hanna, as cited in Green, 2002, p. 114). Functional movements are introduced in ways that value the meaning, emotion and sensory experience of movement, and link function with cognition. Third, they use a non-judgmental teaching style that emphasizes experiential exploration of sensation, breathing, and movement. This may be calming for individuals with dementia, who may experience feelings of anxiety or confusion and distress when trying to meet performance demands.

Finally, complementary exercise approaches may benefit people with dementia through systems of motor learning (Connors, Galea, Said, & Remedios, 2010; Wright, 2000) and implicit memory (Gallego et al., 2011; Yao et al., 2008), systems that allow people with dementia to learn new behaviors, even when their explicit memory, involving direct recall of facts or events, declines (Squire, 2004). Implicit memory is involved when past experiences influence cognitive and emotional associations, perceptions, and behavior without conscious recall of that experience (Sabat, 2006). Procedural, or motor, memory is the ability to learn and recall functional motor responses appropriate to specific situations. Various forms of procedural (Eslinger & Damasio, 1986) and implicit learning (Eldridge, Masterman, & Knowlton, 2002) have been shown to remain intact in early-stage dementia and have been reviewed and recommended for clinical motor learning interventions (Bayles & Kim, 2003; van Halteren-van Tilborg, Scherder, & Hulstijn, 2007).

However, while some studies have shown benefits of complementary exercise interventions for individuals with dementia, little has been done to understand their lived experience when undergoing a mind–body exercise program. One qualitative study of tai chi used focus groups of individuals with dementia (Gibb, Morris, & Gleisberg, 1997) and, therefore, was limited by recall. However, we believe that participant observation and interviews with caregivers may be more suitable methods for such investigation, are particularly suited to examine the nature of the participants’ experience (Gibson, Timlin, Curran, & Watts, 2004; Moore & Hollett, 2003), and have been used to examine implicit memory and social interactions in people with dementia. (Kontos, 2004; Sabat & Lee, 2012).

Given that multicomponent interventions are associated with greater improvements in the physical function in older adults with dementia (Blankevoort et al., 2010), we hypothesized that an exercise program that combines and integrates elements from conventional exercise with principles and movements from mind–body approaches would have wide-ranging beneficial effects in individuals with dementia. We developed an innovative integrative exercise program for individuals with mild to moderate dementia entitled Preventing Loss of Independence through Exercise: PLIE. The observational study reported here was based on instructors’ and research assistants’ fieldnotes collected during a pilot clinical trial (quantitative results reported separately) in 11 individuals with mild to moderate dementia attending an adult day program for people with Alzheimer’s and other dementias in San Francisco, CA (clinicaltrial.gov registry number NCT01371214). Our aim was to use qualitative inquiry to examine how the intervention influenced participants’ lived experiences—in particular, their movement functions, relationship to their body, affect, social interactions and the use of implicit memory.

2. Methods
2.1. Development of Intervention

The PLIE program was developed in a two-year process that included a comprehensive literature review; observations of ongoing local exercise classes for individuals with dementia; interviews with experienced exercise instructors working with individuals with dementia; and a day-long video conference with researchers from the US and Canada, as well as expert instructors in tai chi, yoga, Feldenkrais somatic education, physical therapy, occupational therapy, and dance movement therapy, who had applied these methods in individuals with dementia, and were known in the San Francisco Bay Area or through publications in Alzheimer’s disease-related publications throughout the US (see Acknowledgements). Three authors (EW, DB and WM) evaluated the video recording of this conference and established a program framework integrating key components from each exercise tradition. EW, a certified Feldenkrais instructor, assembled a written exercise protocol, which the team further refined through small group meetings with expert instructors. The PLIE exercise program followed several general principles presented in greater detail in Barnes et al. (submitted for publication) and had a basic class structure that stayed consistent throughout the program. Briefly, the teaching principles included repetition with variation; progressive, functional movements; participant-centered goal orientation; slow-paced and step-by-step instruction; body awareness, mindfulness, and breathing; social interaction and positive emotions (see Table 1).

The basic 45-minute PLIE class structure (see Table 1) began by greeting each person by name to create a respectful and warm group environment (5 minutes). Instructors taught a 5-minute ‘body awareness sequence’, in which participants were invited to touch, rub, or pat their arms, legs, hands, head, or belly, while bringing attention to their bodily sensations. Instructors’ suggestions included: ‘notice your arms’; ‘can you feel your hands?’; ‘notice what you feel!’; ‘how do your legs feel?’ Instructors also guided participants through circular arm movements derived from tai chi with vocalized
Table 1 (a). Teaching principles for PLIE program.

<table>
<thead>
<tr>
<th>Teaching principles</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Repetition with variation</td>
<td>The same basic structure of events is repeated in each class. Movements do include variations, introduced over time, included in program manual. Instructors also include variations introduced by participants.</td>
</tr>
<tr>
<td>2. Progressive, functional movements</td>
<td>Instructors introduce movements involving extending and coordinating arms, legs, and torso, that lead from simpler movements building slowly toward more complexity and variation, from sitting to standing and walking.</td>
</tr>
<tr>
<td>3. Slow pace and responsive, step-by-step instructions</td>
<td>Instructors model movements at a slow pace with attention to the quality and form of the movement. During exercises, instructors direct the participants’ attention to the participants’ ability level at a given day.</td>
</tr>
<tr>
<td>4. Participant-centered goal orientation</td>
<td>A goals assessment is performed before beginning the program. Participants are motivated by relating movements to personal interests and goals.</td>
</tr>
<tr>
<td>5. Body awareness, mindfulness, and breathing</td>
<td>Participants are directed to bodily sensations while tapping, touching arms, feet, legs, torso, etc. Classes include frequent rests during which participants pay attention to breathing and body sensation.</td>
</tr>
<tr>
<td>6. Social interaction</td>
<td>Participants sit in a circle where they can all see each other. Many movements involve touch, interaction, and coordination of movement with others, such reaching across the circle to touch hands or elbows, or standing in a circle holding hands and walking side to side. When participants share experiences, instructors adjust class tempo and incorporate participants’ comments into instruction.</td>
</tr>
</tbody>
</table>
| 7. Positive emotions, non-judgmental teaching style | The program promotes positive emotions by creating a warm, loving, non-judgmental, non-coercive environment in which participants are encouraged to move with comfort. Brief musical selections are used to enhance positive emotions. Instructors invite participants to share appreciations asking ‘what do you appreciate?’.

Table 1 (b). Description of PLIE class structure.

<table>
<thead>
<tr>
<th>Class structure</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Greetings by name; 5 minutes (each class)</td>
<td>To create a respectful and warm group environment.</td>
</tr>
<tr>
<td>II. Body awareness sequence; 5 minutes (each class)</td>
<td>Same sequence every class involving body patting/rubbing, circular arm movement with a vocalized exhalation sound. Then shaking hands and stomping feet.</td>
</tr>
<tr>
<td>III. Exercise sequences; 30 minutes (varies from class to class)</td>
<td>Slightly varied sequence each week, repeated and selected from 20 exercises, adapted from tai chi, yoga, and Feldenkrais, and performed on chairs.</td>
</tr>
<tr>
<td>3. Standing sequences</td>
<td>Weight shifting, stepping side to side, forwards and backwards. Taught only with group as ready, may include arm movements, holding hands.</td>
</tr>
<tr>
<td>IIIA. Integral components of all exercise sequences</td>
<td>Some exercises involve reaching towards others, touching, coordinating movements. ‘Poof hands’, brief movements to music with feet.</td>
</tr>
<tr>
<td>Frequent rests</td>
<td>Instructors introduce rests for periods of up to 1 minute between movement sequences, with mindful attention to body and breathing.</td>
</tr>
<tr>
<td>Music</td>
<td>Music is used briefly for short periods towards the end of a class.</td>
</tr>
<tr>
<td>IV. Closing (repeat opening and appreciations); 5 minutes, each class</td>
<td>Repeat of initial body awareness sequence of body rubbing and arm circle. Instructors then ask group openly, ‘what do you appreciate?’ with no pressure to respond. Resting and goodbyes follow.</td>
</tr>
</tbody>
</table>

exhalations of ‘ohhh’, ‘ahhh’ to bring attention to breathing. After a short period of rest, participants were guided through 30 minutes of PLIE exercises, consisting of a series of 12–15 integrated conventional and complementary movement sequences that increased in complexity as the course progressed. Movements included seated upper and lower body movements; sit-to-stand sequences; standing weight shifting; and stepping side-to-side or forward-and-backward sequences. PLIE instructors verbally guided participants to attend to their bodies while moving, and added frequent rests with mindful attention directed to bodily sensations and breathing between exercise sequences. Each class ended with a repetition of the initial 5-minute body awareness sequence, and a period of resting with an invitation to share appreciations with the group by instructors asking: ‘Is there anything you appreciate?’

To include respect for participants and introduce positive emotion into functional activity, PLIE instructors encouraged participants to join or rest as they wish, refrained from correcting participants’ mistakes or comparing individual performance, and promoted a joyful...
loving presence through verbal and non-verbal communication of positive emotion. To promote the successful execution of movements, and reduce confusion, instructors encouraged participants to move slowly and adjusted their instructional tempo by observing participants’ expressions of comfort or discomfort. Instructors combined the physical modeling of movements with expanded verbal descriptions, sensory guidance through touch, and visual cues.

PLIÉ incorporated a goals orientation by instructors conducting initial phone interviews with caregivers to assess participants’ interests, background and goals. Instructors integrated individual participants’ interests into movement activities to make them personally meaningful.

PLIÉ also sought to engage participants in social interaction within the context of class activities. Participants were asked to sit in a circle to promote interaction. Specific exercise sequences included holding hands and moving together, and gestures encouraging interaction. Sessions also included playful activities, such as participants popping hands open in the direction of others, taking turns and saying ‘poof!’, and the use of music, including participants’ favorite songs, for several minutes each week. Instructors invited participants to describe their experiences while exercising.

We obtained Institutional Review Board approval and conducted an 8-week testing phase led by EW to further refine the program. The subsequent trial, in which this qualitative study was embedded, consisted of two 18-week phases, with one group crossing over from intervention to follow-up and the other from wait-list control to intervention. The length was suggested as necessary by the consulting experts attending the day-long video conference. Classes were conducted between November 2011 and August 2012 by EW, JL, both certified in the Feldenkrais method, and a third instructor (Deborah Marks (DM)) who is certified in Rosen Method somatic education. The three instructors hired for this study had no involvement with the day care center prior to teaching this intervention. The intervention included four home visits, where instructions transcribed from caregivers’ verbal report during bi-weekly phone check-ins (e.g. ‘How are the exercise classes with ___ going.’ ‘Has ___ made any comments about things s/he enjoys about the class?’ ‘How about things s/he doesn’t enjoy?’); (2) transcribed video-recordings of class sessions in weeks 1, 14 and 18 in phase II; and (3) written observations of participants’ behavior prepared by two outcomes assessing research assistants (blinded to group allocation) during weeks 0, 18, and 36 in phase II.

Potential bias included the instructors’ expectations regarding the value of bodily awareness according to their training; however, no instructor had previous experience or expectations teaching this type of intervention to people with dementia that integrated many different types of practices. Only one instructor (DM) had worked previously with individuals with dementia.

2.3. Data collection

Qualitative data for this study primarily consisted of fieldnotes, including: (1) log entries by exercise instructors after each class session, organized into four categories of observations: (a) participants’ movements, (b) comments made by participants about movements, (c) impressions of participants’ experiences, and (d) general observations and (2) narrative reports prepared by instructors after each class and after home visits. The narrative reports were designed to facilitate an ongoing open process of observation, but instructors were not expected to remember every detail from each class session. The reports were discussed in weekly team meetings between exercise instructors and investigators and were used to guide instructors’ responses to the comments, movements, and pacing of study participants in subsequent class sessions. The process of writing fieldnotes after each class and sharing these during weekly team discussions, which frequently challenged and informed interpretations of participants’ behavior, provided nuanced information about class activities and enabled instructors to engage more reflexively in the research process.

These observations were complemented by three additional sources of data: (1) responses to open-ended questions transcribed from caregivers’ verbal report during bi-weekly phone check-ins (e.g. ‘How are the exercise classes with ___ going.’ ‘Has ___ made any comments about things s/he enjoys about the class?’ ‘How about things s/he doesn’t enjoy?’); (2) transcribed video-recordings of class sessions in weeks 11, 14 and 18 in phase II; and (3) written observations of participants’ behavior prepared by two outcomes assessing research assistants (blinded to group allocation) during weeks 0, 18, and 36 in phase II.

Potential bias included the instructors’ expectations regarding the value of bodily awareness according to their training; however, no instructor had previous experience or expectations teaching this type of intervention to people with dementia that integrated many different types of practices. Only one instructor (DM) had worked previously with individuals with dementia.

2.4. Sample

Twenty-two people with dementia were recommended by staff at the Alzheimer’s day facility and recruited by telephone or mail. Inclusion criteria were aged 55 years or older, English language fluency, and participation in the day facility’s program at least two days per week. Twelve participants (seven in Group 1, five in Group 2) and their primary caregivers provided assent or consent, respectively. One participant who gave assent to this study moved out of the area prior to receiving PLIÉ. Therefore, this study was based on 11 participants (pseudonyms are during phase II, the groups switched, and Group 1 moved back to the regular exercise class while Group 2 participated in the PLIÉ program. Caregivers were contacted bi-weekly by instructors throughout the intervention to check for adverse events.
used for participants throughout this paper and are presented with demographic information in Table 2. Baseline Alzheimer’s Disease Assessment Scale (ADAS-Cog; Rosen, Mohs, & Davis, 1984) scores ranged from 13.3 to 34.6, averaging 22.9 (maximum range 0–70, with scores ≥18 indicating greater cognitive impairment). Nine participants were female, and two were male. Their diagnoses were Alzheimer’s dementia (n = 6), vascular dementia (n = 3), and unknown dementia (n = 2). Average age was 84 ± 5 years (range 78–96).

2.5. Analysis
The team interpreted the data using the constant comparative method, developing codes and themes inductively and iteratively (Strauss & Corbin, 1990). First, EW developed a set of codes based on the repeated readings of the data. SA, who had not participated in the intervention or team meetings, then read the data and suggested new codes and modifications to existing codes. EW and SA met and reached consensus on the final list of codes and preliminary themes. EW then returned to the data, cross-referencing fieldnotes and video transcripts in order to identify recurring observations or changes in instructors’ perceptions over the course of the intervention. SA, EW and WM then discussed the data repeatedly and came to consensus on themes related to participants’ experiences in the PLIE sessions and possible impacts of the course on participants’ implicit memory and sense of well-being. Discrepancies and contradictions in the data were discussed, and consensus was reached on how to resolve or report them. A written narrative based on the themes was shared with all authors and revisions were made in response to their feedback. The revised narrative served as the basis for the results reported here.

3. Results

3.1. Functional changes: body awareness and movement memory

3.1.1. Greater awareness of bodily sensations
Instructors’ notes recorded after each class showed that all participants made spontaneous comments suggesting awareness of bodily sensations over the course of the program. While in the first week of class, about half of the participants did not appear to respond to the instructions to attend to bodily sensation, or commented on not feeling anything in particular; by the second or third week, all but two participants said ‘feels good’ or sighed deeply during rests and when the instructor directed their attention towards bodily sensations. In later weeks, all but one participant spoke about bodily sensations, such as the texture of their skin, muscular tension, the size of their belly, and the temperature of their hands. For example, during a class activity involving patting the legs, Doris looked at her legs and said ‘you’re waking up!’

These descriptions sometimes became more detailed as the program progressed. In week 8, for example, Lois touched her clavicle while moving her arm and announced with surprise that she could feel her bone move as she moved her shoulders. Roger, who in earlier weeks had claimed that he could not feel movement-related body sensations, later noted that his hips moved less than his shoulders when turning in his chair. However, not all bodily experiences were described as pleasant and included sensations of pain. Sometimes participants made comments about not wanting to feel their rounded bellies, nor of wanting to feel aches and pains.

3.1.2. Movement memory
Instructors’ notes suggested that, over time, participants appeared to gain procedural or motor memory for movements practiced in class, demonstrating familiarity with exercises in their actions, even when they did not recall previously attending class. For example, Jill sat down and asked what the class was for, even as she started moving her toes in and out in the style that was taught in previous classes. Instructors also observed participants spontaneously begin to perform the next movement in a sequence from previous classes without instruction. In another instance, an instructor asked Susan to move both knees in and out while sitting. She appeared unaware that she had only moved one of her knees. The instructor encouraged her to guide her knees with her hands. In later sessions, Susan was able to move both of her knees easily without using her hands. Similarly, Violet reported discomfort while she extended her arm to the side and behind her. The instructor suggested that she use her whole body in order to extend her arm more easily. In subsequent sessions, Violet continued to move in the way the instructor had previously suggested.

3.1.3. Increasing functional skill
Overall, participants were able to perform progressively more complex movements over the course of the program
and demonstrate increasing functional skill. Instructors’ notes and reports indicated that participants increased their range of motion over the course of the program in areas such as reaching down their legs, crossing their legs, and turning to look behind themselves. Instructors observed that participants initially could not get out of a chair without using their arms, but they became increasingly capable of doing so over time. Improvements in balance and walking were also remarked upon by several caregivers during home visits. However, Paul, Clara, and Susan had significant balance challenges at the start of the program and never gained the ability to safely walk independently. Also, some improvements fluctuated between sessions, appearing and then receding, seemingly dependent on participants’ mood or energy level.

Eight participants made comments suggesting the awareness of improved movement capabilities and comfort. Two participants – Roger and Violet – rolled their shoulders in ways that instructors previously had observed were difficult for them, saying ‘This class is good for my body’. One said ‘I think this class is good for my hip’. Doris commented that she could reach to cut her toenails more easily. Other participants, however, showed little awareness of changes that instructors observed.

3.2. Emotional changes: personal meaning and stories

3.2.1. Acceptance of resting in the present moment – ‘To just be here’

Six participants seemed to instructors to exhibit impatience at the start of the program, whereas all increasingly exhibited enjoyment of class activities over time, including periods of rest with present-moment awareness. For example, Katrina sat upright on the edge of her chair during a rest in an early session, firmly asking ‘what’s next?!’ In later weeks, she relaxed back into her chair during rests. She often smiled, breathed deeply and commented about feeling ‘more peaceful’.

All except Paul at some point spoke about the experience of resting as a new, personally meaningful experience in relation to their life histories. For example, Lois told the instructor that the slow pace of the class was ‘helping to improve her condition’, which she then described as having trouble relaxing. She described discovering feeling pleasure in allowing her mind to wander during the quiet moments in the class. She stated, as did others, that she had spent most of her life worrying about others, and that it was nice to discover that she could take time for herself ‘to wander’. Others, like Clara, expressed enjoyment about not having to worry about the past or anticipate the future, ‘to just be here’ in the moment. However, three participants did not show enjoyment with resting until the last quarter of the program.

Four participants initially talked without relating the content to what others had said, seemingly disconnected and at random, whereas later they were able to focus internally during rest. Also, a greater inclination to fall asleep appeared to be one consequence of relaxation for Susan, Gwen, and Roger, who sometimes later awakened expressing they had needed to rest.

3.2.2. Personal stories with emotion

Eight participants spontaneously shared personal stories or songs during class sessions. These narratives appeared to emerge from the experience of moving and relating to others in class, and were initially accompanied by weeping and expressions of distress that instructors found emotionally moving. After sharing stories, sometimes repeating the same story during several subsequent sessions, participants appeared more at ease, joyful, and connected with others. For example, immediately after an exercise in which the class participants imitated an airplane with their arms, Katrina told of a death she witnessed in an airplane; she repeated the story during several class sessions, becoming less agitated with each telling. Eventually, she described a different, more pleasant memory of having offered a pillow to comfort an upset passenger. In another example, Violet heard a song, and cried as she recalled that as a young girl she had sung the song with her brother, who was now deceased. Afterwards, she appeared calmer, smiling warmly, rocking gently, with slow breathing, with increased eye contact and engagement with others.

Gwen frequently recounted a story about a long weekend excursion, which became richer in detail with each telling. Her daughter later expressed surprise that her mother remembered that much detail. Her daughter also reported that Gwen began sharing personal stories with her grandchildren, while participating in the PLIE program – stories she had not recalled previously.

3.2.3. Attitudes toward the PLIE program and exercise

At the start of the program, six participants expressed skepticism about the class and frequently asked about its purpose. They occasionally commented that the movements seemed unusual or silly. Two participants also seemed uninterested in exercise in general, and two negatively compared the class to sports that they had done when they were younger. Violet commented that she worked harder in her daily life at home, an assertion that was contradicted by her caregiver.

Over time, however, instructors noted that participants’ attitudes toward the classes changed and that all participants began expressing enjoyment and appreciation for the class. Six participants showed interest in performing these exercises at home. Susan asked repeatedly for home study materials. Arlene’s caregiver reported that he saw his mother lifting some small weights that she had never used before, as well as practicing getting in and out of a chair. Jill, who previously enjoyed long walks at home, and initially did not want to exercise with others at the center, began telling instructors during later home visits that she preferred to exercise with others at the center. Also, Roger, who frequently compared the program unfavorably with prior experiences with the conventional
exercise, commented at the final session, ‘maybe it’s not worthless’.

3.3. Social changes: interpersonal relationships

3.3.1. From anxiety to ease and coherence in interactions

Six participants initially demonstrated what appeared to be anxiety in the presence of others, such as nervous eye contact, reserved behavior, desire for physical distance, or verbal complaints; over the course of the program such behaviors diminished. During a home visit, an instructor observed Jill repeatedly asking a series of questions, forgetting she had done so, yet becoming increasingly agitated. When she performed movement exercises with the instructor and focused attention on her bodily sensations, Jill relaxed and stopped repeating the same questions. Instructors noted similar changes with others in class. Violet frequently kept her purse on her lap, or secured her purse strap under her chair, fearing that others, including her own daughter (observed during home visits and confirmed by daughter), might steal it. She started to take her purse off her lap as she became more engaged in moving with the group during classes. Over time, she stopped securing her purse strap under her chair and would often rest with her eyes closed, smiling broadly, expressing contentment and enjoyment of the company of other group members.

Participants also appeared to exhibit more coherent behavior and be more alert and responsive while performing exercises that involved group participation. For example, Susan, who fell asleep frequently during class, often awoke suddenly when asked to reach forward to touch hands as a group. In a similar exercise involving touching elbows, instructors observed participants spontaneously interact and offer creative suggestions to each other, whereas previously they had been less socially engaged and responsive.

Another example of increasing behavioral coherence involved playful activities. In the exercise involving popping hands open and saying ‘poof!’ to each other, instructors noted that in the first third of the program, participants often looked away, held separate conversations, did not respond to ‘poof!’ back to another participant until prompted by the instructor, or were late to respond. Over the course of several weeks, participants generally began to watch each other more alertly and seemed more attentive to their environment and each other. Instructors noted that participants — particularly Roger and Jill — needed less prompting to respond to movement instructions during the final weeks of the program. They took turns initiating movement, laughed and smiled, and conversed with each other more coherently and sensibly. Social interaction also appeared motivating. Jill who previously did not sing in class joined others in singing. The instructor commented in surprise that she had a beautiful voice. She replied, ‘Well, I never thought so when younger, so I didn’t speak up, but now, I’ve started to speak up more here, and I plan to more’.

3.3.2. Making friends, caring for others

Instructors observed that participants who were initially reserved, or hostile, with each other became more comfortable, appeared to make friends, and expressed a caring attitude for each other over the course of the program. For example, Clara, Lois, and Susan were very quiet during early class sessions. As the program progressed, they started engaging other participants with personal questions about themselves and their families. Arlene, who initially had difficulty in understanding class instructions and performing movements slowly, often expressed anger and left the room during the first several sessions. Clara and Katrina made sharp comments or facial expressions of dislike, including rolling their eyes, grimacing, or covering their ears, as she spoke. Over time, Arlene began to share personal stories and listen to the stories of others. One day Arlene and Lois together sang a song they both loved. From then on, Arlene smiled, listened, participated in the exercises more frequently, enjoying slow movements and rests, and spoke of having a friend she trusted in class. Other group members began to respond to her with greater kindness. When Arlene shed tears of empathy for Katrina’s story, an instructor noted being deeply touched because she found herself capable of caring for her more deeply. Likewise, Gwen’s caregiver noted her mother had previously been ‘self-absorbed’, and now to her surprise had started giving her back rubs at home and asking how she felt. The caregiver described Gwen as being ‘more like her old self’, generous and caring for others.

In early weeks participants seemed eager for class to end, and often asked when lunch would arrive. By the last third of the program many participants mentioned ‘enjoying just being here with each other’, and in final weeks participants lingered, and did not get up to leave, even when the instructor said repeatedly that the class was over. They sat smiling, looking at each other, appearing to be enjoying feelings, relaxing comfortably, and emotional connection. In a video-taped class, Jill said, ‘I appreciate being here with all of you. I look forward to this day. I’m home alone, and I think, I’ll be here with all these people’.

4. Discussion

PLIE is a novel program integrating conventional with complementary mind-body exercise to address the needs of people with dementia. This qualitative study of 11 individuals with mild-to-moderate dementia suggests that PLIE was associated with changes in participants’ behavior over time in domains involving physical function, emotion, and social relationships. Although the results were tempered with reports of variation among participants, these findings support and elaborate the quantitative results, which suggest that PLIE may improve physical performance, cognitive function and quality of life and reduce caregiver burden (Barnes et al., submitted for publication). Our observations reveal rich experiential aspects of the PLIE program for participants, which involve body awareness, movement memory, and meaningful connections with others, and are consistent with the view that PLIE utilized implicit memory systems to support
functional independence and improve the quality of life for these participants.

With regard to procedural memory, instructor observations suggest that most participants demonstrated an overall increased ability to perform functional movements, including a greater ability to sit and stand safely. Because participants appeared to be able to understand class instructions better when instructors paced activities slowly, the instructors had the impression that the slow pace of movements and step-by-step instructions may have contributed to their ability to learn. Implicit learning may have occurred in social interactions, as participants expressed an increasing valuation of their interpersonal connections. Participants also appear to have increased their trust in one another over time, which may have led to greater enjoyment of group exercise. With social engagement, participants appeared to relate more coherently and intimately with other participants, demonstrating greater empathy, reduced anxiety, and increased pleasure in the company of others. These changes were observed even when participants did not recall the class and frequently wondered about its purpose.

The greater ability of participants to enjoy the present-moment experience may be related to the emphasis on awareness of bodily sensations, a key aspect of complementary exercise approaches (Mehling et al., 2011). As participants attended to, and reported, bodily sensations and breathing, while moving more slowly, they showed less impatience and anxiety and expressed more pleasure and joy of ‘just being here with each other’ in the present moment. This suggests that the impacts of PLIE were related to social interactions within the group, and is consistent with research that has shown that people with dementia tend to experience less anxiety when thinking about present or past experiences, as opposed to future experiences (Duval et al., 2012), and the calming effects of mindful breathing (Burg & Michalak, 2011).

We were surprised to discover that experiences of moving and sensing in class appeared to lead participants to spontaneously share personal stories that evoked strong emotional responses. However, this outcome is consistent with proposals by motor development and clinical psychology researchers about the therapeutic benefits of mindful movement practices for implicit memory in general (Fogel, 2009; Van der Kolk, 2006), and for aging populations in particular (Rejeski & Gauvin, 2013). They have argued that mind/body therapies’ focus on bodily sensation – in particular proprioception (the sense of position and movement of the body in space) and interoception (the sense of the internal state of the body and its organs) – might be a way of access ‘implicitly known’ emotions related to past experience through sensory awareness of movements and associated feelings. This in turn may allow people to process and resolve lingering emotional experiences of past distress carried into present day life, and thereby be better able to relax and engage with others.

The observation that the quality of social engagement among participants increased over the course of the program deserves further discussion. Shared humor and interpersonal understanding, and exhibiting friendship, concern, and empathy for others, all appeared to increase for participants during the intervention. These behaviors have been defined as indicative of social cognition in individuals diagnosed with dementia (Sabat & Gladstone, 2010). Our findings add to prior reports that greater engagement in social activities was correlated with reduced cognitive decline for healthy elders when combined with physical activity (Bennett, Schneider, Tang, Arnold, & Wilson, 2006).

Furthermore, observation of the participants in the PLIE program seemed to confirm reports that people with dementia retain a sense of self and identity (Caddell & Clare, 2010, 2011). When individuals with dementia experience difficulty with the explicit memory and are treated as people who no longer have personal values and desires, or who experience interactions in which their needs, personal identity, and values are ignored, they tend to withdraw socially and risk further cognitive decline (Kitwood, 1997; Kelly, 2010). However, embodied activities (Kontos, 2004, 2005) have been studied and suggested to be important means by which persons with dementia maintain their selfhood. The PLIE program, which offers non-judgmental respect for personhood while engaging in meaningful and interactive physical exercises, may help to prevent cognitive decline in the elderly with dementia through its combination of mindful movement and respect for participants’ moment-to-moment experience (Kontos, 2005).

Our study has several limitations. Although three class sessions were video recorded, the majority of observations were based on instructors’ fieldnotes. Future studies may seek to use more rigorous participant-observation methods as well as in-depth interviews with participants, caregivers, and instructors and more extensive video documentation. Furthermore, this report is based on a small sample, and people with dementia often exhibit a wide range of behaviors that may reflect implicit styles indicative of their personal and cultural experiences. For example, participants of Asian ethnicity shared fewer personal stories and were less expressive of personal experiences of other participants. Also, while we attempted to include caregivers’ reports, many caregivers were not involved in daily interactions with participants and had difficulty providing detailed information on changes during the program.

In conclusion, this qualitative study of the PLIE program suggests that individuals with dementia, even when less able to retrieve or reconstruct information from memory in an explicit way, may be able to learn functional skills and develop personally through an integrative exercise program. Our findings suggest that the PLIE program may lead to physical, emotional and social changes including greater behavioral coherence, improved social interactions and increased functional well-being. By combining conventional exercise with a focus on mind/body awareness in a social group setting, PLIE may offer not only functional improvement, but also help participants to experience themselves in new ways, retain a sense of self, and foster social cognition. These changes, in turn, may delay cognitive decline and improve the quality of life for individuals with dementia and their caregivers. Integrative exercise approaches – that combine conventional and
complementary approaches and include a focus on procedural learning, mind/body awareness and social interaction—deserve further investigation.

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**References**


