

Key Components of Qigong for People With Multiple Sclerosis: A Survey of Clinicians, Researchers, and Instructors

Global Advances in Integrative Medicine and Health

Volume 13: 1–12

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DOI: 10.1177/27536130241280721

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Abstract

Background: Preliminary evidence suggests that Qigong (QG), a mind-body therapy, may help address symptoms of multiple sclerosis (MS), but the heterogeneity of QG content and delivery may affect its feasibility, acceptability, and efficacy.

Objective: To survey researchers, clinicians, and QG instructors with experience working with people with MS to identify key components of MS-specific QG guidelines and protocols.

Methods: We conducted an online survey to identify QG forms and movements considered helpful for MS, reasons for selection, characteristics of effective learning environments, and recommended dosage and frequency of practice. Quantitative data were analyzed using summary statistics. Qualitative data were analyzed using reflexive thematic analysis.

Results: Forty-seven experts, including QG instructors, clinicians, and QG and MS researchers, completed the survey. Respondents had a mean (SD) of 20 (11) years of QG teaching experience, 26 (12) years of clinical practice, 24 (9) years of QG research experience, 13 (5) years of MS research experience, and worked with at least 3 (2) people with MS. Approximately 125 QG forms/movements were recommended. Some forms were specifically recommended to address MS symptoms (e.g., emotional regulation, balance and coordination, muscle strength and flexibility, immune regulation, and circulation). Some respondents felt that any QG form could be beneficial if basic principles were met (e.g., intentional movement, posture, focused awareness, rhythmic breathing/movement, and a relaxed mind and body). Instructor qualities included the ability to convey information clearly, being caring and compassionate, proficient in QG, and having basic knowledge of MS. To promote confidence in learning QG, recommendations included having simple, easy-to-learn movements with modifications based on physical ability. We provide a sample protocol based on these recommendations.

Conclusions: This study provides expert guidance for developing a QG protocol for an MS population, including content and delivery recommendations.

Keywords

qigong, multiple sclerosis (MS), tai chi, survey

Received January 30, 2024; Revised August 1, 2024. Accepted for publication August 19, 2024

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Introduction

Multiple sclerosis (MS) is a neurodegenerative disorder affecting nearly 1 million people in the United States (US), resulting in demyelination and axonal damage in the central nervous system (CNS).¹⁻³ Myelin damage and axonal degeneration occur in different locations throughout the CNS and can lead to temporary or permanent loss of neuronal function.² Common symptoms include fatigue, muscle weakness and spasticity, chronic pain, bladder and bowel dysfunction, cognitive decline, anxiety, and depression.⁴

Qigong (QG) is an ancient Chinese practice developed to promote health and wellness and includes meditative postures, rhythmic movements, breath regulation, and self-massage.⁵ Tai Chi, originally a martial arts practice, has been adapted in the West as a mind-body exercise to promote health and can be considered a sub-type of QG.^{6,7} Preliminary studies suggest that QG (including Tai Chi, which we include in our definition of QG)⁶ may improve physical function, balance, cognition, mood, and quality of life in people with MS.⁸⁻¹⁴ Possible explanations for why QG may benefit MS outcomes include its multi-component nature that integrates physical, psychological, and cognitive practices.¹⁵ Postures and movements often incorporate strength-building, balance, and coordination combined with mindful attention to movements, visualization, and meditative practices. Movements commonly involve standing and/or slow walking but can be adapted to seated or reclined positions, thus making it adaptable to different levels of disability. Biochemically, some evidence suggests that QG can reduce the cytokine interleukin-6 (IL-6) linked to chronic inflammation and autoimmunity.¹⁶ Elevated IL-6 has been associated with accelerated disease progression in MS, including increased demyelination and reduced synaptic plasticity.¹⁷ Thus, by lowering IL-6, QG may be a promising therapy for MS. Other studies have reported Tai Chi's impact on immune function and inflammation.^{18,19}

Despite the potential benefits of QG for people with MS, research on QG for MS is still in its infancy. Variability in the content and delivery of QG contributes to challenges in assessing efficacy and comparing studies. For example, QG is highly heterogeneous, with thousands of styles and forms varying in activity level, complexity, and difficulty.⁶ Since QG is commonly taught in a group class setting, other factors related to the learning and practice environment may also influence its effectiveness, such as the instructor's experience, the social dynamics of a class, and the availability of one-on-one support.²⁰ These components may be essential in influencing how students learn, integrate, and ultimately benefit from a QG practice.

This study aimed to seek input from experts in QG and MS to (1) inform the development of a QG protocol for MS that could be tested in a clinical trial and (2) serve as a starting point for developing QG practice guidelines for people with MS. Similar guidelines have been developed for cancer

patients that include the structure and delivery of QG, instructor competence, and screening and instructions to ensure safe participation.²¹ Recommended QG program content for cancer includes warm-up exercises, an easy-to-learn QG or Tai chi form, meditation, self-massage, and time for interactive discussion.²¹ Accreditation guidelines are being developed for QG instructors and training institutions to ensure informed, quality QG delivery tailored to different chronic conditions.²² Due to the highly variable, unpredictable, and multifactorial symptom presentations in MS, specific guidelines may be beneficial to minimize adverse events and maximize benefits.

Methods

Study Design

This study was approved by the National University of Natural Medicine Institutional Review Board (IRB#: LB11122). We conducted an online questionnaire to capture qualitative and quantitative data on key components of a QG intervention for people with MS from an interdisciplinary group of experts. Our recruitment population included QG/Tai Chi and MS researchers, clinicians (e.g., physicians, physical/occupational therapists, psychologists, acupuncturists/East Asian medicine practitioners) who work with people with MS through QG/Tai Chi or other mind-body movement therapy, and QG/Tai Chi instructors with experience working with people with MS. We deliberately included a diversity of stakeholder groups to not only get opinions about QG protocols for MS, but to better understand appropriate ways to teach a movement therapy to people with MS. We limited our population to people who spoke English and had experience working with people with MS in the US.

QG and MS researchers, defined as anyone who has published in this domain in the scientific literature, were identified through literature reviews, online databases, professional contacts, and snowball sampling. We identified QG instructors through professional contacts, snowball sampling, and web searches, including the Qigong Institute, National Qigong Association, and the International Medical Tai Chi Qigong Association. Clinicians were primarily identified through their association with research or QG instruction. Inclusion criteria included the ability to read, write, and communicate in English and ≥ 5 years of experience working with at least three people with MS either (1) conducting research in QG and MS; (2) teaching QG (including Tai Chi); or (3) clinical experience using QG or other mind-body movement therapy. These criteria were based on what we thought was a reasonable minimum threshold of experience in QG and MS and what could be achieved through our recruitment strategy. Candidates who worked with one-to-two people with MS and demonstrated extensive experience and mastery of QG (e.g., ten or more years of teaching/training) and/or had experience working with people with

other neurological conditions, were considered eligible on a case-by-case basis, based on in-depth follow-up communication with the candidate to identify their experience and expertise.

We sent recruitment emails to potential candidates and emailed those who expressed interest an electronic screening form to confirm eligibility. We emailed eligible candidates a link to an online consent form and survey. We administered the screening form, consent form, and survey through a HIPAA-secure REDCap® database. All participants were compensated \$100 for completing the survey. The survey was open from June 11, 2022, to October 6, 2022.

The survey included 107 questions, grouped into the following categories: demographics (40), recommended QG forms/movements for MS (8), learning environment (20), and recommendations for designing a clinical trial (39). We conducted three rounds of pretesting in 10 volunteers who met demographic criteria similar to those of our target audience (e.g., researchers, clinicians, instructors with experience in QG and/or MS) to establish subjective face validity and readability. The survey was estimated to take 15-20 minutes to complete. We followed the Checklist for Reporting of Survey Studies (CROSS) reporting guidelines for presenting our data.²³ A copy of the questionnaire is provided in [Supplemental Table 1](#).

Data Analysis

Quantitative data were analyzed using summary statistics. Qualitative data were analyzed using reflexive thematic analysis in Dedoose® software.²⁴ Three research team members (LB, JV, and NP) separately reviewed and coded the first 12 responses to each qualitative question. LB then created the initial codebooks, and JV and NP added additional codes as needed. The team then met to discuss the codebook, update and consolidate codes, and validate congruity with assignment of codes. Each member then completed the coding for separate questions. The team then met to review responses and codes to further discuss and update the codebook, with up to three rounds of analyses.

Results

Demographics and Characteristics of Survey Respondents

We initially generated an email list of 777 potential candidates, primarily obtained from a national directory of QG instructors available from the Qigong Institute. From this initial list, 56 (7.2%) responded as being ineligible. Of the remaining, a total of 64 people completed the screening form (8.8%), and of these, 58 (90%) consented to join the study, with 47 out of 58 (81%) completing all domains of the survey. We analyzed data only from these 47 respondents who fully

completed the survey (see [Figure 1](#) for a CONSORT-like diagram).

Respondents had a mean (SD) age of 60 (11) years, with 25 (53.1%) female and 36 (75%) white ([Table 1](#)). All respondents resided in the US, except one who lived in Sweden but had taught QG in the US for over 20 years. Respondents identified as being QG instructors (91%), Tai Chi instructors (55%), other mind-body movement instructors (e.g., yoga) (38%), clinicians (e.g., physicians, psychologists, physical therapists, acupuncturists) (38%), QG researchers (23%), MS researchers (9%) and other researchers (6%), with respondents able to self-identify in multiple categories. All 18 respondents who identified as “other” type of movement instructors were also QG instructors (in addition to some also being clinicians and researchers). Similarly, the three respondents who identified as “other” researchers were also QG instructors (in addition to some also being clinicians and researchers). Seventy-four percent reported having a personal QG practice for a mean (SD) of 30 (13) years. Respondents had a mean (SD) of 20 (11) years of QG teaching experience, 26 (12) years of clinical practice, 24 (9) years of QG research experience, 13 (5) years of MS research experience, and worked with at least 3 (2)

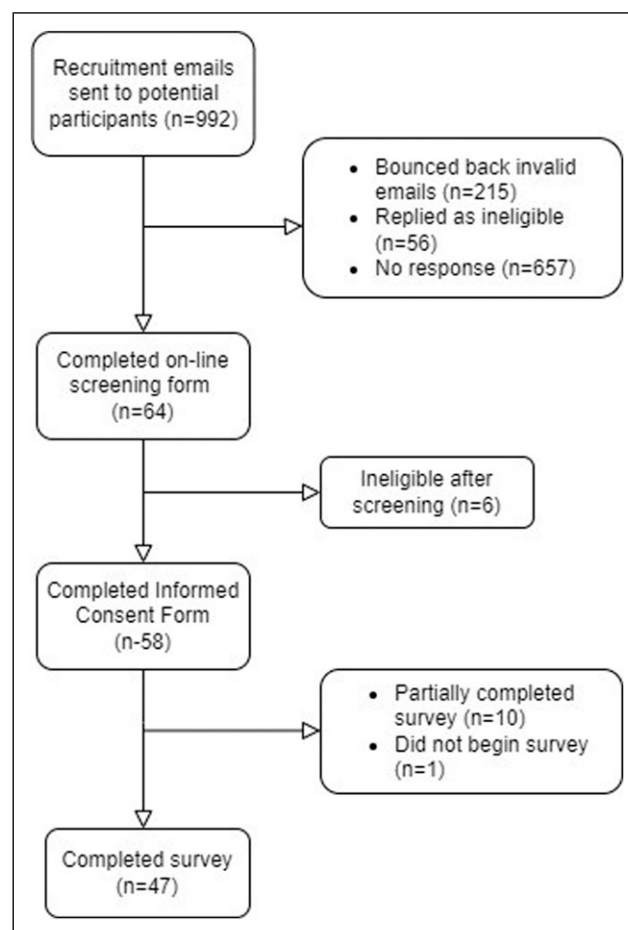


Figure 1. CONSORT-like diagram of study recruitment and enrollment.

Table I. Demographics and Characteristics of Survey Respondents.

| Measure | No. (%) | Mean (SD) |
|---|----------|-----------|
| Mean age (SD) (n = 47; range:36-78) | | 60 (11) |
| Sex | | |
| Female | 25 (53%) | |
| Ethnicity | | |
| Hispanic | 2 (4%) | |
| Non-hispanic | 45 (96%) | |
| Race | | |
| American indian/Alaska native | 1 (2%) | |
| Asian | 6 (13%) | |
| Black/African american | 1 (2%) | |
| White | 35 (74%) | |
| More than one race | 1 (2%) | |
| Other | 3 (6%) | |
| Education (highest degree) | | |
| High school Diploma/GED | 6 (13%) | |
| Associate degree | 5 (11%) | |
| Bachelor's degree | 10 (21%) | |
| Master's degree | 14 (30%) | |
| Doctorate | 12 (26%) | |
| Country of residence | | |
| US | 46 | |
| Sweden | 1 | |
| Role related to qigong/Tai chi and/or MS (one or more) | | |
| Researcher (QG/Tai chi) | 11 (23%) | |
| Researcher (MS) | 4 (9%) | |
| Researcher (other) | 3 (6%) | |
| Clinician | 18 (38%) | |
| Instructor (QG) ^a | 43 (91%) | |
| Instructor (Tai chi) | 26 (55%) | |
| Instructor (other exercise/Movement) | 18 (38%) | |
| Personal practice (QG/Tai chi) | 35 (74%) | |
| Personal diagnosis of MS | 3 (6%) | |
| Mean years of research experience (SD) | | |
| QG/Tai chi research (n = 11; range:12-40) | | 24 (9) |
| MS research (n = 4; range:7-20) | | 13 (5) |
| Other research (n = 3; range:5-20) | | 10 (9) |
| Years of clinical practice (n = 18; range:9-47) | | 26 (12) |
| Number of patients with MS (n = 18; range:1-9) | | 3 (2) |
| Mean years of teaching experience (SD) | | |
| QG (n = 44; range:5-45) | | 20 (11) |
| Tai chi (n = 27; range:1-48) | | 20 (12) |
| Other exercise/Movement (n = 18; range:1-55) | | 25 (16) |
| Mean number of students with MS (SD) | | |
| QG (n = 44; range:1-10) | | 3 (3) |
| Tai chi (n = 27; range: 1-9) | | 3 (3) |
| Other exercise/Movement (n = 18; range: 1-5) | | 2 (1) |
| Mean years of personal QG/Tai chi practice (n = 35; range:5-53) | | 30 (13) |

^aRespondents who were not QG instructors included a MS neurologist/physical therapist, a traditional East Asian medicine clinician, a psychotherapist specializing in traditional East Asian "shen" therapy, and a medical Qigong practitioner.

people with MS. Survey respondents also self-identified as belonging to one or more of the following professions: acupuncture/East Asian medicine/medical QG (n = 12), clinical psychology/behavioral health (n = 5), physical therapy (n = 2), somatic therapy/education (n = 2), neurology (n = 1), neuropsychology (n = 1), naturopathy/integrative medicine (n = 2), massage therapy (n = 1), homeopathy (n = 1), and dental hygiene (n = 1). Respondents came from 24 US states, plus one living in Sweden. Three respondents who were QG instructors (one of whom was also a clinician) also reported having a personal diagnosis of MS, including stabilizing or reversing the course of their disease through QG.

Qigong Forms and Movements for MS

Respondents recommended approximately 46 QG forms, 23 Tai Chi forms, and 56 single QG movements/practices (totaling 125), although there is likely a fair amount of redundancy (see [Supplemental Table 2](#)). Because QG can consist of repeated single movements, repeated groups of movements, or a series of choreographed movements (defined as a “form”), the single movements listed could be part of a longer QG or Tai Chi form. Also, some movements/forms may be the same but called by different names. We grouped commonly recognized QG forms if there were slight variations in the name or if the equivalent Chinese or English names were used. For example, the Eight Section Brocade Qigong form is also known as the *Ba Duan Jin*; and Five Element Qigong is also known as the Daoist Five or *Wu Xing Gong*. Individual Qigong practices included specific movements (e.g., standing, walking, arm movements, whole body movements), meditation, self-massage, sound/vocalization, visualization, and breathwork. Respondents recommended modifications to movements (e.g., seated instead of standing, visualization) based on the practitioner’s ability.

Qigong Benefits for MS

Common reasons for selecting specific QG forms/movements for MS included calming the mind/nervous system, improving balance and coordination, improving muscle strength and flexibility, immune regulation, and improving circulation. One respondent explains:

“The [specific Qigong] practice increases mind-body integration, proprioceptive awareness, increased circulation. It can help practitioners feel more energized or reveal the need for stress reduction and relaxation. Learning to use the basic Qigong posture as well as the “walking steps” promote balance and stability. People often feel more stable as a result of grounding, an integral part of the practice. Gentle stretching throughout the practice helps loosen tight muscles, relieves stiffness, increases range of motion, [and] promotes blood flow...” (P09, QG Instructor)

Key Component of Qigong for MS

Key motor components recommended for people experiencing mild-to-moderate MS symptoms focused on engaging the body in simple, gentle, rhythmic movements involving mindful standing, walking, rotating, and stretching. Responses included practices aimed at addressing specific MS symptoms. For example, one common QG posture is standing with parallel feet, shoulder-width apart. One respondent explained that this simple standing posture “stimulates the brain and CNS by practicing balance and standing still (P06, QG instructor and licensed acupuncturist (LAc)).” Mindful, slow walking was described as beneficial for gait and “neuromuscular response (P17, QG researcher, instructor, and medical QG and behavioral health provider).” Benefits from movements were also described through a Traditional Chinese Medicine (TCM) lens. For example, movements that gently stretch the hamstrings and back activate the Urinary Bladder Meridian that runs along the dorsal side of the body and is “energetically connected to the brain and CNS (P06, QG instructor and LAc).” Movements that involve lateral bending or gentle twisting activate the Gall Bladder Meridian (which runs along the lateral aspect of the body), indicated for “improving coordination, building muscular strength, and boosting energy/vitality (P04, QG instructor).” This meridian is said to support brain function by “clearing a foggy mind, enhancing short-term memory, concentration, and information processing (P04, QG instructor).”

Additional practices included acupressure self-massage/tapping, breathwork, meditation, sound healing, and visualization. Self-massage on specific acupoints was said to “open blockages and promote free-flowing *qi* [vital life force] and blood (P04, QG instructor).” Tapping specific meridians along the body was reported to “increase *qi* flow by gathering the *qi*, purging old *qi*, sending *qi* to weak areas of the body (P08, QG instructor).” Benefits from breathing practices (such as abdominal breathing) included “a strong stimulation of the vagus nerve (P14, QG instructor),” as well as helping the “immuno-digestive-neuro-adrenal axis to regulate...general health and reduce hidden pathogen load (P16, QG instructor and LAc).” Having a meditation component was considered essential for MS by “training to quiet the mind and increase focus... [thereby] changing the ANS [autonomic nervous system] response from one of SNS [sympathetic nervous system] dominance to PNS [parasympathetic nervous system] dominance (P17, QG researcher, instructor, and medical QG and behavioral health provider).”

For people with greater levels of disability, seated movements that emphasize the mental components of QG, including breathwork and meditation, were noted:

“Practice Qigong in a chair, including a wheelchair. Emphasize the mental aspect of the form, feel you are part of the universal *qi* field. Practice the easier forms like push-pull, open and close, gathering *qi* from the earth, pull *qi* down from above, etc. For all

levels of MS, I encourage simple forms of sitting: meditation, focus on basic abdominal breathing and with awareness of the *qi* as being an innate part of our being.” (P08, QG instructor)

“Many of the most powerful Qigong forms, especially useful for someone with mobility issues, are the practices that focus on visualization and breathwork that involve very little external movements.” (P01, QG instructor, naturopathic physician, LAc)

Respondents also stressed the importance of simplicity:

“I cannot emphasize enough the importance of the idea of using very simple forms that are very targeted for addressing each of the five biological systems addressed by the five elements and their associated emotions because people with MS are already experiencing a neurological overload so it can be very difficult for them to learn more complex movements—especially in a way divorced from what the movements are regulating.” (P45, QG instructor and medical QG practitioner)

“For students with moderate MS, working on basic movements and simple forms enables them to focus on practicing mindful movement at a slower pace where they do not need to worry about holding back the pace of the rest of the class. They can focus on improving their strength and balance and learn how to control their steps and transition their weight. All of these help with mobility.” (P57, QG instructor)

Others stressed the importance of individualizing QG based on the person’s needs, which may fluctuate over time:

“My approach is customized to each individual... I start all clients with foundational Qigong practices for mental acuity and calming. I find Tai Chi walking (each of the 4 directions) is very beneficial for gait management and strengthening neuromuscular response. As they progress with these basics then I introduce more complex forms requiring deeper balance and coordination....The goal of the training is to balance one’s mental, emotional, and physical relationships so that optimum function can be achieved. What works varies greatly by person and their particular circumstances. Especially when it comes to TCM Theory, what works for one person may not work for another. It is very individualized which is why it is often hard to quantify to western medical models of research.” (P17, QG researcher and instructor, medical QG and behavioral health provider)

“It should be emphasized that MS varies from day to day and from individual to individual. There is no form that is guaranteed to be practicable for any person on any given day. The instructor should assess each person on a week by week, class by class basis.” (P18, medical doctor, QG researcher and instructor)

Incorporating Qigong Principles

Some respondents did not list a specific movement or form but instead stressed that any QG form could achieve benefits

if basic principles were included. These principles can be summarized as (1) intentional movement grounded in TCM theory (e.g., stretching/opening meridian pathways); (2) correct alignment and posture to promote balance and maximize the flow of *qi*; (3) focused awareness; (4) rhythmic movement and breathwork; and (5) relaxed mind and body. Exemplary responses include the following:

“I believe that any and all Qigong forms...can be and will be beneficial for someone with MS, as long as they are taught properly.... Moving the *qi* - feeling and directing the *qi* through the body - is done in any Qigong form and that is where the healing is.” (P01, QG instructor, naturopathic physician, LAc)

“Any real Tai Chi movement is appropriate for anyone who can tolerate the motions without pain or discomfort. The benefit for MS derives primarily from the quality of movement, not the moves themselves. Emphasis should be on Large Frame motions with excellent Alignment and Relaxation (Song) and Balance / Central Equilibrium (Zhong Ding). Proper body Structure, Balance, and Internal Alignments allow the body to remain functional and even powerful without reliance on muscular tension.” (P41, QG instructor)

Qigong Delivery/Instructional Formats

When asked about recommended instructional formats for people with MS, most respondents (79%) recommended a combination of group and individual instruction, while 15% recommended only group classes and 6% only individual instruction. Regarding delivery method, most people (60%) recommended a hybrid online and in-person delivery, while 38% recommended in-person and 2% recommended online. Most respondents considered using a teaching aid, including audio and video recordings, written instructions, and/or photos, essential or useful.

Instructor Qualities

Regarding perceived favorable qualities of an instructor, all respondents considered the ability to convey information clearly as essential, 94% considered being caring and compassionate as essential, and 81% considered proficiency in QG as essential (Table 2). Sixty-eight percent of respondents (comprised mostly of QG instructors who were also researchers and/or clinicians) thought having a basic understanding of MS was “essential,” while 32% considered this “useful.” Less essential were training in working with people with MS (36% essential, 64% useful), certification by a QG master (40% essential, 49% useful), and certification by an accredited institution (26% essential, 62% useful).

To optimize the QG learning environment, we asked how a QG instructor could help people with MS (1) feel comfortable and safe in class, (2) develop confidence in learning QG, (3) ensure that their individual needs are met, and (4) feel motivated

Table 2. Instructor Qualities Recommended by Survey Respondents.

| | Essential (%) | Useful but Not Essential (%) | Not Useful (%) | No Opinion (%) |
|---------------------------------------|---------------|------------------------------|----------------|----------------|
| Certified by accredited institution | 26 | 62 | 6 | 6 |
| Certified by a QG master | 40 | 49 | 4 | 6 |
| Demonstrated proficiency | 81 | 17 | 0 | 2 |
| Ability to convey information clearly | 100 | 0 | 0 | 0 |
| Caring and compassionate | 96 | 4 | 0 | 0 |
| Basic understanding of MS | 68 | 32 | 0 | 0 |
| Training in working with people w/MS | 36 | 64 | 0 | 0 |

to learn and practice (Table 3). Recommendations for helping MS students feel safe and comfortable included ensuring the physical space felt safe through props (chairs, mats, grab bars), ADA access (including restrooms), and temperature control (particularly regarding heat intolerance, a common MS symptom). Class format and structure, such as providing rest breaks, keeping the class size small, and tailoring classes to people with MS or restricted mobility, emerged as another important theme. Another theme was having clear guidelines around physical and emotional safety, such as maintaining an accepting, non-judgmental class environment. Other themes were fostering a sense of community by dedicating time for socializing and including family members or caregivers in class.

Survey respondents suggested several methods to develop confidence in learning QG, including regular instructor feedback and encouragement, starting slowly with simple movements, encouraging students to stay within their comfort zone, providing teaching aids (e.g., videos, written instructions), demonstrating movements, and providing ample opportunity for repetition and practice. To ensure individual needs are met, themes included assessments of needs and limitations, individualized instruction (in class or at a separate session), and providing appropriate modifications. Finally, peer and family support and education about QG benefits, principles, and theory were encouraged to help people with MS feel motivated to learn and practice. Other themes to motivate learning included helping to set practice goals, inspirational stories, and promoting a fun and joyful class environment.

Qigong “Dosing” for MS

Regarding practice duration and frequency, the average (mode) recommended QG “dosage” to maximize benefits for MS symptoms included two classes per week (range 1 to 7 days) for 45 minutes each (range 30 to 90 minutes) and daily home practice for at least 20 minutes (range 10 to 60 minutes). An average (mode) of 12 weeks (range 6 to >24 weeks) was estimated to be needed to detect changes in MS motor symptoms, and six weeks (range 6 to >24) for non-motor symptoms. The recommended (mode) class size was ten students (range 5 to 25), with an instructor with five or more years of teaching experience (range “no minimum” to ≥ 20).

Ensuring Fidelity of a Qigong Protocol for MS

We also asked how we might ensure the fidelity of a QG protocol used in a clinical trial. Several respondents emphasized that with any QG protocol, flexibility for modifications based on individual needs was necessary:

“The protocol needs aspects of a foundation practice but flexibility for modifications.” (P08, QG instructor)

Some suggested scaling down the duration/frequency/intensity of any components:

“It would be pretty straightforward to list out all the attributes that can be modified to scale the intensity down. Duration of practice, amount of repetitions, amplitude of movement, standing/sitting/lying down, taking breaks in between repetitions etc. From there you could easily create a master flow chart/algorithm to guide the instructor so they can make modifications on the spot that are custom fit for the people in the room while still adhering to the standards of your research.” (P16, QG instructor and LAc)

Others recommended identifying protocols for modifications based on symptom presentation and disability level:

“Instructors would benefit from education about MS as well as knowledge of what kinds of physical challenges participants might be facing. While “pre-set” protocols for modifications may not be necessary, learning about what kinds of modifications/assistance students might need at different stages of the disease progression seems prudent.” (P09, QG instructor)

Figure 2 summarizes our results, proposing four “pillars” that can guide QG instruction for people with MS: goals, content, environment, and instruction.

Integration of Results – Example Protocol

Based on these findings, an example QG protocol for MS might resemble the following: A 60-minute class specifically for people with MS consisting of 10 minutes of group check-ins, 15 minutes of warm-ups including acupressure self-

Table 3. Recommendations for Creating a Safe and Supportive Qigong Learning Environment.

| How can the instructor help people with MS... | Representative Quote |
|--|---|
| I. Feel comfortable and safe in class | |
| a. Physical environment (props, temperature, ADA access) | <i>"Well maintained access ramp to facility. Accessible restrooms. Sturdy chairs, some with arms for those who need them. Air conditioning. Chairs available and arranged for all participants."</i> (P37, QGI) |
| b. Class structure (breaks, small classes, tailored classes) | <i>"Encourage people to self-pace... keep classes shorter - take one or more breaks."</i> (P18, MD, QGR and QGI) |
| c. Clear guidelines around physical and emotional safety | <i>"It is critical to create an environment where the instructor facilitates acceptance, non-judgement, and privacy for participants to feel safe –and also provide access to the instructor privately so that clients can explore or share more sensitive aspects of their journeys."</i> (P45, QGI, MQGP) |
| d. Fostering a sense of community and building rapport | <i>"Class should feel accepting and non-competitive. They should feel comfortable and supported... we had a potluck lunch at the end of every 8-week class session. For some folks this was the highlight of their social calendar. The group bonded and supported each other."</i> (P32, QGI) |
| e. Inclusion of family and/or caregivers in classes | <i>"I also invite any caregiver to attend the class at no charge."</i> (P42, QGI) |
| II. Develop self-confidence in learning QG | |
| a. Regular feedback, affirmation, encouragement | <i>"Make it clear that it is better to it wrong than not at all. Provide teachers who will never judge participants, but instead provide encouragement, no matter what."</i> (P03, QGR and QGI) |
| b. Start slowly and simply | <i>"Begin slow and simple with encouragement and clear, respectful guidance"</i> (P17, QGR, QGI, MQGP, BHP) |
| c. Stay in your comfort zone/go at your own pace | <i>"Teach them to honor their mental, emotional, and physical signals to prevent overwork or unnecessary stressors. I have them focus on healthy boundaries between strength, flexibility, and pain levels. Whichever one is asking for attention, is to be respected."</i> (P17, QGR, QGI, MQGP, BHP) |
| d. Provide learning resources (video, written instructions) | <i>"Handouts or videos they can refer to are helpful."</i> (P32, QGI) <i>"Make [a] video of [the] Qigong form available."</i> (P01, ND, LAc, QGI) |
| e. Demonstrate movements | <i>"Make demonstrations available for all participants. I had a teaching partner. One of us nearly always did a seated version and one a standing version."</i> (P37, QGI) |
| f. Repetition and practice | <i>"Encouraging home practice; even just a few minutes a day, makes a difference."</i> (P01, ND, LAc, QGI) <i>"I give "homework" the first class. This consists of ankle exercises they can easily do while watching a commercial on TV. We build on the idea that the outcome they get depends upon what they put in."</i> (P32, QGI) |
| III. Meet their individual needs | |
| a. Assess individual needs and limitations | <i>"Before accepting a person into your class, interview them. Find out their goals, their perceived limitations. Do they have any other concerns about learning such as dyslexia that would be important to know. Finally ask them is there anything that would make you feel more comfortable and safe?"</i> (P47, QGI) |
| b. Provide modifications | <i>"Teachers need to always emphasize that movements can be modified to people's abilities and no one should be aiming to do more than what their body can do."</i> (P57, QGI) |
| c. Individualized instruction and feedback | <i>"One-on-one instruction, be specific to each student, each student will bring their own issues; remember they are a person, not a MS person-this is key to everything."</i> (P08, QGI) |
| IV. Become motivated to learn and practice | |
| a. Peer and family support and encouragement | <i>"Ask about people who are absent, express concern. Whole group clapping, encouragement, celebrations, potlucks. Stories and sharing."</i> (P37, QGI) |
| b. Education on QG benefits, principles, theory | <i>"Provide little bits of information on Qigong theory. The Qigong teacher is also a teacher on the basics of Traditional Chinese Medicine–Qigong is Chinese Medicine."</i> (P08, QGI) |
| c. Setting goals | <i>"Set reasonable goals and benchmarks, follow-up consistently and celebrate when a goal is reached, then set new goals."</i> (P52, QGR, MSR, QGI, YI) |
| d. Inspirational stories | <i>"...any testimonials or research that supports the use of Qigong/Tai Chi for MS could only help with the desire to learn."</i> (P13, QGI, LAc) |
| e. Make it fun | <i>"Overall, be accepting, positive, and have some fun while doing it. Class should feel relaxed."</i> (P32, QGI) |

Abbreviations: QGI: Qigong instructor, MD: medical doctor, QGR: Qigong researcher, MQGP: medical Qigong provider, ND: naturopathic doctor, LAc: licensed acupuncturist, BHP: behavioral health provider, MSR: MS researcher, YI: yoga instructor.

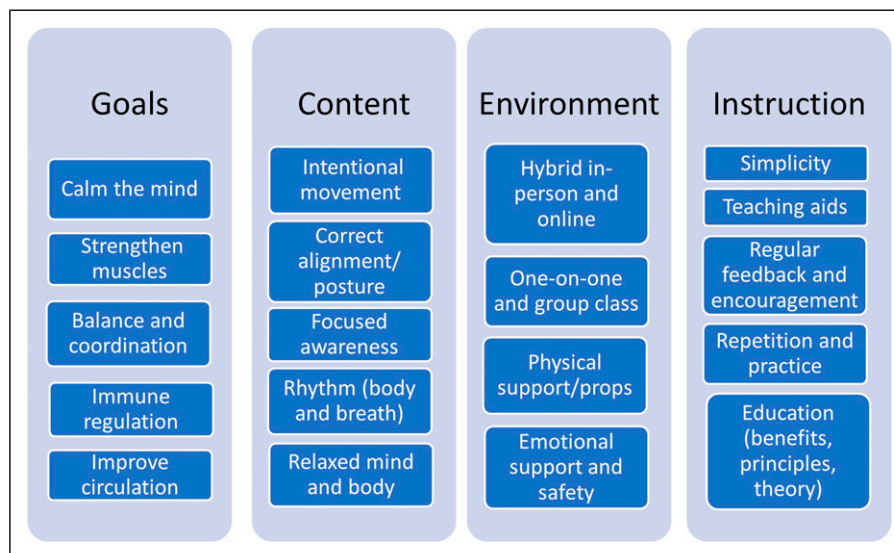


Figure 2. Four “pillars” to guide QG instruction for people with MS.

massage, 20 minutes of QG practice such as Eight Section Brocade followed by Tai Chi walking, 10 minutes of seated meditation, and 5 minutes of closing remarks. The Eight Section Brocade is well-known, simple, easy to perform, and includes components such as stretching the back, gentle rotation, raising the arms, crossing the mid-line, standing postures that strengthen the legs, and rhythmic breathing. Tai Chi walking provides a walking component to help with balance and coordination. Modifications might include performing the movements seated (foot movements for the walking could be performed while seated), reducing the range of motion of movements, reducing the number of repetitions, and visualizing movements.

Other components of the class structure and delivery could include a frequency of two times per week for 12 weeks and five days a week of home practice for 20 minutes with a provided video. The class size would have no more than ten students. The instructor would have at least five years of QG teaching experience, plus knowledge of MS and its symptoms, and specialized training in working with people with MS. Emphasis might be placed on basic QG principles, including moving with intention, rhythmic breathing, feeling relaxed when performing the movements while maintaining an awareness of proper alignment and posture. The instructor would set ground rules for maintaining a safe and supportive classroom environment. The space would be ADA accessible with chairs and bolsters available for support, and room temperature control. An online option might be available for those unable to attend in person. The instructor would provide one-on-one support if needed, recommend modifications, provide encouragement and feedback, allow for rest breaks, and repeat movements several times to develop a flow. The instructor would also offer written and verbal information about QG principles and theory.

Discussion

This is the first study surveying experts to inform protocol development and guidelines for QG content and delivery for people with MS. Approximately 125 QG forms and movements were recommended for MS. While this is not a small number, it is, in fact, just a small proportion of the estimated thousands of QG forms/movements.⁶ It is important to note that this list should be interpreted as an example of the diversity of QG and not necessarily as a comprehensive list of prescribed movements for MS. Our goal was not to identify a single QG form that is superior to others for MS, but rather to understand the fundamental components of QG that may be important to consider in a protocol for MS. For example, respondents listed QG forms, movements, and practices based on their ability to address neurologic, musculoskeletal, immune, cognitive, and psychological functions. Respondents also described several mechanisms of action based on TCM theory, such as activation of meridians (e.g., Urinary Bladder, Gall Bladder, Kidney) connected to the brain and CNS. Research suggests a link between meridian pathways described in TCM theory to inter- and intramuscular fascial planes of loose connective tissue that may impart increased electrical conductivity, pressure sensitization, and flow of interstitial fluids.²⁵ This might explain, in part, a possible mechanism by which QG movements and gentle meridian stimulation through massage, tapping, breathwork, or vocalization could affect motor and non-motor symptoms in MS.

The heterogeneity of QG forms recommended also suggests that the form may not be as important as how it is presented and taught. Many respondents felt that any QG form/movement could benefit people with MS if basic principles were met (e.g., intentional movement, correct

alignment/posture, focused awareness, rhythmic breathing/movement, and a relaxed mind and body). Mills, who developed a manual of simple QG movements for MS, recommends a similar approach.²⁶ His QG program for MS consists of seven stages: (1) cultivating safety through grounding, breathing, and visualization; (2) releasing tension through stretching, shaking, and bouncing; (3) postural alignment; (4) self-healing by creating “inner space” through seated, simple Tai Chi movements and visualization; (5 & 6) developing a sense of balance and “finding your feet again” through simple standing and walking movements; and (7) meditation for gathering and centering.²⁶ He places a large emphasis on addressing the sympathetic nervous system response. In our study, most respondents similarly emphasized calming the nervous system and keeping movements simple and gentle.

In addition to the content of a QG protocol, the class structure and learning environment are also critical to ensuring the safe and successful adoption of QG by people with MS. Wayne and Kaptchuk, in describing Tai Chi as a complex, multicomponent intervention, suggest several therapeutic components including psychosocial interactions, alternative health paradigm/philosophy/spirituality, and ritual/icons/environmental effects.¹⁵ In our analysis, these components can be grouped into aspects of the QG class structure and learning environment, which are generally under the instructor’s control. Thus, instructor training may be critical to developing a QG protocol for MS, particularly in creating a safe and supportive environment through the physical classroom space, social interactions, emotional support, and individualized modifications. This would also necessitate some basic training in MS, including understanding common symptoms and disease progression.

One of our study goals was to provide expert input to inform the development of a QG protocol for MS for clinical trial research. Results generated from this study provide options of QG forms and movements that could be refined and tested in future studies. Additionally, results pertaining to class structure, including class size, frequency and duration of instruction and home practice (i.e., “dosing”), could be tested in a clinical trial.

Our findings serve as a starting point for developing QG guidelines for people with MS. Our results share common themes with guidelines developed for the structure and delivery of QG for cancer patients.²¹ Both stress the need for physical accessibility to accommodate different mobility and activity tolerances and rest breaks. Although the cancer guidelines do not specify the frequency of classes, they do provide a class schedule for a 60-minute class that aligns closely with our sample class protocol.²¹ Other common themes include screening tools to assess individual needs, starting with simple movements that can be progressed over time, and video or written instructions for home practice. Both sources recommend instructors be effective communicators, empathetic, able to perform the QG movements with

competency, and have a basic understanding of the disease process. Lastly, instructors should be able to provide education on QG theory and allow time for socializing.

One unique aspect of MS that distinguishes it from other medical conditions is the high variability in disease onset, clinical course, and symptom presentations.²⁷ Due to the localized nature of lesions within the CNS and the unpredictability of demyelinating events, symptoms can vary over time within and between individuals. Thus, understanding this variability related to specific MS symptoms is critical for teaching QG effectively to an MS population and maximizing any potential therapeutic benefit. Reflecting this understanding, most survey respondents felt it was essential that instructors have a basic understanding of MS to deliver an effective practice. The Medical Tai Chi and Qigong Association recommends accreditation standards for QG instructors working with chronic medical conditions, such as training in biomedicine, including neuroscience.²² Although accreditation of QG instructors is controversial,²² our findings reinforce the importance of a basic understanding of the challenges and limitations people with target disease conditions experience to ensure student safety and maximize benefits. In addition to the current study, our group has conducted a related study collecting qualitative data from people with MS who regularly practice QG. The results of this study (publication pending) will further provide insights into which elements of QG people with MS find beneficial and will complement the data from this study.

Strengths and Limitations

This study successfully collected expert opinions from a diverse set of instructors, researchers, and clinicians concerning the content and delivery of QG to a US-based MS population. Our respondents had a high degree of training and experience, representing much of the US, with an equal balance of men and women.

Our primary limitation was a low response rate resulting in potential nonresponse bias. We found it challenging to specifically identify those within our primary target audience (i.e., researchers, QG instructors, and clinicians with experience working with people with MS through QG or other movement therapy) with the information readily available. Thus, we intentionally cast a wide net that likely included people who did not meet our inclusion criteria. Had we hand-picked the invitees based on personal contacts, our response rate may have been higher, but it would have compromised generalizability and breadth in doing so. Additionally, the length of the survey and the sizeable qualitative component likely contributed to a higher survey burden and lower response rate. Respondents’ expertise in QG and MS was self-reported. Another source of bias was limiting the survey to a US-based, English-speaking population, thus excluding QG experts in China and other places where many QG masters and researchers reside. Although having input from a larger

international population of experts would enhance our results, our target intervention was for people with MS living in the US, thus we feel our sample is appropriate. Our sample was primarily white race, and future work would benefit from having a more racially diverse sample. Another limitation was that our survey only included three participants with a diagnosis of MS. Although these participants were able to provide a patient perspective in addition to being QG instructors and QG practitioners, input from more people with MS who regularly practice QG would be helpful in informing practice guidelines.

Results from this study will help inform future studies to develop consensus-based QG protocols for MS that could be tested in clinical trials and disseminated to QG instructors and movement-based therapists who work with people with MS.

Conclusion

This study provides a foundation for developing QG guidelines and protocols for people with MS. Our results suggest that QG for people with MS may include forms that provide general health benefits but also target mechanisms of action specific to MS, such as calming the mind and nervous system and improving muscle strength, balance and coordination, immune regulation, and circulation. Respondents identified a wide range of QG forms and movements, suggesting flexibility in selecting QG forms/movements for MS if fundamental principles are included and modifications can be tailored to individual needs. Principles such as correct posture, intention, focus, rhythm, and relaxation were highlighted. The most salient instructor qualities were the ability to convey information effectively, be caring and compassionate, demonstrate proficiency in QG, and have a basic understanding of MS. Other notable themes included keeping movements simple, fostering a sense of community, providing encouraging feedback, and encouraging students to honor their individual journey. Although this research focuses on MS, our general findings can likely be applied to other medical conditions that involve limited mobility and/or cognitive function.

Acknowledgements

We thank our survey respondents for their time and willingness to participate in our survey. We are thankful to Anne Starks Acosta for her assistance with Dedoose software.

Author Contributions

LB: Conceptualization, Methodology, Investigation, Formal Analysis, Writing-Original draft preparation. **JV:** Formal Analysis, Validation, Writing- Reviewing and Editing. **NP:** Formal Analysis, Validation, Writing- Reviewing and Editing. **LW:** Validation, Formal Analysis, Writing- Reviewing and Editing. **GY:** Writing- Reviewing and Editing. **RB:** Supervision, Funding Acquisition, Writing- Reviewing and Editing. **HZ:** Supervision, Funding Acquisition, Writing- Reviewing and Editing.

Declaration of conflicting interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: LB has received payment for teaching QG since 2005. The other authors declare no conflicts of interest.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the National Center for Complementary and Integrative Health (NCCIH), Building Research across Inter-Disciplinary Gaps (BRIDG) Grant R90AT008924 to LB and T90AT008544 to JV and NP. Additional funding through NCCIH includes Grant K24AT009465 to GY, K24AT011568 to RB. LW was supported by the National Center for Medical Rehabilitation Research within the National Institute of Child Health and Human Development (K23HD101667) and the Portland VA Health Care System. Study sponsors and funders did not have a role in study design, collection, management, data analysis, or manuscript composition and submission. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health..

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Supplemental Material

Supplemental material for this article is available online.

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