Integrated Approaches to Yoga and Self-Care for Caregivers and People with Disabilities

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Yoga for people with moderate disability associated with Multiple Sclerosis

Protocol Development & Pilot Trial Results

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Co-investigators:

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School of Health Professions(1,2), New Jersey Medical School(3), Rutgers, The State University of New Jersey, Newark(1,3), Stratford(2), School of Medicine, Rowan University, Stratford(4), NJ, USA

Funding:

New Jersey Health Foundation & a private donation from Hugh Evans, MD
Rationale

There is a need for research on yoga in persons with multiple sclerosis (MS) due to:

- Widespread use
- Much anecdotal evidence of benefits
- Little formal research on safety and efficacy

Purpose

1. Create a yoga intervention for persons with moderate disability due to MS for use in research and potentially, use by population with MS

2. Conduct a pilot trial to begin to assess:
   - Feasibility
   - Safety
   - Effects on Physical and Mental performance
   - Effects on Quality of life
   - Biological effects
Methods

Know thyself”*  
*Words originally inscribed in gold on the Temple of Apollo at Delphi

- Modified Delphi process with a panel of experts from across health care fields and yogic training, and people with MS who have taken yoga, was utilized to help design the yoga program.

Delphi Study Process

- A method using sequential questionnaires or interviews to achieve consensus from a panel of experts on a particular issue.

- Data collected though online survey program
## Panelists experience with MS

<table>
<thead>
<tr>
<th>Experience</th>
<th>Mean yr. (SD)</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have MS diagnosis</td>
<td></td>
<td>5 (19 )</td>
</tr>
<tr>
<td>Work in a professional capacity with persons with MS:</td>
<td></td>
<td>15 (56)</td>
</tr>
<tr>
<td>As a clinical educator</td>
<td>11 (4.55)</td>
<td>3 (25)</td>
</tr>
<tr>
<td>As a physician</td>
<td>13 (7.48)</td>
<td>3 (25 )</td>
</tr>
<tr>
<td>As a rehabilitation therapist</td>
<td>21 (0)</td>
<td>1 (8.3)</td>
</tr>
<tr>
<td>As a yoga teacher</td>
<td>11.25 (6.10)</td>
<td>8 (66.6)</td>
</tr>
<tr>
<td>As a yoga therapist</td>
<td>8.29 (5.77)</td>
<td>7 (58.3)</td>
</tr>
<tr>
<td>As a yoga researcher</td>
<td>9.33 (4.92)</td>
<td>3 (25 )</td>
</tr>
<tr>
<td>As a clinical psychologist</td>
<td>NS*</td>
<td>1 (8.33)</td>
</tr>
</tbody>
</table>
Styles in Yoga Training and Practice

- B.K.S Iyengar
- Kundalini
- Tantra
- Vinyasa
- Anusara
- Ishta
- Himalayan Tradition
- Yoga of the Heart (Cardiac/Cancer)
- Self Realization Fellowship
- Walt Baptiste/Eric Small
- Ashtanga
- Kripalu
- Adaptive yoga
- Radiant Child yoga
- Gentle Hatha
Training

• Manual containing all practices was produced and given to all participants and teachers.
• Experienced yoga teachers were trained by the study team in the specific practices.
• Study performed at Still Point Yoga, Laurel Springs, NJ.
Panelist ranking of yoga practices for people with moderate disability associated with MS

<table>
<thead>
<tr>
<th>Rank</th>
<th>Yoga practices</th>
<th>Unimportant N (%)</th>
<th>Of little importance N (%)</th>
<th>Important N (%)</th>
<th>Very important N (%)</th>
<th>Weighted Score</th>
<th>#**</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Pranayama (Breathing)</td>
<td></td>
<td></td>
<td>3 (12.5)</td>
<td>21 (87.5)</td>
<td>3.88</td>
<td>24</td>
</tr>
<tr>
<td>2</td>
<td>Relaxation practices</td>
<td></td>
<td></td>
<td>3 (13.6)</td>
<td>19 (86.3)</td>
<td>3.86</td>
<td>22</td>
</tr>
<tr>
<td>3</td>
<td>Meditation practices</td>
<td></td>
<td></td>
<td>6 (25)</td>
<td>18 (75)</td>
<td>3.75</td>
<td>24</td>
</tr>
<tr>
<td>4</td>
<td>Asana (postures)</td>
<td></td>
<td></td>
<td>7 (29.2)</td>
<td>17 (70.8)</td>
<td>3.71</td>
<td>24</td>
</tr>
<tr>
<td>5</td>
<td>Yoga Philosophy</td>
<td>1 (4.2)</td>
<td></td>
<td>6 (25)</td>
<td>17 (70.8)</td>
<td>3.61</td>
<td>24</td>
</tr>
<tr>
<td>6</td>
<td>Guided Imagery</td>
<td></td>
<td></td>
<td>6 (25)</td>
<td>12 (50)</td>
<td>3.25</td>
<td>24</td>
</tr>
<tr>
<td>7</td>
<td>Mudras (hand positions)</td>
<td></td>
<td></td>
<td>7 (30.4)</td>
<td>10 (43.5)</td>
<td>2.96</td>
<td>23</td>
</tr>
<tr>
<td>8</td>
<td>Chanting (vocalizations)</td>
<td>2 (8.7)</td>
<td></td>
<td>6 (26.1)</td>
<td>10 (43.5)</td>
<td>2.78</td>
<td>24</td>
</tr>
</tbody>
</table>
## Classes

<table>
<thead>
<tr>
<th>Class Order</th>
<th>Approx. Time</th>
</tr>
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<tbody>
<tr>
<td>Philosophy:</td>
<td>10 mins</td>
</tr>
<tr>
<td>Pranayama/Breathing:</td>
<td>15 mins</td>
</tr>
<tr>
<td>Asanas/Postures:</td>
<td>40 mins</td>
</tr>
<tr>
<td>Relaxation practice</td>
<td>10 mins</td>
</tr>
<tr>
<td>Meditation:</td>
<td>10 mins</td>
</tr>
</tbody>
</table>

## Practice Principles

- Safe, nurturing, environment
- Slow, mindful practice
- Coordinated w/breath
- Inclusive, accepting
- Individually adapted & centered
Class Content

- **Kanpur Series** (ie. Joints & Glands series - Himalayan Tradition): eyes, face, whole body, sitting, lying down, gradually more standing

- **Classic poses:** sitting, standing, prone, supine

- Extensive use of chairs and wall, with blankets for support

- Two yoga teachers and at least one study team member at all classes
The Pilot Trial

- Fourteen women, ages 34-64 ($M=53.5$)
- 2-26 years since MS diagnosis ($M=13.9$)
- Score of 3-6 ($M=4.67$) on the Self-Report of MS Disease Severity
- Completed 8-weeks of two-1.5 hour yoga classes per week and daily home practice.
Feasibility and Safety

- **Recruitment:** Southern New Jersey and Philadelphia area, online announcements at University, local flyers and newspaper ads
- 72 individuals screened
- 16 eligible and scheduled for the study
- 15 were enrolled
- 1 withdrew due to unrelated health problem
- 14 completed program and all testing sessions
- Attendance was high (89%)
- Classes were well tolerated
- 1 transient phlebitis after blood draw on final testing day
- 19 other adverse events reported
- All were determined to be either minor (e.g. transient soreness) or unrelated to the study
Multiple Sclerosis Functional Composite

T25WT
Timed 25 ft. walk test

PASAT-3
Paced serial addition test

9HPT – Dom
9 hole peg test - dominant hand

9HPT – Non
9 hole peg test - non-dominant hand

* p<0.05 T0 to T1
† p<0.05 T0 to T2
Other Physical Performance Measures

**MDRT**

Multiple direction reach test

- Front
- Back
- Left
- Right

**5STS**

5 Times sit to stand

**6MWT**

6 Min. walk test

* p<0.05 T0 to T1
† p<0.05 T0 to T2
Quality of Life

MFIS = Modified Fatigue Impact Scale; PES = Pain Effects Scale; SSS = Sexual Satisfaction Survey; BLCS = Bladder Control Scale; BWCS = Bowel Control Scale; IVIS = Impact of Visual Impairment Scale; PDQ = Perceived Deficits Questionnaire; MHI = Mental Health Inventory; MSSS = Modified Social Support Survey; MSWS-12 = 12-item Multiple Sclerosis Walking Scale
Conclusions

- **Feasibility and safety** of this pilot study was demonstrated.
- Results indicate **benefits in physical, mental, and quality of life**.
- Biological/immunological results are complex, as is MS disease, and difficult to interpret. However, **decreases in IL-6 and CRP** are interesting, as are the patterns of results in individuals, and deserve further study.
- **Qualitative results** indicate important changes.
- A **larger randomized controlled trial would be needed** to determine intervention-specific results.
Dementia and Caregiving

- **Dementia**: overall term for diseases and conditions characterized by decline in memory, thinking skills and other cognitive abilities that affect a person’s capacity to perform everyday activities.

- **Alzheimer’s disease (AD)**: most common type of dementia; estimated 5.2 million Americans; eventually require the aid of a caregiver.

- **Family caregivers**: Majority of care - at home.

- **Caregiving** for a family member with a chronic degenerative disease can be particularly stressful and challenging.

- **Negative health outcomes**: likely related to stress.
Purpose

- Investigate the safety and feasibility of a single arm pilot trial of an integrated yoga, wellness and caregiving skills program for caregivers of family with Alzheimer’s disease or other dementia.

- Measure caregiver wellbeing, burden, self-efficacy, and health; validated assessment tools pre & post intervention.
Intervention Development

An Interprofessional Process

1. Topics identified as desirable and effective from the literature
2. Identify and meet with potential team members
3. Whole team meeting: overview and feedback
4. Module team meetings: refine contents of modules
5. PhDs in basic science, psychiatric rehabilitation, physical therapy, psychology, health sciences, and public health, physician assistants, occupational therapist, registered dietician, integrative medicine MDs, yoga teachers and yoga therapists
Support for the CAREGIVER

Caregivers of family members with Alzheimer’s or other Dementia;
Relevant Education, Gentle yoga Integrated with Valuable Everyday skills and Relaxation©

Intervention Design

- **Study type:** Single arm, pilot trial
- **Intervention:** 8 wk, 90 (to 120) min. classes, 1/wk
- **Site:** Atlantic Health Chambers Center for Wellbeing, Morristown, NJ
**Intervention Design**

- **Sessions:** Interactive class in an area supportive of caregivers, followed by an integrated yoga class

- **Assessments:** Weeks 0, 9, and 16

- **Inclusion criteria:** Caregiver of family member with Alzheimer’s or other dementia for minimum of 16 hr./wk, able to perform gentle yoga movements and provide letter from primary care Dr. with permission to participate.

- **Exclusion criteria:** unable to speak or understand English, <18 yr. age, current radiation or chemotherapy, or decompensating medical condition

- **IRB approvals:** Rutgers Newark IRB & Atlantic Health System
Caregiving:
- Nutrition
- Activities of Daily Living
- Safe movement and posture

Self-care
- Coping skills, Mindfulness, Resiliency, Spirituality,
- Exercise, Sleep

Yoga
- Yogic Philosophy, Breathing, Postures,
- Relaxation, Meditation
Class/Module Contents

1. Alzheimer’s disease and The Eight Dimensions of Wellness*
2. Coping Skills, Self-efficacy and Mindfulness
3. Resiliency, Spirituality & Self-Care
4. Healthy, Mindful Eating and Tips for Efficient Meal Preparation
5. Safe, Effective Assistance of Activities of Daily Living (2 sessions)
6. Transitions: Palliative & End of Life Care
7. Integrative Health & Wellness Options for the Caregiver and Final Discussions

*Wellness Model developed by Dr. Peggy Swarbrick
Yoga Intervention

- Two yoga instructors, alternating sections
- Chairs, blankets, wall, and floor as support,
- Asanas modified as needed
- Binders including each week’s practices
- Class outlined in table with practice cues
- Changes to planned protocol & observations recorded
- **Asana**: standing, sitting, reclining, and twist poses: sitting joints and glands series
- Content progressed in number of practices and challenge with time.

**Philosophy, Pranyama, Relaxation, Meditation:** content based on earlier studies

<table>
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<th>Duration</th>
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<tr>
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<td>20 minutes</td>
</tr>
<tr>
<td>Relaxation practice</td>
<td>10 minutes</td>
</tr>
<tr>
<td>Meditation</td>
<td>5 minutes</td>
</tr>
</tbody>
</table>
Results

Recruitment: Within Rutgers and Atlantic Health and organization meetings (Alzheimer’s organizations & United Way of Northern NJ)

- Enrollment: 8 people, 50 to 84 yr. age, 2 males, 5 caring for parent, 3 for spouse. One withdrew due to caregiving and transportation challenges.

Feasibility: The study was feasible, with successful recruitment, retention and effective delivery of the intervention.

- Attendance: Participants attended all sessions or missed one.
- Adherence: Deviations from original protocol were minor, occasionally omitting a posture due to time constraints. Timing for most classes was closer to 2 hours.

Safety: Participants were provided with sheets each week to report any adverse events and to call PI with questions or concerns. The study was safe, with no reported adverse events.
Outcomes Measures

Assessment tools:

1. The Caregiver Well-Being Scale (Tebb, 2013)
2. The Zarit Burden Interview (Zarit, 1980)
5. Caregiver Activity Scale (Davis, Marin et al. 1997)
6. Pittsburgh Sleep Quality Index (PSQI) (Buysse, Reynolds et al. 1989)
7. Kentucky Inventory of Mindfulness (Baer, Smith et al. 2004)
8. Intrinsic Spirituality Scale (ISS) (Hodge, D.R., 2003)
10. Promis-43 (NIH)
11. Physical Caregiving ADL Survey

Results

Program evaluation Quotes:
The best part(s) of participating in this program were “Being in the company of other caregivers. Knowing that I was not alone. Getting help in dealing with my feelings. Learning to cope better.”
“Everything was GREAT about this program.”
“I appreciate the time and effort everybody allocated to set up these sessions. All of it was wonderful!”
“By learning about all of the subjects covered, just made me more aware there is support out there, whether it be intellectual, physical, emotional and spiritual.”
“Thoroughly enjoyed it!”
“Hearing what other caregivers are going through; there is a shared sense of camaraderie.”

9 week Program evaluation: Summary; Participants strongly agreed or agreed that the study was valuable, appropriate, well taught, and that they would use the information or practices (except one individual did not plan to continue practicing yoga).

16 week evaluation: Participants reported variable use of practices or information learned, from not at all to multiple times per day from 9 to 16 weeks. There was considerable regular use of practices and knowledge from both the education and yoga aspects of the program. Details of unpublished results removed for posting.
Support for the Caregiver

Team

S. Gould Fogerite,¹ C. Milak,¹ M. Swarbrick,¹,² Z. Haigney,¹ M. Carola,¹ G. Mahon,¹ J. S. Parrot,¹ D. Kietrys,¹ E. Anderson,¹ J. Schwenkler,¹ J. Joseph Roach,¹ M. Zechner,¹ R. Eubanks,¹ J. DiLena,³ G. Campanile,⁴ G. Topfer,⁵ P. Feiner,⁵ D. Speer,⁶ M. Silva,⁷ A. Perlman,⁸

Caregiver Wellness Programs

Current programs with Wellness and Self-Care Education, Mindfulness, and Gentle Yoga for Caregivers of adult family with mental illness and/or developmental disability

- Content developed through focus groups and interviews with stakeholders, and informed by team’s previous studies and practice.
- Several 5 week programs, multiple 1, 2, or 3 week programs
- Now expanded to professional caregivers, hotline support providers, other caregiver groups, and community support groups
- Some ongoing offerings are focused more on yoga, some more on mindfulness
- Programs begun in 2017, ongoing in 2018 & 2019
Caregiver Wellness Programs

• **Funded by:** New Jersey Division of Mental Health and Addiction Services (NJDMHAS), through a Transformation Transfer Initiative (TTI) contract from the National Association of State Mental Health Program Directors

• Rutgers Health University Behavioral Health Care (RUBHC), Dr. Margaret (Peggy) Swarbrick, RUBHC Director of Practice Innovation and Wellness, managed the project with NJDMHAS liaison Margaret Molnar.

• Dr. Susan Gould Fogerite, Associate Professor, Departments of Clinical Laboratory and Medical Imaging Sciences and Physician Assistant Studies and Practice, Rutgers School of Health Professions, contributed guidance for the project and was responsible for the curriculum content and instruction on yoga.

• Dr. Ken Verni, Training and Consultation Specialist, Director of NJ Center for Mindful Awareness, was responsible for the curriculum content and instruction on mindfulness.

• Dr. Patricia Nemec assisted Dr. Swarbrick in creating the overall lesson plans, wellness self-care content and combined self-care topics with yoga and mindfulness content.

• Dr. Swarbrick and Dr. Amy Spagnolo (SHP) provided instruction and facilitated discussions on the wellness education component.