

# Exceptional courses of disease related to the use of complementary and alternative medicine?

The course of serious disease is difficult to predict, even for experienced clinicians. In the encounter with complementary and alternative medicine (CAM), patients occasionally experience an inexplicable change. Some find that they undergo an unexpected positive development, whereas others experience an unexpected, negative change. Can scientific studies of exceptional courses of disease experienced by patients provide us with useful knowledge?

Since 2002, the National Research Center in Complementary and Alternative Medicine (NAFKAM) at UiT The Arctic University of Norway has registered unusual courses of disease associated with the use of CAM (1–2). As of 1 November 2015, the Registry of Exceptional Courses of Disease contains 412 reports, whereof 383 are reported as positive and 29 negative. Cancer, multiple sclerosis, chronic fatigue syndrome and asthma/allergy are the largest diagnostic groups. The most frequently used forms of CAM are acupuncture, nutritional advice, homeopathy, herbs and nutritional supplements, reflexology and healing.

The information in the registry is largely of a descriptive nature and cannot be used to assess the efficacy of complementary and alternative forms of medicine. However, the information in the registry forms the basis for research into patient experiences with CAM and the public health services (1–3).

## What is an exceptional course of disease?

«Exceptionally good courses of disease» are disease histories in which the patient experiences unexpected recovery or significant reduction in symptoms. «Exceptionally poor courses of disease» are courses in which the patient experiences an unexpected exacerbation associated with the use of CAM (1–2, 4).

A comprehensive amount of patient information is collected at registration: contact information, personal information, the patient's own assessment of their disease history, and treatment. With the patient's consent, information is also collected from the health services and alternative therapists.

An experienced general practitioner at the National Research Center in Complementary and Alternative Medicine performs a medical assessment of the anonymised patient history based on given criteria (2). When it is considered that there is a more than 10% probability that the course of disease can be explained on the basis of given (conventional) medical treatment,

the conclusion is *non-exceptional course*. If there is a less than 10% probability that the course of disease can be thus explained, this indicates a *possible exceptional course*.

An anonymised, possible exceptional course of disease is then reviewed by an independent, experienced specialist in the relevant field. During this assessment, diagnostic certainty, variability of measurement variables, the known natural course of the disease, its manifestation of sym-

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ptoms and its prognosis for given degrees of severity are considered. Where the expert concludes that there is a less than 1% probability that the course can be explained based on given (conventional) medical treatment, the course of disease is considered to be an *exceptional course of disease*.

The research centre and the registry also have routines for notifying the health authorities if the registry receives multiple reports of negative patient experiences from using CAM (5).

Unexpected and unusual positive courses of disease are frequently interpreted as spontaneous remission, irrespective of the patient's perceptions, experience and reflection. The Registry of Exceptional Courses of Disease will help to generate hypotheses to fill the knowledge gap between insufficient scientific evidence of efficacy, and patient-interpreted efficacy of CAM (1–3, 6).

## The patient perspective in medical treatment

Health policy governing documents such as *Future Care* ascribe Norwegian patients an active role in their own treatment (7). Studies show that many patients omit to tell health personnel about their use of complementary and alternative therapy, although expressing a strong desire to discuss the use of such therapy with their doctors (8–9).

The doctor should actively ask the patient about use of complementary and alternative therapy. This reinforces the doctor-patient relationship and, as a consequence of this, also patients' confidence in the health services. Good communication on choice of treatment may serve to prevent patients from rejecting effective medical treatment in favour of undocumented alternative therapy (9–10).

## Exceptional courses of disease should be reported

The Registry of Exceptional Courses of Disease forms the basis for research into best and worst outcomes associated with the use of various forms of complementary and alternative therapies. It also maps experiences of using complementary and alternative therapy, as well as experiences with the public health services. Patients' reasons for using such therapy can provide important input to the health authorities' objectives for patient co-determination and personalised medicine (3, 8, 11).

In accordance with its mandate, the National Research Center in Complementary and Alternative Medicine will continue its work on the registry. It is therefore desirable that doctors who are aware of positive or negative courses of disease associated with the use of complementary and alternative therapy should help to ensure that these are registered. Contact information for reporting to the registry is available at [nafkam.no](http://nafkam.no).

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