



Use and perceived effectiveness of complementary therapies in Parkinson's disease



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ABSTRACT

Introduction: Complementary therapies are commonly used by people with Parkinson's disease to relieve symptoms not fully addressed by pharmacologic and rehabilitation therapies currently available through medical clinics and programs. Three prior surveys in the US have shown that 40–85% of patients have used complementary therapies. We were interested in understanding what complementary therapies (CTs) our patients had used, to treat what symptoms, and whether they felt that the treatments were effective.

Methods: Patients scheduled for a return visit to a center neurologist were mailed a survey and instructed to bring the completed survey to their clinic visit. The survey contained questions on CTs used, effectiveness, and for what symptoms was the CT helpful. Willingness to participate in CT research was also included in the survey.

Results: 272 of 435 people with Parkinson's disease who completed the survey (62.5%) had tried some kind of CT, including a higher proportion of women than men (75.7% vs 53.8%; $p < 0.01$). Massage was the most frequently used therapy followed by yoga, Tai Chi, meditation and acupuncture. A high proportion of patients found the CT to be effective, for instance meditation was viewed as helpful by 85% of patients. Almost 2/3 of patients said they would be willing to participate in a research study of a CT.

Conclusions: Complementary therapies are frequently used by people with Parkinson's disease coming to our center, and are viewed to be helpful for both motor and non-motor symptoms. Formal research assessments of therapies such as meditation are warranted.

1. Introduction

With the introduction of dopaminergic therapy 50 years ago, Parkinson's disease (PD) was transformed from a fatal disease into a chronic disease, with a course of twenty years or (much) longer and with a complex and varied set of symptoms. In addition to the motor symptoms classically recognized in PD, there is growing awareness that PD-related non-motor (cognitive, mood, autonomic, sleep) symptoms can be problematic and reduce the quality of life in people with PD. Given the long and slowly progressive course of PD, the lack of disease-modifying therapies, the increasing awareness of the broad spectrum of symptoms, and incomplete benefits of prescribed medications, people with PD are increasingly likely to pursue additional or alternative avenues to relieve their symptoms. According to a 2007 survey, Americans spent well over \$30 billion dollars/year on complementary and alternative medicine [1].

Unfortunately, medical providers often have little awareness of which patients are utilizing what complementary therapies (CT), what

symptoms they are trying to treat, and whether the treatments are beneficial. Previous surveys of Parkinson's patients in the United States have shown a high utilization of CT ranging from 40 to 85% of surveyed patients [2–4; in Massachusetts, Colorado, and Delaware]. Outside the US uptake of CT has ranged from 25% in Argentina to 76% in Korea [5,6]. The current study was undertaken to assess the prevalence of CT utilization by patients attending our Parkinson Foundation Center of Excellence in Minnesota, understand the perceived effectiveness of the CT, and identify the symptoms for which patients were seeking relief.

2. Methods

We conducted a survey of patients who were seen at Struthers Parkinson's Center. Surveys were sent by mail to 883 patients who had follow-up appointments with one of the center's four neurologists during March–July 2016, with instructions to bring the survey to their neurology appointment. Surveys were labelled with an identifier that permitted linkage to the medical record for determination of age,

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gender and diagnosis.

The study was approved by the Park Nicollet Institute Institutional Research Board.

2.1. Survey

The survey asked whether the patient had tried any of a list of 11 different “non-medication treatments” (we deliberately did not use the term “complementary”, feeling that “non-medication” was a more neutral term). The eleven listed treatments were taken from a National Center for Complementary and Alternative Medicine (now the National Center for Complementary and Integrative Health) listing of alternative treatments (specifically, Tai Chi, Yoga, Aromatherapy, Essential oils, Acupuncture, Acupressure, Massage, Meditation, Visualization, Reiki, and Homeopathy). Subjects who had tried a treatment were then asked if they felt the treatment was effective or not (yes/no), and what symptom(s) they felt the treatment benefitted. A space was provided at the end of the survey for patients to write in other “non-medication treatments” that they had tried that were not on the list. Our focus was on method-based treatments and thus, over-the counter medications, supplements, or vitamins were not included as “non-medication treatments”. Patients who had tried at least one of the listed CT’s and/or had written in another non-medication treatment were grouped and compared to those who had not tried any CT or other non-medication treatment.

Those who had not tried any of the listed treatments were asked to select from a list of choices as to why they had not tried them. Finally, all subjects were asked if they would be interested in participating in a research study involving a non-pharmacologic treatment.

2.2. Statistical analysis

Continuous variables were compared with the Student’s t-test. The frequency of categorical variables was compared with the χ^2 test. The statistical analyses were performed using Minitab statistical software program. A value of $p < 0.05$ was considered to be statistically significant.

3. Results

3.1. Population characteristics

883 surveys were sent and 500 were returned (56.6% response rate). 442 of 500 (88.4%) had Parkinson’s disease, compared to 86.7% of those who were mailed the survey. Seven returned surveys were blank. We report results of the 435 non-blank surveys completed by people with Parkinson’s disease. Of these respondents, 262 (60.2%) were male, and the average age was 70.6 ± 9.3 years (Table 1). This is comparable to those who were mailed the survey (60.9% male, average age was 71.9 ± 10.0 years).

3.2. Non-medication utilization

Of the 435 respondents, 221 (50.3%) had tried at least one of the 11 non-medication treatments listed, with some trying up to 8 different treatments (average 2.3 different therapies) (Fig. 1). An additional 51

Table 1
Demographics.

Count	Overall	Tried Listed TX	Tried Any TX	Tried No TX
	435	221	272	163
Age	70.6 ± 9.3	69.3 ± 9.0	69.4 ± 8.9	72.6 ± 9.7
Male (%)	n = 262 (60.2%)	40.1%	53.8%	46.2%
Female (%)	n = 173 (39.8%)	67.1%	75.7%	24.3%

patients wrote in some type of treatment they had tried that was not among those listed in the survey (thus creating a total of 272/435 patients, or 62.5%, who had used a complementary therapy) (Table 1). 163 patients (37.4%) had not used any of the treatments listed, and did not write in any other “unlisted” treatments either.

Of survey respondents, 65.5% indicated that they would be interested in participating in a research trial involving a non-pharmacological treatment, including 52.9% of those who had not tried any treatments, and 75.4% of those who had tried one of the 11 specified treatments (differences were not significant).

Only 53.8% of men, but 75.7% of women had, tried some type of treatment ($p < 0.01$ for both).

3.3. Perceived effectiveness of CT

Massage was the most commonly used treatment (29.7% of patients), and was also felt by a high proportion of patients to be effective (78.3%) (Figs. 1 and 2). Yoga, Tai Chi, Meditation, and Acupuncture had also been tried by over 10% of patients (Fig. 2). The treatments most commonly felt to be effective were Meditation (85.5%), Visualization (79.2%), Massage (78.3%), and Acupressure (78.6%). Nine of eleven non-medication treatments were felt to be effective by over 50% of the patients who had tried them (Fig. 2).

Table 2 shows the responses to an open-ended question that asked patients what symptom(s) they felt benefitted from a particular treatment that they had tried. The responses are listed verbatim.

Another open-ended question asked “Are there other non-medication treatments that you have tried that are not listed above?” The number and variety of responses to this question surprised us. Responses were classifiable into five general categories: a large variety of exercise activities; non-exercise activities (such as art and music activities); visits to allied health or other practitioners (such as chiropractors or psychologists); oral/cutaneous treatments; and other (such as bright light therapy).

Finally, patients who had not tried any of the specific CT listed in the survey were asked why they had not tried CT. Respondents to this question included the 163 individuals who had not tried any CT, as well as the 51 who had not tried a specified treatment but who had written in a CT (214 total subjects). The most common reasons that respondents indicated they had not tried any of the listed CT were 1) they didn’t know about them (40.7%), and 2) the doctor had not suggested trying them (25.7%). Less commonly cited were: lack of research evidence (15.4%), don’t know where to find them (15.4%), don’t believe they will work (12.1%), don’t need them (10.7%), and cost (9.3%).

4. Discussion

This study differed from previous surveys, in that we asked not only about the use of CT, but about the symptoms that our patients were trying to treat, why they didn’t try a CT, and about the perceived effectiveness of the CT that respondents had tried.

We found a high degree of interest in CT within our Parkinson’s population, as shown by the over 50% response rate to the survey itself, the observation that well over one-half of PD patients had tried a CT, and the finding that almost two-thirds of respondents would be interested in participating in a research study involving a CT. This is consistent with prior surveys showing an uptake of CT in Parkinson’s disease of 25%–85% [2–10].

Gender emerged as a significant factor in our population, with 75.7% of women but only 53.8% of men having tried some kind of CT. Although this is consistent with the findings of Pecci [5] and of Lökk [9], other patient surveys did not show a gender difference [2,4,6,7,10].

The perceived efficacy of CTs was quite striking, with over 75% of patients feeling that massage, visualization, acupressure, and meditation were effective. The perceived success of yoga, Tai Chi,

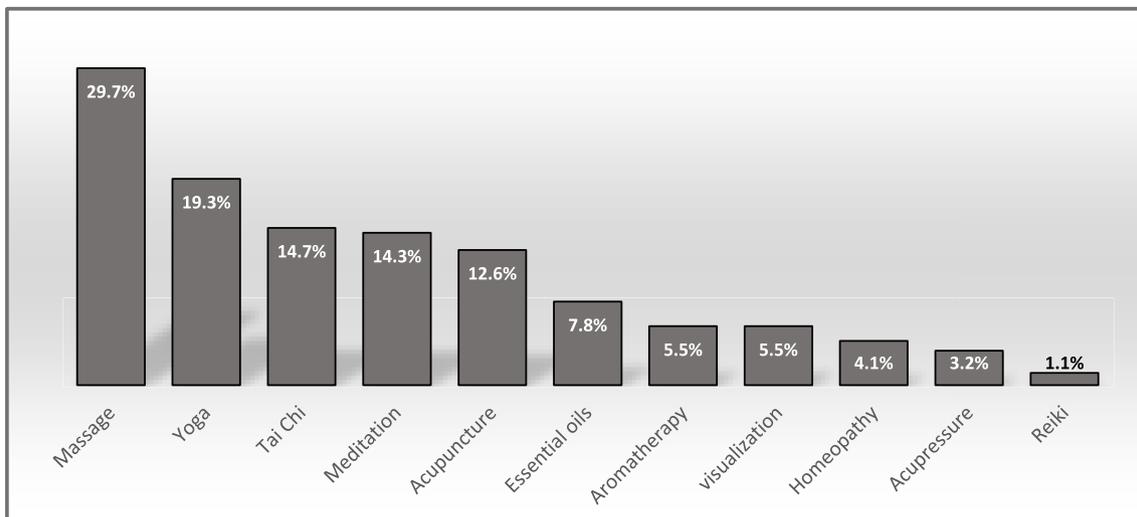


Fig. 1. Percent of patients who tried specifically listed non-medication treatments (N = 435). The survey asked individually about each of the eleven treatments.

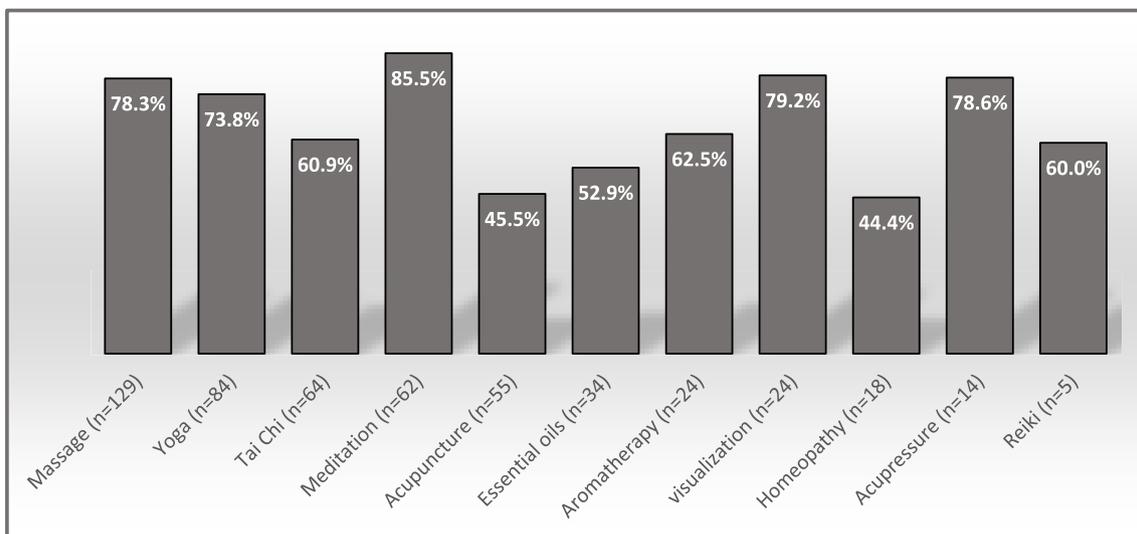


Fig. 2. Percent of patients trying non-medication treatments who found them to be effective.

aromatherapy, essential oils, and Reiki were somewhat lower, but still over 50%. Of the eleven specified treatments in our survey, acupuncture and homeopathy were least likely to be viewed as beneficial.

We were surprised at the large number of non-medication

treatments for Parkinson's disease that people wrote in, suggesting that a subset of patients consider a wide range of activities as having potential health-enhancing effects in the setting of Parkinson's disease.

Meditation stands out as having been viewed by 85% of patients to

Table 2

Patient-identified benefits of non-medication treatments.

Treatment	Symptom that improved
Tai Chi	balance; anxiety; movement and balance; movement was easier; helps my stiffness; tension; calming, memory; stretching improvement my movement.
Yoga	movement and balance; balance; balance, focus, strength; strength; relieves stiffness, more flexible; flexibility; Parkinson's; more fluid motion; posture; walking; tremor.
Aromatherapy	restlessness; anxiety, mood, works great; calming; relaxation; nausea; alertness; helped sleep; calming effect.
Essential Oils	sleep; calming; digestion and sleep; relaxation; Parkinson's; pain; helps my anxiety; achy joints, RLS, GI issues.
Acupuncture	pain; mood, sleep; leg/feet cramping/allover well-being; sore shoulder; back pain; muscle tightness, pain; overall jitteriness/tremor; eased pelvic pain; calming tremor; helps relieve pain.
Acupressure	relaxed tight muscles; stiffness; pain; specific release.
Massage	stiffness; sore/stiff muscles; stiffness, relaxation; relaxing of muscles; pain; foot cramping; calming; relax, decrease pain; relaxed the muscles; tense muscles; muscles aches; calms tremors.
Meditation	thinking more clearly/focus; affirms my positive attitude; anxiety; anxiety/depression; reduced tremor; calming; stress; muscle tightness.
Visualization	calms dyskinesia; helps with freezing; quieting; emotional well-being; calming; tremor reduction; hope for the future; irritability, pain, muscle tightness, relaxation.
Reiki	Parkinson's; tremor.
Homeopathy	Parkinson's; fatigue; fatigue, digestion; pain; ear problem; muscle pain.

be helpful in reducing such symptoms as stress, tremor, muscle tightness, and anxiety, and/or improving attitude and clarity of thought. We have no further details as to what our patients considered to be “meditation”. However, a PubMed review of “Parkinson’s” and “meditation” or “mindfulness” reports from 2010 to 2017 yielded results from five studies [11–16] and one case report [17]. The studies included a total of 142 subjects, 82 of whom completed a course of treatment (6 weeks in one study, 8 weeks in the others). Two studies included controls, and the others were nonblinded open label trials. Results included improvements in depression, anxiety and stress as measured by the Depression Anxiety Stress Scales [16], reduced anxiety, depression, and rigidity, improved gait and balance and increase in the Five Face Mindfulness Questionnaire (FFMQ) “Observe” scale [15], a non-significant improvement in function and wellbeing on the PDQ-39 [14], and improved Unified Parkinson’s Disease Rating Scale (UPDRS) motor scores, increased FFMQ Observe score, and increased gray matter density in multiple brain regions of interest on MRI [12,13], and changed patterns of coping and improved mindfulness in the context of loss [11]. A more focused study of the effects of meditation in Parkinson’s disease seems warranted.

The strengths of this study include 1) the numbers of patients surveyed (435 surveys analyzed; prior surveys included 80–325 patients), and 2) it was a convenience sample of patients attending clinic—a “real-world” sample of patients. However, the results reflect patient behavior at a single location, which could reflect a more empowered patient group than those who do not have access to the comprehensive services of a Parkinson Foundation Center of Excellence. We also do not know anything about the behavior of survey nonrespondents. As no patient identifiers were collected, the demographic and clinical characteristics of survey responders and those who benefited from CT could not be determined. Payor information was not collected, therefore, the role of financial constraints in using CT could not be determined. However, the authors believe that most complementary treatments were paid for as an out-of-pocket expense.

Obviously, a single yes-no, retrospective question about perceived efficacy of a treatment, and an open-ended description of the symptoms effectively treated, in no way replaces a double-blind, randomized, controlled, trial. Well-designed clinical trials would permit a much more nuanced understanding of what symptoms improve with which treatment, and facilitate the possibility of third-party payment for such treatments. But in the meantime, this survey reminds us that our patients are seeking out alternative strategies to reduce their symptom burden, and that these treatments seem to help them. Table 2 also provides some insight as to the symptoms for which we do not currently have satisfactory medical or pharmacological treatments, for which patients seek answers elsewhere: balance, anxiety, tremor, pain, fatigue, and mental clarity, to name a few.

Patients rely on the medical team—doctors, nurses, and allied health providers—to at least make them aware of the possibility of CT, if not overtly recommend them. We run the risk of assuming, in the internet era, that our patients already know about these non-prescription, outside-the-clinic kinds of treatments, which this study suggests that some do not. Medical practitioners may not want to give the impression that they are endorsing a treatment for which there is no double-blind, randomized controlled report of benefits and side effects. But while we wait for formal studies to occur, if 85% of people with Parkinson’s disease who use meditation find it beneficial (this study), and none of 500 studies of Tai Chi have shown it to worsen any condition or have any serious adverse effects [18], perhaps we should at least ensure that patients are aware that these activities exist and are used, successfully, by a number of patients.

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Declarations of interest

None.

Author roles

- (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data: Donley, McGregor, Wielinski, Nance
- (2) drafting the article or revising it critically for important intellectual content: Donley, McGregor, Wielinski, Nance
- (3) final approval of the version to be submitted: Donley, McGregor, Wielinski, Nance

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