

PATIENT CASE REPORT

A Patient-defined “Best Case” of Multiple Sclerosis Related to the Use of Complementary and Alternative Medicine

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Key Words

Multiple sclerosis, MS, complementary and alternative medicine, CAM, case report, exceptional cases, Norway

ABSTRACT

Chronically ill people are frequent users of complementary and alternative medicine (CAM). Some patients experience great benefits from their use of CAM, like patient “XX” in this case report. XX was diagnosed with secondary progressive multiple sclerosis in 2004 and has reported a “best case” after the use of Dr Birgitta Brunnes’ unconventional treatment. The patient reports that many of her symptoms that, according to her neurologist, were irreversible are gone or have been greatly reduced. Such patient-defined “best cases” related to the use of CAM should be further explored to optimize and safeguard patients’ treatment decisions and treatment outcomes.

摘要

慢性病患者经常使用补充和替代药物（CAM）。一些患者在CAM的使用过程中获益极大，比如本病例报告中的患者“XX”。2004年，XX诊断患有继发进行性多发性硬化症，而在接受Birgitta Brunnes医生的非常规治疗之后，该患者作为“最佳病例”进行报告。根据其神经科医生的意见，该患者报告称，她的许多症状永久性消失，或得到了极大的缓解。对这种与使用CAM相关的患者定义的“最佳病例”，应该进行进一步的探索，以优化并保护患者的治疗决策和治疗结果。

RESUMEN

Las personas que padecen enfermedades crónicas son usuarios frecuentes de la medicina complementaria y alternativa (CMA, por sus siglas en inglés). Algunos pacientes experimentan grandes beneficios a partir del uso de CAM, como es el caso de la paciente “XX” que se analiza en este caso clínico. Dicha paciente fue diagnosticada con esclerosis múltiple secundaria progresiva en el año 2004 y fue registrada como el “mejor caso”, luego de recibir el tratamiento no convencional de la Dra. Birgitta Brunnes. La paciente reconoció que muchos de sus síntomas, que según su neurólogo eran irreversibles, desaparecieron o se redujeron en gran medida. Dicha paciente, catalogada como el “mejor caso” relacionado con el uso de CAM, debe ser sujeta a análisis más profundos para optimizar y resguardar las decisiones que toman los pacientes sobre el tratamiento y los resultados del mismo.

Multiple sclerosis (MS) is an unpredictable condition both with respect to alternating exacerbation and remission of symptoms and variant symptom patterns.^{1,2} Studies show anxiety regarding what the future holds³ and high levels of depression and uncertainty in MS patients when they are compared to patients with other chronic diseases.⁴ MS-related depressive symptoms could be a function of prior disease-related impairment, life stress, and possible escape avoidance coping.⁵ Some MS patients experience conventional disease- and symptom-modifying drugs as having little influence on symptoms, functioning, or quality of life, while commonly experiencing adverse effects.⁶⁻⁸ Between 27% and 100%⁹ of MS patients use complementary and alternative medicine (CAM) to treat and live better with their symptoms. The Cochrane Collaboration defines CAM as

a broad domain of healing resources that encompasses all health systems, modalities and practices, and their accompanying theories and beliefs,

other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period. CAM includes all such practices and ideas self-defined by their users as preventing or treating illness or promoting health and well-being.^{10(p693)}

THE REGISTRY OF EXCEPTIONAL COURSES OF DISEASE

This case report was selected from the Registry of Exceptional Courses of Disease (hereafter referred to as “the Registry”). The Registry includes Scandinavian patient-defined, self-reported positive and negative exceptional courses of disease related to the use of CAM. To be included, the patients must have or have had a disease or health problem, must have experienced what they perceive to be exceptionally positive or exceptionally negative health effects, and must relate these health effects to the use of CAM. In a “best case,” the patient experiences reduced disease symptoms or full recovery.^{3,11-13}

³ For more information on the Registry, see pages 70-75 of this issue.

As of October 1, 2011, 72 patients diagnosed with MS were included in the Registry, all reporting "best cases." Acupuncture, nutritional therapy, reflexology, herbs and food supplements, homeopathy, massage/aromatherapy, and spiritual healing were the most frequently used CAM modalities among these patients.

CASE PRESENTATION

Context and Goal

We here present a self-defined "best case" of MS. The presentation is based on the Registry questionnaire, medical records, a medical assessment, and an in-depth interview. The goal is to describe a patient-defined "exceptionally positive" course of MS as seen from both a patient and medical perspective.

Medical, Social, and Family History

"XX" is a 46-year-old married Norwegian woman with several children. She is a university graduate who had been working full time for some time after being diagnosed but is now on a 100%-disability pension. Approximately 28 years ago, she had a facial paralysis on her right side from which she fully recovered after 1 to 2 months. About 15 years ago, she experienced 2 episodes of herpes zoster (shingles). She has otherwise been healthy. Several of XX's close relatives also have been diagnosed with MS.

Presenting Condition

When she was in her 20s, XX was diagnosed with probable MS but was not herself informed of the diagnosis. A few years later, she experienced partial loss of sensation in her legs and was finally officially diagnosed with secondary progressive MS at the age of 41 years. Her main symptoms were fatigue, problems with leg coordination after experiencing strain for some time, periodical memory problems, and urge-characterized urination. Subsequently, XX experienced severe fatigue and reduced sensation in her feet, legs, and fingers. She even found brushing her teeth exhausting. She continued to have problems holding and emptying the bladder and also experienced depression.

Treatment

No conventional treatment was provided by doctors within the conventional healthcare system. Within a year after being diagnosed, XX discovered the treatment given by Birgitta Brunes (BB), MD, and decided to participate in one of BB's courses.

BB is a Swedish medical doctor who herself suffers from MS and who has worked with treatment and rehabilitation of MS patients since 1994. She has developed a systematic approach to symptom alleviation, which she presented in a book¹⁴ published in the Scandinavian countries. With her colleagues, she gives courses for MS patients that usually last 4 days and focus on psychological factors (emotions, stress, etc), social factors, and medical treatment. These elements are combined in a treatment plan individually adapted for each patient.

BB does not consider her treatment as CAM per se.¹⁵ Her theory is based on conventional medical knowledge and practical experience from many years of working as a general practitioner. The treatment is only considered alternative in relation to the prevailing medical understanding of the cause and treatment of MS. The intention is not to heal MS but to alleviate MS symptoms.

The treatment rests on 3 pillars:

1. Neurotransmitters (noradrenaline, dopamine, acetylcholine, serotonin), vitamin B₁₂, and amino acids adjusted according to individual need;
2. detoxification (for instance, removal of amalgam or elimination of toxic environmental factors)^{14,15}; and
3. Psychotherapeutic treatment of basic psychological traits.

XX's Individualized Treatment

Use and Adjustment of Medication and Supplements. After careful self-testing, XX has found the suitable dosage for the different medications, and she is making necessary adjustments as time passes. Her current intake of medication and supplements include lofepramine (a tricyclic antidepressant) plus tablets containing norepinephrine to prevent urge incontinence. She asserts that these drugs also give her energy. She also takes acetylcholine and anticholinesterase in addition to phosphatidylcholine and lecithin from the health food store, which she contends create "heat" and help her empty the bladder and intestines. The intake of serotonin tablets and 5-hydroxytryptophan (5-HTP) from the health food store help her keep a brighter outlook on life and to be positive, sleep well, and not worry about the future and her illness. At the same time, she takes specially adapted amino acids for MS patients that attend to the muscles while she is not using them.

Detoxification. XX had her 8 amalgam fillings removed over a period of 2 years. To be able to tolerate the discomfort related to the removal of the fillings, she took large doses of cortisone for 3 weeks each time.

Psychotherapeutic Treatment. For almost 4 years, XX has rested systematically. Meditation and rest in the form of mental control and relaxation have been important. This has gradually helped her get better because according to her, "the body has economized on the neurotransmitters which the nerves are supposed to bring to the muscles." XX did not want to stop working, even though she understood that the job drained her of the little energy she had. The realization that she had to spend all her energy on herself in order to have a chance of getting better has been very important for her. Now she spends most of her time with her family. She is able to make herself and her own health a priority without feeling guilty.

Other Measures. In consultation with BB, XX has changed her diet according to advice from the MS center at a Norwegian hospital. She first omitted red meat,

fat, and dairy products and later omitted sugar and yeast, artificial sweeteners, and natural sugars.

OUTCOMES

Medical Assessment

MS and cancer cases in the Registry are assessed by medical doctors. Medically exceptional courses of disease are defined as courses occurring with less than 1% probability after the given conventional treatment based on current medical knowledge. The assessment of this case concluded, "Interesting description of Dr. Brunès' treatment and the experienced effects of this. This is, however, not a medically exceptional course of disease."

Patient's Perspective

XX thinks that the CAM treatment consisting of vitamins and minerals from the health food store along with "mind control" in the form of meditation and positive thinking support the conventional medical treatment included in BB's treatment model. The patient writes,

The supplements administer my immune system and the rest of my physical health, which again makes me stronger and helps me handle my MS better. . . . The reason why I experience my MS-course as exceptionally positive is that many of my symptoms that according to my neurologist were irreversible, now are gone or have been greatly reduced. I have a sense of touch in all fingers and toes and under the whole soles of my feet. Four years ago I was numb to my knees and sometimes all the way to my chest. I have more energy, can do more things myself, and I do not need to rest the whole day. I have much more control of the bladder. Going to the bathroom 13 to 16 times per 24 hours has now been reduced to about half of this. I have also learnt to handle the disease and to have a positive outlook on life. I am no longer melancholic. I actually feel that my life has never been as good as it is now, in spite of the many limitations caused by the disease.

Follow-up Care

XX can contact BB by phone whenever she feels the need for follow-up care.

Confidentiality and Informed Consent

The Regional Committee for Medical and Health Research Ethics and the Norwegian Data Inspectorate have approved the Registry. The patients have given their informed consent. Information that could identify the patient in this case report has been avoided. The patient has read and approved the case report.

DISCUSSION

BB and her treatment model have been criticized because the treatment is unconventional and expensive and the outcomes have not been validated through clinical studies.¹⁶ BB's treatment model includes a holistic and psychosocial medical approach to MS treatment.

Many arguments have been raised for a more patient-centered and biopsychosocial medicine to optimize and safeguard modern patients' treatment decisions and treatment outcomes.^{17,18} A qualitative study of patients' experiences and reflections with regard to their reported "best cases" of MS in the Registry found that these patients, independently of treatment systems, changed over time their position from passive recipients of conventional health care to explorers of healthcare. The concept of "explorer" implies action and entails all the social, cultural, and economical capital¹⁹ needed by the patients to take responsibility for and cope with their situations. As explorers, the patients, like XX in this case report, influence how an intervention is chosen and used. CAM facilitates the patients' own efforts that patients believe are needed for improved health and well-being in their lives with MS.¹³

CONCLUSION

A holistic and psychosocial medical approach to MS treatment, including hope and the ability for the patient to cope, was of vital importance to XX's positive outcome of the MS treatment presented in this case report. The patient-experienced benefits of CAM reported in "best cases" so far generate unexplored and complex questions worthy of further research.

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