



Use of complementary and alternative medicine in patients with multiple sclerosis in Germany

Mario Gotta^a, Christoph A. Mayer^b, Jutta Huebner^{a,*}

^a Klinik für Innere Medizin II, Hämatologie und Onkologie, Universitätsklinikum Jena, Am Klinikum 1, 07747 Jena, Germany

^b Klinik für Neurologie, Johann Wolfgang Goethe Universität, Schleusenweg 2-16, 60528 Frankfurt am Main, Germany



ARTICLE INFO

Keywords:

Multiple sclerosis
Complementary and alternative medicine
Patient-physician communication

ABSTRACT

Background: The use of complementary and alternative medicine (CAM) for chronic diseases such as multiple sclerosis (MS) is becoming an increasingly important issue for those affected. Especially in Germany there are only a few studies dealing with CAM, as yet. The aim of this study was to assess the prevalence, the methods used, the subjective benefits as well as physician/patient communication.

Methods: A structured questionnaire including demographic and disease-specific data, CAM use, perceived benefits as well as physician/patient communication was sent to real and web-based self-help groups for MS in Germany.

Results: 343 answers could be evaluated. 77.3% of the participants were females. The mean age was 45.0 ± 11.9 years and the duration of the disease was 12.0 ± 9.6 years. 81.9% said they were using CAM, nearly half (44.8%) used it alternatively to conventional medicine. The average number of CAM- methods used were 3.6. The most popular methods were vitamin supplements, Yoga/Thai chi/Qi Gong, relaxation techniques and meditation. Approximately half (139/49.5%) of CAM users disclosed this to their treating neurologist. Yet, 37,6% have doubts on the competence of the respective physician.

Conclusion: Patients with MS have a strong interest in CAM. Usage as alternative therapy is widespread and puts patients at risk of progress of the disease. As patient/physician communication on the topic is increasing, neurologists should be attentive to guiding their patients through safe complementary methods.

1. Introduction

Multiple sclerosis (MS) (or encephalomyelitis disseminata) is a chronic, neuroinflammatory disease of the central nervous system which causes an increasing damage to the neural axons and may lead to permanent restrictions. Around 2.3 million people are affected worldwide.¹ In Germany approximately 200,000 patients are affected according to the latest data.²

The etiopathogenesis of MS remains unclear. Autoimmune, infections and genetic factors may all contribute to the disease^{3–5} There are three clinically distinguishable courses of the disease: the relapsed-remitting course (RRMS), the secondary-chronic progressive course commonly following the RRMS course (SPMS, progression independently from relapses) and the primary-chronic-progressive (PPMS, commonly not showing relapses).⁶ The disease is considered as incurable. Drugs aiming at reducing the relapse rate are often associated with side effects.^{7,8} During the course of the disease, associated symptoms such as pain and sleep-disorders may occur resulting in anxiety, stress, fatigue and depression.⁹

In other chronic progressive diseases, Parkinson's disease or various types of cancer for example the usage of complementary and alternative medicine (CAM; natural healing methods, traditional healing methods) is wide spread.^{10–13} There is no uniform definition of CAM. Various definitions have been used in previous literature so far.^{14,15} In general these are methods which have not yet entered medical routine either due to proven lack of efficacy, lack of empirical evidence of efficacy or lack of supportive academical data derived from sufficiently conducted and controlled clinical trials.^{16,17}

CAM methods are used in addition to (complementary) or instead of (alternative) conventional medicine.

There is no evidence-based accepted CAM treatment as a standard therapy by the MS Therapy Consensus Group (MSTKG). In various surveys concerning CAM in MS patients, usage was up to 80%.¹⁸ Frequently used CAM are special diets, vitamin and dietary supplements, relaxation techniques, acupuncture and homeopathy.^{14,19,20} Often patients turn to CAM after unsatisfactory experiences with doctors and conventional medicine. With CAM, they are looking for a milder therapy with fewer side effects. These methods help them to feel more

* Corresponding author.

E-mail addresses: mario.gotta@yahoo.de (M. Gotta), christoph.mayer@kgu.de (C.A. Mayer), jutta.huebner@med.uni-jena.de (J. Huebner).

involved in their treatments and the decisions made.²¹ To date only a few studies have focused on the use of CAM by patients with MS in Germany.^{14,22} Many of the aforementioned publications are from North America and Scandinavia. Cancer patients have shown a different user rate and methods, which also varies between countries.^{10–13} Accordingly, data concerning CAM and MS from abroad may not be valid in Germany.

An aspect that is rarely noticed in previous literature is where patients search for information about CAM and how decisions are communicated between patient and doctor. Furthermore, only a few studies deal with the satisfaction of complementary and alternative medicine in patients with MS.

In summary, CAM is largely described by patients as a positive therapy without major setbacks and little or no side effects.²¹

The aim of the current study is to obtain an overview of the prevalence of CAM use in Germany and subjective perceived benefits. Furthermore, we aim to assess information and communication pathways patients' use.

2. Methods

2.1. Survey

A first version of the questionnaire for CAM for patients with MS was developed in collaboration with the working group Prevention and Integrative Oncology at the German Cancer Society and the Department of Neurology at the University Hospital Frankfurt. It consists of a survey developed in the field of oncology which is already widely used and published.

In a pilot phase the survey was tested in a self-help group of 28 affected patients and revised in a few points according to patients' comments. The final version contained 23 questions divided into 6 categories:

1. General attitude and opinion about complementary and alternative medicine
2. Demographic data
3. Disease-specific aspects
4. Use of CAM and reasons for it
5. List of common CAM and satisfaction of each
6. Communication of CAM with different physician groups and medical practitioners

The survey consisted of closed questions which could only be answered with "yes", "no", "I do not know" or "I am not sure" and questions with multiple answers were allowed. In Section 1 a free text field was inserted. In Section 5 a list of current CAM methods was prepared. In the adjacent three columns it was then indicated whether the respective method was currently used, whether it was used before the MS diagnosis and how satisfying was the respective method (Likert scale 1–6, 1 = very satisfied, 6 = not at all satisfied).

The questionnaire was provided by PDF and as Questback online survey tool.

2.2. Study participants

For the distribution of the questionnaire all 16 MS associations were asked by e-mail to support the survey. After a short information on the aims and conduct of the survey, the participants could click on the PDF file of the questionnaire which could also then be returned by e-mail. All patients older than 18 years with physician-confirmed multiple sclerosis were eligible to participate in this study. Nine national associations responded positively to the request; the remaining 7 failed to answer. In addition, the link was posted in 3 virtual self-help groups on the social network Facebook. The survey started on January 13, 2015 and ended on June 13, 2015.

2.3. Statistical analysis

Statistical analysis was performed using IBM Statistics SPSS version 22. In order to summarize the empirical data, descriptive statistics were compiled. Continuous data was displayed as a mean \pm standard deviation. Chi-squared or *T*-test were used to determine associations between nominal variables. For all statistical analyzes, the significance (α) was set to $P < 0.05$.

2.4. Ethics vote

According to the regulations of the Ethics Committee of the University Clinic of J.W. Goethe University Frankfurt/Main, an anonymous survey did not require an ethics vote.

3. Results

3.1. Demographic data

A total of 470 people responded to the online questionnaire and 273 of these were completed. In addition, we received 70 questionnaires by mail and e-mail so that a total of 343 questionnaires could be evaluated. 265 participants (77.3%) were women. The average age of all participants was 45.0 (SD 11.9) years. The data on demography and disease are given in [Table 1](#).

The median duration of the disease since the physician's first diagnosis was 12.0 (SD 9.6) years. 158 (46.1%) of the interviewees and thus almost half said they had a relapsed remitting course. Prevention of attacks with at least one drug was used by 199 (58%). The most frequently used drug was interferon, which was used by 73 (35.3%) of the patients. 74.3% ($n = 255$) of the interviewees indicated how long their last relapse was. About half of these were less than a year ago (45.9%). Within the last five years, 85.5% ($n = 218$) of the patients suffered a relapse. The severity of MS can be classified using the Expanded Disability Status Scale (EDSS). The mean value of those who made an indication ($n = 328$) was 3.69 (SD 2.01). More than 90% of respondents experienced MS-specific symptoms during the course of the disease. [Table 2](#) shows an overview of all symptoms. Against the complaints, 44.9% of participants took medications. Most patients suffered from general fatigue (79.6%), with a score of just 6 on the Likert scale it also shows this to be the highest degree of impairment.

3.2. Use of CAM

Of all 343 participants 281 (81.9%) stated that they use at least one of the CAM therapies mentioned in the questionnaire. Although women used these more frequently than men (83.8% vs. 75.6%), no association could be detected ($p = 0.101$). Similarly no significant difference can

Table 1
Demographics of survey respondents ($n = 343$).

Variable		n (%)
Gender	Female	265 (77,3%)
	Male	78 (22,7%)
Age (years)		45 (12,0)
MS Duration (in years)		12,0 (9,6)
MS Type	Relapsing remitting	158 (46,1%)
	Primary progressive	25 (7,3%)
	Relapsing progressive	44 (12,8%)
	Secondary progressive	60 (17,5%)
	Unsure of type	56 (16,3%)
EDSS Score (Mean (SD))		3,69 (2,01)
DMT use	Yes	199 (58%)
	No	144 (42%)

[EDSS = Expanded Disability Status Scale; DMT = Disease Modifying Therapy; SD = Standard deviation].

Download English Version:

<https://daneshyari.com/en/article/8563538>

Download Persian Version:

<https://daneshyari.com/article/8563538>

[Daneshyari.com](https://daneshyari.com)