

ORIGINAL ARTICLE

Understanding unexpected courses of multiple sclerosis among patients using complementary and alternative medicine: A travel from recipient to explorer

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Abstract

Complementary and alternative medicine (CAM) is frequently used by patients with multiple sclerosis (MS). Some MS patients experience unexpected improvements of symptoms, which they relate to their use of CAM. The aim of this study was to obtain knowledge and develop understandings of such self-defined unexpected improvement of MS symptoms. Two cases were constructed based on documents and 12 qualitative interviews. Our aim was not to make generalisations from the cases, but to transfer knowledge as working hypotheses. We identified four health-related change processes: the process of losing bodily competence; the process of developing responsibility; the process of taking control; and the process of choosing CAM. The patients explained unexpected improvements in their MS symptoms as results of their own efforts including their choice and use of CAM. In our theoretical interpretations, we found the patients' redefinition of history, the concept of treatment and the importance of conventional health care to be essential, and leading to a change of patients' position towards conventional health care from recipients to explorers. The explorers can be perceived as boundary walkers reflecting limitations within the conventional health care system and as initiators regarding what MS patients find useful in CAM.

Key words: *Chronic illness, illness experience, complementary and alternative medicine, multiple sclerosis, coping, Norway*

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One of the greatest challenges facing conventional health care today is chronic disease, as the number of chronically ill persons is constantly rising and many patients with chronic disease suffer profoundly from their condition physically, emotionally, socially and spiritually (Davidhizar, 2001; Kleinman, 1988; Wagner et al., 2001). Chronic diseases are defined by the US National Center for Health Statistics as diseases lasting 3 months or more, and that generally cannot be prevented by vaccines or cured by medication, nor do they just disappear. The leading chronic diseases in developed countries include arthritis, cardiovascular disease, epilepsy, obesity and cancer (MedicineNet.com, 2010). During the

course of their chronic disease many patients choose to try out complementary and alternative medicine (CAM). The content of the concept of CAM depends on culture and geography, and changes over time as the borders between conventional health care and CAM are constantly changing. 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. Boundaries between CAM and within the CAM domain and that of the dominant health care system are not always sharp or fixed. (Zollman & Vickers, 1999, p. 693)

In Norway where this study was conducted, CAM can be provided either by a CAM practitioner operating outside of the government-funded health care system or by licensed health personnel (Fønnebo & Launsø, 2009; WHO, 2009). Self-reported use of CAM among patients varies widely between studies, possibly because of different definitions of CAM modalities and users (Kristoffersen, Fønnebo, & Norheim, 2008). However, several recent studies demonstrate an increasing use of CAM among Western patients. The prevalence of CAM usage have been reported as higher among women, individuals with higher education, and individuals with poor self-reported health (Cohen, Ek, & Pan, 2002; Fønnebo & Launsø, 2009; Hanssen et al., 2005; Kessler et al., 2001). In the Norwegian context, a recent study among the general population shows that, “over the previous 12 months”, 48.7% of the respondents had received CAM by CAM practitioners outside of or by health care personnel inside the health care system. Approximately 18% had received CAM by providers four or more times “over the previous 12 months”. The highest proportion of female users of CAM was found in 15–24-year olds (Fønnebo & Launsø, 2009).

CAM usage among the chronically ill tends to be higher than in the general population (Olsen, 2009). Studies report frequent use of CAM among patients with arthritis (82.8–90.5%) (Callahan et al., 2009), cancer patients in 14 European countries (39%) (Molassiotis et al., 2005) and among MS patients (27–100% in different studies) (Olsen, 2009). It has been argued that this trend suggests a continuing demand for CAM therapies that will affect health care delivery for the foreseeable future (Bodeker, Kronenberg, & Burford, 2007; Kessler et al., 2001).

The choice of CAM has been analysed both as a positive choice towards CAM and a negative choice towards the established health care system (Astin, 1998; Siapush, 1998). Studies have called positive attention to CAM as a treatment system framing development of personal responsibility, control and self-care management of chronic disease (Foote-Ardah, 2003; Goldstein, 2003; Thorne, Paterson, Russell, & Schultz, 2002), and a treatment system facilitating “holistic” treatment including focus on body, mind and spirit (Astin, 1998; Siapush, 1998; Sirois & Gick, 2002). Negative attention has been called to CAM in a safety perspective because of the unregulated nature of

many CAM products and providers in many countries (WHO, 2002). Several potential risks related to patients’ choice and use of CAM have been described in the literature: for example, contamination and negative interactions between herbal products and pharmaceuticals (Bjelakovic, Nikolova, Gluud, Simonetti, & Gluud, 2007); refusal of important conventional treatment and delay of diagnosis (Malik & Gopalan, 2003); CAM as an economical burden (Utian, 2005); and problematic notions of self-healing and hyper-positivity (Broom, 2009).

Some chronically ill patients experience unexpected improvements of their symptoms which they relate to their use of CAM (Hök, 2009; Jacobson et al., 2005; Launsø et al., 2006; Lee, 2004). In this article we wanted to explore such unexpected positive courses of disease because they can be rich in information and context, and can illustrate both the unusual and the typical (Patton, 2002; Stake, 1995) regarding patients’ treatment choices and treatment experiences. “Unexpected positive courses of disease” were in this study understood as courses that differ from what was expected by the patients following poor medical prognoses and the experience of worsened symptoms before the use of CAM. We limited our focus to CAM-users diagnosed with multiple sclerosis (MS).

MS and CAM

MS is a chronic and progressive neurological disorder, which can lead to severe disability. The effects include negative impacts on physical, emotional and cognitive functioning. The aetiology of the disease is unknown (Li et al., 2004; Riise, Nortvedt, & Ascherio, 2003). In 1996, the United States National Multiple Sclerosis Society standardised four subtype definitions: *relapsing remitting*; *secondary progressive*; *primary progressive*; and *progressive relapsing MS* (Lublin, Reingold, & National Multiple Sclerosis Society Advisory Committee on Clinical Trials of New Agents in Multiple Sclerosis, 1996). The *relapsing-remitting* subtype is characterised by unpredictable relapses followed by periods of months to years of relative remission with no new signs of disease activity. This describes the initial course of 85–90% of individuals with MS. *Secondary progressive MS* describes around 65% of those with an initial relapsing-remitting MS, who then begin to have progressive neurological decline between acute attacks without any definite periods of remission. Occasional relapses and minor remissions may appear. The *primary progressive* subtype describes the approximately 10–15% of individuals who never have remission after their initial MS symptoms (Miller & Leary, 2007). Primary progressive MS is

characterised by progression of disability from onset, with no, or only occasional and minor, remissions and improvements. *Progressive relapsing MS* describes those individuals who, from onset, have a steady neurological decline but also suffer clear superimposed attacks. This is the least common of all subtypes (Lublin et al., 1996). There is a high prevalence of MS in many populations all over the world. In Norway, we have an average prevalence of 125–130 per 100,000 inhabitants (Myhr, 2005). The sex ratio among adults diagnosed with MS is two women per one man, irrespective of ethnicity (Fraser & Polito, 2007).

MS is unpredictable both with respect to alternating exacerbation and remission of symptoms and the variant symptom patterns across patients diagnosed with MS (Kirkpatrick Pinson, Ottens, & Fisher, 2009; Thorne, Con, McGuinness, McPherson, & Harris, 2004). Studies show anxiety for what the future holds (Antonak & Livneh, 1995) and high levels of depression and uncertainty when MS is compared to other chronic diseases (Rudick, Miller, Clough, Gragg, & Farmer, 1992). Results suggest that MS-related depressive symptoms are a function of prior disease-related impairment, life stress and possible escape avoidance coping (Aikens, Fischer, Namey, & Rudick, 1997). MS patients are facing the fact that their disease can not be cured by any known conventional treatment, although for some patients the progression can be slowed down medically and a number of secondary symptoms can be treated (Sørensen, Ravnborg, & Jønsson, 2004). Many MS patients experience that conventional disease modifying drugs do little to treat their MS symptoms, improve functioning or enhance quality of life (Freeman et al., 2001). The symptomatic treatments are generally characterised by having only partial effects on the symptoms and by having a number of adverse effects (Sørensen et al., 2004). MS patients may therefore seek different methods to treat and live better with their MS symptoms (Freeman et al., 2001). We know from the literature that MS patients in general are frequent users of CAM (Apel, Greim, König, & Zettl, 2006; Nayak, Matheis, Schoenberger, & Shiflett, 2003; Schwarz, Knorr, Geiger, & Flachenecker, 2008). In a review of the literature, Olsen (2009) found that from 27 to 100% of MS patients reported use of CAM. MS patients' choice of CAM and their experiences with use of CAM need more research (Apel, Greim, & Zettl, 2007; Marrie, Hadjimichael, & Vollmer, 2003; Nayak et al., 2003; Olsen, 2009; Pucci, Cartechini, Taus, & Giuliani, 2004). It has been argued from a public health perspective that knowledge on patients' experiences with CAM is needed to change

the public health care in terms of safeguarding and optimising patients' treatment choices regardless of treatment systems (Bodeker et al., 2007). We have not found any other research on a group of MS patients who report that they have experienced unexpected improvements of their MS symptoms and relate this to their use of CAM.

Aim and research question

The literature review describes a setting where more research on chronically ill patients' choice of CAM, and these patients' experiences with what they find useful in CAM, can be of value both for individual patients and for the development of public health care programmes in the future. Our aim with this study was to obtain knowledge and develop understandings based on MS patients' experiences with unexpected courses of MS that they relate to their use of CAM. The research question was: What characterises courses of MS where patients using CAM experience unexpected improvements of their MS symptoms?

Design

We chose to explore the patient-defined unexpected courses of MS by constructing two cases including material collected from documents and qualitative interviews. Yin (2003, pp. 13–14) defines a case study as an empirical inquiry and a research strategy that investigates a contemporary phenomenon within its real-life context, and an especially useful research strategy when the boundaries between phenomenon and context are not clearly evident. Yin points out that the case study benefits from the prior development of theoretical propositions to guide data collection and analysis. Case studies have been used as exploratory, descriptive and explanatory research, and to generate theory and initiate change (Blaikie, 2000). The purpose of presenting our analysis by constructing two cases as typologies (Weiss, 1994) was to demonstrate the contexts and complexity of the patients' self-defined exceptional courses of MS related to their use of CAM. We found descriptions that included the contexts and the complexity of our material to be essential for the development and discussions of hypotheses and theoretical perspectives with respect to our research question. We found case construction suitable for our material and research question, as case studies enable comparison and complexity, and detail of the unusual case to be studied in depth (Anaf, Drummond, & Sheppard, 2007; Stake, 1995).

Material

The Registry of exceptional courses of disease

In this study, the users of CAM that have experienced unexpected improvements of their MS were selected from the Registry of Exceptional Courses of Disease (in the following referred to as “the Registry”). The Registry was established at the National Research Center in Complementary and Alternative Medicine (NAFKAM), Norway in 2002. The main goal was to create a database available for researching and voicing patients who have experienced unexpected improvement or worsening of their disease and relate these experiences to their use of CAM. Internationally, NAFKAM is the first research institution to establish a Registry for patients having experienced exceptional courses of disease encompassing severe and chronic diseases such as MS and cancer. Previous approaches to collecting best cases after the use of CAM have been limited to cancer and were initiated in the USA and in Germany (Büschel et al., 1998; Jacobson et al., 2005; Lee, 2004). The focus in these settings has been to research the primary outcome such as tumour response (Launsø et al., 2006). A need for an improved understanding of the ways in which CAM is used by individuals with cancer reporting exceptional treatment experiences has been demonstrated in Sweden (Hök, 2009).

The exceptional courses of disease submitted to the Registry constitute a self-selected sample of patients from Norway and Denmark. It is therefore impossible to establish incidence or prevalence of being an exceptional patient based on this material. The patients are informed about the Registry by patient associations,¹ doctors, alternative practitioners, media, and so forth. In the Registry “exceptional courses of disease” refer to both best and worst courses related to use of CAM. In best courses of disease patients report disease remission, cure, symptom relief and prolonged survival. In worst courses of disease patients report severe adverse reactions, delay of diagnosis and refusal of important conventional treatment. In best courses of disease, the patients do not define improvement of their courses of disease related to the use of CAM as miracles or spontaneous remissions, although their exceptional courses of disease can include spiritual or religious experiences or practices. The term “miracle” implies a relationship to the divine and thereby to questions of faith (Pawlikowski, 2007; Stempsey, 2002). “Spontaneous” means something that occurs naturally and not as a consequence of an intervention. Thus, spontaneous remissions are defined as recoveries without reason or cause (Bakal,

2001) and are recognised in many health disorders (Ledingham & Warrell, 2000).

To be included in the Registry the patient must (a) have received a medical diagnosis; (b) have experienced unexpected improvement or worsening of the course of disease; and (c) relate this improvement or worsening to the usage of CAM. The data material on each patient in the Registry consists of medical records, a medical assessment and a registration form. Some of the patients have attached letters, notes, books, etc. The courses of disease in the Registry are assessed by medical doctors. Medically exceptional courses of disease are defined as courses that occur with less than 1% probability after the given conventional treatment based on current medical knowledge. The Registry constitutes a basis for research both on the patients’ body of knowledge and on the medical assessments of the courses of disease. The medical perspective and the patient perspective can be perceived as complementary perspectives underpinning different aspects of a chronic disease and living with a chronic disease. In this article we limit our focus to exploring what characterises exceptional best courses of MS from the Registry based on the patients’ experiences. MS patients were chosen between patients diagnosed with different chronic diseases because they are frequent users of CAM and their chronic condition gives them longstanding, extensive treatment experience both from the conventional health care system and from their use of different CAM modalities and providers (Apel et al., 2006; Nayak et al., 2003; Olsen, 2009; Schwarz et al., 2008). We also chose MS patients because earlier research initiatives on unexpected positive courses of disease related to the use of CAM have been limited to cancer (Büschel et al., 1998; Hök, 2009; Jacobson et al., 2005; Launsø et al., 2006; Lee, 2004).

The multiple sclerosis (MS) patients in the Registry

As of 31st December 2008, 222 patients were included in the Registry (68% women, 32% men). Of these, 58 patients were diagnosed with MS, 36 from Norway (23 women, 13 men) and 22 from Denmark (16 women, 6 men). The 58 MS patients ranged in age from 34 to 66 years, with a mean of 50.0 and 44% of patients received higher education. High level of education among users of CAM has been identified in several studies (Hanssen et al., 2005; Marrie et al., 2003; Molassiotis et al., 2005). The mean number of years since being diagnosed with MS was 12.2. The mean number of years and the usage of CAM after the MS-diagnosis was 8.2. About 44 of the 58 patients used more than one CAM therapy. The most frequently used CAM

modalities among MS patients in the Registry was acupuncture (51.7%), reflexology (37.9%) and nutritional therapy (31%). Thirteen of the 58 MS patients in the Registry had been using alternative treatment exclusively over many years.

Sampling and participants

Twelve MS patients (nine women, three men) were selected in June 2007 for qualitative interviews. The selection was based on document analysis of the material in the Registry on each of the patients focusing on selection criteria for the qualitative interviews. We wanted a sample of MS patients that reflected variation in criteria important to explore our research question: gender, age, level of education, time since diagnosis, commitment to CAM before and after the diagnosis, experiences within conventional health care, use of complementary treatment or alternative treatment exclusively, and patients' reasons for defining their courses of disease as exceptional. The document analysis showed great similarities between Norwegian and Danish patients in those criteria. For practical reasons such as economy and transcription of interviews, we therefore chose to select only Norwegian MS patients for the qualitative interviews. Twelve patients received letters of invitation including practical and ethical information. All of them agreed to participate in the study. The 12 MS patients ranged in age from 39 to 55 years. The distribution of MS subtypes (Lublin et al., 1996) in our interview material was three patients diagnosed with relapsing remitting MS, six diagnosed with secondary progressive MS and three diagnosed with primary progressive MS. The number of years since being diagnosed with MS varied from 6 to 21. There are more MS patients that received higher education in the interview group than in the group of MS patients in the Registry (10 out of 12). The patients in the interview group had been using CAM from 3 to 20 years. The most frequently used CAM modalities in the interview group was acupuncture (six patients) and nutritional therapy (six patients), followed by homoeopathy (four patients), massage (four patients) and healing (four patients). Nine of the patients used more than one CAM therapy. Three of the patients had been using several alternative treatments and alternative providers exclusively over several years.

Methods

The choice of research methods is not just a technical choice, but reflects epistemological issues. We chose a qualitative design to explore what

characterises courses of MS where patients using CAM experience unexpected improvements of their MS symptoms. A qualitative research design can not provide us with causal explanations or provide causal links between usage of CAM and health-related outcomes, although the patients in this study claimed to have experienced positive effects of CAM use. A qualitative methodology was chosen because qualitative studies can contribute to a deeper understanding and more thorough knowledge of important issues in health and well-being than quantitative studies, given a situation where we have limited earlier knowledge of our phenomenon of interest, and we want to study patients' experiences with reference to their usage of CAM from a contextual perspective. Launsø and Rieper (2006) call attention to the use of qualitative methods in CAM research because patients using CAM often have chronic and complex illnesses, and because the principles of alternative treatment formulated by CAM practitioners often incorporate the patients' subjectivity, everyday life and general environment.

Document analysis

The concept of document was limited in this study to include written texts (Prior, 2003): medical records, medical assessments, letters from patients to hospitals and doctors and the Registry's registration form. We found the content analysis to be a suitable approach for our study (Prior, 2008). Document analysis was in this study first used as a basis for identifying superior themes in the written material on MS patients in the Registry as a foundation for developing research questions. Thereafter, document analysis was used to develop sampling criteria for qualitative interviews based on the selected research question. Finally, some information from the documents was used in the case construction, for example, information of medical diagnoses and assessments.

Qualitative interviews

Qualitative interviews were used as our main source of information. We understand in-depth interviews as interactional, reciprocal and reflexive processes. Thus, interview data are seen as socially constructed data, based on the interaction between researcher and participant (Denzin & Lincoln, 2003; Kvale, 1996). The in-depth and open-ended interviews were performed face-to-face and directed towards understanding the patients' perspectives on their lives, experiences or situations as expressed in their own words (Minichiello, Aroni, Timewell, & Alexander, 1990). Main interview themes were:

personal history, getting the MS diagnosis, being a patient in conventional health care, doctor–patient communication, use of CAM, patients' own efforts and the reasons for defining the disease course as exceptional. Each interview lasted between 90 and 150 min, and was conducted by the author A.S. and a research assistant with comprehensive knowledge of the Registry. The interviews were audio-taped and transcribed verbatim by a professional transcriber.

Ethical considerations

The Regional Committee for Medical and Health Research Ethics has granted approval for the Registry and this research project, and both have been approved by the Norwegian Data Inspectorate. The transcriber has signed a written consent to professional confidentiality. The voluntary participation as well as participants' ability to withdraw participation at any time was emphasised by the researchers both previous to and during the study. We provided information about the study aim and the research procedures, including information about the themes for the interviews and that all information shared with the researchers would be confidential. Because we knew that many of our informants suffered from their MS, we needed to consider whether the interviews were possible to complete. We asked the patients to take breaks and informed them about the ability to end the interview anytime they wanted. We were aware of the difference between therapy and research in our meetings with the informants. The two patients referred to in the cases have read through and approved the presented material.

An ethical concern in this study involved legal issues related to Norwegian laws, affecting, for example some MS patients' use of cannabis, and patients bringing with them unlicensed medication from abroad. The Regional Committee for Medical and Health Research Ethics approved that we could inform the study participants that we would not initiate legal proceedings around any cases of possible violation of laws affecting patients' use of drugs or unlicensed medication.

Data analysis

Qualitative interviews and documents were used as data sources for case construction and a flexible mode of inquiry (Ellis, 2003). In the description of methods and material we showed how the selection of MS patients to be interviewed built on document analysis of written texts. The first author (AS) conducted a pilot interview with a patient who we knew, based on the document analysis would provide us with a substantial amount of information.

Preliminary analyses of this interview together with document analysis were used as a basis for developing the final interview guide. Furthermore, 11 interviews were completed during the period of July 2007–March 2008. As a first step in the analysis of the 12 in-depth interviews, the interviews were coded in NVivo (QSR, 2009) according to the main interview themes and other important themes emerging in the material based on our interpretations and research question: expectations of conventional health care, relinquishing conventional health care, social network, patients' criteria for choosing conventional and alternative treatments and treatment providers, experiences with alternative treatments and practitioners, content of the concepts of disease and treatment, and processes of knowledge building and change.

First level of analysis

We worked with two levels in the data analysis. At the first level we applied a case-focused analysis and an issue (theme)-focused analysis on the 12 interviews. A case-focused analysis makes the researchers aware of the respondent's experience within the context of their lives. An issue (theme)-focused analysis concerns itself with what could be learned about specific issues, events or processes (Weiss, 1994). Based on information from documents and qualitative interviews we constructed the cases *Mona* and *Anna* as typologies. We chose to present variations and patterns in our material as cases instead of presenting an analysis based on quotations from the 12 interviews, because we found that the cases better could visualise the important contextual aspects in our empirical material (Yin, 2003). We chose to use *Mona* and *Anna*'s courses of MS as cases instead of constructing ideal types. This implies that all information in each case is from just one patient (Weiss, 1994). *Anna*'s and *Mona*'s exceptional courses of MS were chosen as cases among the 12 possible cases because these two courses of MS reflect both essential differences (commitment to CAM and use of CAM) and essential main features (e.g., experiences of loss of body, limitations in conventional health care and the choice and use of CAM) in the study's material. The construction of the cases is based on the concepts used by the patients. We here used the inductive analytical strategy. *Anna* is diagnosed with secondary progressive MS. *Mona* has the same diagnosis, described in her medical journal as remitting with incomplete remission. In the analysis of documents and interviews, we did not find different subtypes of MS to be essential in regard to our research question.

We investigated the phenomenon “unexpected improvements of MS symptoms related to patients’ use of CAM” within its real-life context. Yin (2003) argues for this analytical strategy especially when the boundaries between phenomenon and context are not clearly evident. We identified themes of the patients’ experiences with the process of developing an exceptional course of MS. In the analyses of the 12 qualitative interviews and of documents on the 12 interview persons in the Registry material, we found that the patients emphasise their life conditions in many aspects when they explain their self-defined exceptional best courses of MS. We therefore chose to illustrate our empirical findings in a context, using case construction based on information from the qualitative interviews and written material in the Registry. We included quotations from the qualitative interviews to illustrate our interpretations. Because of this contextual perspective, the life conditions and disease courses in the two cases we present are interwoven.

Second level of analysis

At the second level of analysis we performed an issue (theme)-focused analysis (Weiss, 1994) on the two cases, Mona and Anna, based on the case- and issue (theme)-focused analyses on the first level. Statements from the material were brought to a general level in order to compare and contrast (Weiss, 1994). We searched for thematic categories and patterns across the two cases and associations between phenomena within one case (Spencer, Ritchie, & O’Connor, 2003).

We did not intend to provide causal links between treatment and outcomes in our analysis. Our aim was not to make generalisations from the two cases the way empirical generalisation is possible in, e.g., survey research. We found that the two cases were in some way congruent. Congruent cases make it possible to transfer knowledge as working hypotheses (Gobo, 2008). Guba and Lincoln (1989) argue that transferability depends on similarity, in such a way that patterns of events that occur in one case recur in the other.

Results

First level of analysis: the cases Mona and Anna

Mona. She is a 54-year-old woman who was diagnosed with MS in 1989. Her MS was at the time of the interview in 2007 characterised by neurologists as secondary progressive according to the US National Multiple Sclerosis Society’s subtype definitions (Lublin et al., 1996). Mona is a committed user of alternative treatments. She has been

using acupuncture, gestalt therapy, nutritional therapy, homoeopathy, healing, massage, reflexology, dietary advice, Tibetan medicine, Feldenkrais, anthroposophical medicine, chelation treatment and art therapy during her MS course. Mona grew up with a manic-depressive mother and an alcoholic father. In her childhood and youth she took on several duties of caring, not only taking care of her parents but also her alcoholic neighbour and a friend who had lost her mother. She married in her early twenties and had two children. Because of her own childhood, it was very important for her to be a resource for her children. In 1989 she was about to finish her education in arts. At the same time her marriage was becoming really complicated, and she and her husband got divorced. Mona had not had any contact with her mother for 2 years and was in therapy to enable her to handle her childhood when her mother died in a dramatic fire: “It was like everything at once. I was terribly weary . . . I was about to walk up a hill and didn’t think I would manage. And I was cold, I was very skinny at the time, only forty some kilos”.

Mona had earlier seen a doctor, a healer and a homoeopath because of her fatigue and her diffuse symptoms. A friend of Mona, who was a doctor, now got her hospitalised and within a short time she was diagnosed with MS. After 3 weeks of hospitalisation and cortisone treatment she came to home and was bedridden for several weeks with partial paralyses. Earlier she had started studies to become a nurse and during that time she became interested in anthroposophical medicine that focuses on self-determination, autonomy and dignity of patients. This medical philosophy fitted better with Mona’s way of thinking regarding treatment than what she learned at nursing school. When she returned home from the hospital, an alternative practitioner gave her Bernie S. Siegel’s book *Love, Medicine and Miracles* (Siegel, 1988):

There I got confirmation to start my inner work; visualisations, inner travels, using music, relaxation. // I told myself that my children should not have a mother to care for like I have had myself. My mother didn’t get help from the conventional health care system except too many tablets with severe side effects.

After a few weeks Mona decided to stop using conventional treatment: “I felt like a diagnosis the way the specialists talked to me. // I was prescribed cortisone tablets. // They had nothing else to offer me, and the side effects were really bad”.

While still bedridden, she chose to use visualisation, music therapy and autogenic training, and she

gradually improved to the point where she was back on her feet. During the next 16 years Mona used alternative treatments exclusively: homoeopathy, reflexology, acupuncture, massage, art therapy, gestalt therapy, healing, dietary advice, Tibetan medicine, Feldenkrais, anthroposophical medicine and chelation treatment. She found certain combinations to be helpful: "Each one needs to find their personal keys".

Mona prioritised spending money on alternative treatments even though her financial resources were limited. She emphasised the alternative practitioners' focus on her individual history and life situation, which implied that she could take an active part in the treatment of her MS symptoms. She had received considerable support from her ex-husband, her present husband and friends when times were tough. Mona's inner work has been focusing on what worked best for her and on accepting what was tough and difficult:

To me the diagnosis meant loss – loss of body – loss of a lot. I got divorced and had financial problems. MS means a lot of strong anxiety – what happens inside? I have spent a lot of energy not wanting to have MS.

Today, she explains her disease with her tough childhood and youth, and many strains in her adult life: "Today I see that heavy mental pressure over time was what set the MS off, so preventing stress is my best medicine". Mona now constantly works with her psyche by using several techniques which she has explored over many years. She has made changes in her life conditions, eats healthy foods and has moved to the country side. She has re-married, does not take on tasks that are too big and works with creative projects that also contribute to her inner work with the past.

Sixteen years after the MS diagnosis, in 2005, Mona chose to contact the conventional health care system again. Via her social network and the Internet she had learned about new conventional treatments used at German hospitals which she found interesting. Since 2005, she has tried out several hospitals and neurologists to find a doctor that she can communicate with and who she finds supportive both in relation to trying out new conventional MS treatments and in relation to her use of alternative treatments. Then, she has chosen a neurologist and a physician whom she finds supportive. The neurologist is also educated in acupuncture and has recommended acupuncture, and a special physiotherapeutic treatment based on an integrated mind-body perspective as supplements to the conventional treatment.

Mona's disease course is in the process of being medically assessed in the Registry. Mona herself has defined her course of MS as exceptional because she thinks that her condition would have been considerably worse if she had kept on letting herself be controlled by the doctors and not using alternative treatments:

I know that my disease course is unusual. // If I had given away the responsibility and taken cortisone and let myself be controlled, I would have been in a totally different place. // If I hadn't taken all these alternative therapies and walked the road I have walked, I would have been in a wheelchair a long time ago. // In the end we are our own teachers and masters ... I feel that I'm starting to own more of my story even though a lot is still too painful to relate to.

Anna. She is a 49-year-old woman who was diagnosed with MS in 1991 at the age of 31. Her MS was at the time of the interview in 2007 characterised by neurologists as secondary progressive according to the United States National Multiple Sclerosis Society's subtype definitions (Lublin et al., 1996). She has not been using any alternative treatments as much and as long as Mona. She has tried out acupuncture, nutritional therapy and a special complementary treatment that will be further described.

In 1991, Anna was 31 years old, and had then for many years, from time to time, had diffuse symptoms:

At the age of 13 I was hospitalised – after having received 13 amalgam fillings within one week a short time before. I had a really bad headache, hyper reflexes, and a lot of other strange reactions ... Looking back, I am convinced that the mercury was giving me the problems.

In her youth Anna was an active athlete and was used to pushing herself physically and mentally. In 1982, she started noticing different symptoms, like losing the sense of touch. She also had a lot of sinusitis and throat infections at that time. Today she sees that as part of what set the MS off. The first clear symptoms showed up in 1986 when she was diagnosed with optic nerve inflammation. At that time she was married, had a child and was working full time in conventional health care. In 1991 Anna was diagnosed as having MS after relapses and being paralysed in one arm. She received cortisone treatment and experienced a very good effect from this for several years. Her doctors encouraged her to live as before. Anna grew up with the attitude that ill

persons had lived unhealthy lives and she felt ashamed of getting a diagnosis. She kept the disease a secret from most of the people around her, had her second child in 1993, and worked harder than ever to manage everything she thought she should manage physically and mentally. Both her children had physical diseases that took a lot out of her and her husband was away 80% of the time because of work. She did her best to live as before but she was too exhausted for that.

All MS relapses were treated with cortisone for 5 years after the diagnosis before β -interferon was introduced in 1997. At that time β -interferon was being tried out at Anna's hospital:

I had always thought that if my feet got bad, I could still do theoretical work, but when I realised that it could influence my vision, I got a bit scared. So then I let myself be talked into taking β -interferon, and of course I regret that today because I got really sick from those medicines.

During the 3 years with β -interferon, she went from working part time being "invisibly ill" to being 100% disabled. She experienced paralyses in arms and legs, and blindness on one eye. She had to use a catheter and had serious difficulties with concentration:

And the doctors didn't stop it ... After almost three years the doctor who was on duty when I came in said that "I am glad it is me who is on duty, because the whole time I have been against you taking β -interferon." And no one told me that they were even discussing it, right? And they had voted on this. It was 5 against 4 neurologists who let me get *this* sick. I was so mad at them that I could have killed them, right. // In December 2000 I could stop the β -interferon and I regained some of my self-respect when we agreed to stop. // The doctors treated me like a patient who could not do anything herself. // They always just said that "there is nothing you can do, this just follows its course," almost like predetermined fate in a way. But for me that didn't make sense. As a health care provider, I thought there is a whole lot that patients can do themselves.

When she was talking about β -interferon, the doctors were sorry that she had become so much worse. They did not think it was because of the treatment, but rather that the disease had moved into a progressive phase. They offered to help Anna apply for a place at a nursing home. She was then 40 years old.

At this point she got really angry with the doctors and her situation and decided to do something herself. She looked up different alternatives and chose to spend time at a health centre that provided CAM. She received training and gained new understanding of her disease and her situation. She also received dopamine, noradrenalin, acetylcholine and serotonin used in a non-conventional way, in addition to diets and supplements.

It was like coming home, it was fantastic. This doctor told me the first time she saw me that I was responsible for my own life, and that I had the possibility to make changes in living my life with MS. // Part of the treatment that shocked me was that they said "lay down! You are so hyper. You need to find out how much you can actually handle," which was very little.

Little by little, with the signal substances, resting and rethinking her way of living with MS, Anna improved. She found that this treatment met the needs of both body and soul. To let the brain rest was an important part of the treatment. She learned that she had to say "No" from time to time, including to things that she would have been happy to do. Today she does not get mentally tired any more, and she has no more relapses. During Anna's process of trying out CAM, in 2002, she and her husband got divorced. Her husband had a job with a lot of travelling and their two children had both been ill for a long time. When Anna's husband told her that he was exhausted and that she had to deal with her situation herself, she found divorcing him was the best thing to do to handle her life, although she still regrets the divorce.

After having taken responsibility for her living with MS and having chosen and used CAM, Anna experienced great improvement of her MS symptoms and quality of life. Based on this, she has defined her course of disease as exceptional. Anna's course of disease has been medically assessed both by medical doctors in the Registry and by an external neurologist. The conclusion was that Anna's course of disease is medically exceptional because she did experience great improvement of several physical symptoms 10 years after the onset of her MS.

Second level of analysis: identification of health-related change processes

In our analysis at the second level, we emphasised exploring both the unique and diverse variations in the constructed cases, as well as the common patterns that cut across variations. Mona and Anna's

experiences are congruent in many aspects, but the cases differ in commitment to CAM and use of alternative treatment exclusively versus complementary. Mona was using alternative treatment even before she was diagnosed with MS. Over time she was using a great number of alternative treatments, and for 16 years she was using alternative treatment exclusively, handling her MS without using any conventional treatments or visiting neurologists. Anna tried out most of the treatments she was offered in conventional health care over many years. She then chose a medical doctor outside the conventional health care system as her treatment provider. This doctor offered a combination of conventional and alternative treatment. Despite these differences, we found that the common patterns in the two cases best explain and add knowledge to a feasible understanding of exceptional best courses of MS among patients using CAM. We have earlier argued that the two cases are chosen and constructed as typologies (Weiss, 1994) because they are rich in information. They show both essential differences (commitment to CAM and use of CAM) and essential main features (e.g., experiences of loss of body, limitations in conventional health care, and the choice and use of CAM) in the material of documents and qualitative interviews.

We identified four common health-related change processes that can contribute to understanding patient-defined exceptional best courses of MS: the process of losing bodily competence; the process of developing responsibility; the process of taking control; and the process of choosing CAM. The conventional health care system can be seen as the background against which the four processes develop. The processes weave into each other, and can develop and change over time.

The process of losing bodily competence

Both Mona and Anna experienced that losses of bodily competence can mean losing their self-image and positions in their private and work life. They were living busy lives that demanded bodily competence and not much time to focus on themselves. Anna experienced that the loss of bodily competence was something she was ashamed of and wanted to hide. This loss was also too much of a strain for her marriage, as she was not able to take care of the children adequately with her husband travelling a lot. Also Mona felt that the loss of bodily competence reduced her ability to be a good mother, something that was very important to her because of her own childhood. In the process of losing bodily competence, we found the patients' experience of the limitations in what the conventional health care

system could offer to help them prevent or handle their loss of bodily competence to be essential. Facing their loss of bodily competence and the limitations in the conventional health care system, Mona and Anna activated their own efforts by the processes of developing responsibility and taking control.

The processes of developing responsibility and taking control

After a process of losing bodily competence, Anna and Mona went through a process of developing responsibility in handling their lives with MS. In this process they did not focus on the disease only in terms of treatment. Seen in light of the disease, Mona and Anna re-assessed their life histories and identified those conditions which, according to their understanding, had caused or contributed to their courses of MS. Mona had experienced a complex and in many ways painful life story before she was diagnosed with MS. Anna's life story is different, but still with clear traits in common with Mona's story. Anna had always expected much from herself and took on heavy work loads. Both Mona and Anna point at physical and mental overload over many years as possible reasons for getting MS. Their own re-interpretations of the past created the basis for experiencing their course of MS as a learning process, which enabled them to work on changing patterns, habits and lifestyles. The disease was to a small extent seen as chance or fate, and to a larger extent seen as a result of their choices and priorities. Thereby Mona and Anna claim to own and influence their courses of disease. For Anna, the turning point in the negative development of her MS came when she saw a doctor offering complementary treatment. This doctor told her that Anna herself was responsible for handling her situation and that in her case being active in relation to her MS disease meant to relax more. Anna learnt to actively set limits, and both Anna and Mona today emphasise the importance of living a quieter life than before in order to have a better life with MS. Based on their experience and knowledge on their life conditions including the disease, Anna and Mona developed responsibility for their way of living in the past, the present and the future. This interpretation of disease meant that it became a goal for Anna and Mona to take better care of themselves. Today, Mona has re-married and moved. More and more she relates to her life story through her inner work, alternative treatments and changed life conditions, even though there is still a lot that she has difficulty relating to. To be responsible for her situation, including living with MS, means to be aware of context and history.

To be responsible also makes it possible to start a process of taking control. These two processes are inextricably interwoven. Both Anna and Mona emphasise that taking control, instead of being controlled by the doctors, was an important step on their way to experiencing an exceptional best course of MS. As MS patients in the conventional health care system, neither of them was satisfied with the doctor–patient communication or the treatments they were offered. Mona and Anna have used their families, friends, the Internet and other sources in exploring new ways to live a better life with MS. An important aspect of taking control was the process of choosing CAM.

The process of choosing CAM

In the process of taking control, Mona and Anna were actively looking for alternative treatments and practitioners that could accommodate responsible patients taking control of their lives with MS. This included their personal efforts, like Mona’s inner work. One important reason both for Anna and Mona to choose CAM was that they had experienced severe side effects from the conventional treatments which they had been given. Mona focuses on her previous and ongoing mental processes and mental work when she today explains her exceptional course of MS. Using alternative treatments is a part of these processes and work. Treatment choices are not final. Being in control and taking responsibility means to continually evaluate the situation, in the way Mona did when she found out about new conventional treatment and again contacted the conventional health care system after 16 years. For Anna, the use of CAM has changed her understanding of her disease and her capacity for activity.

Comprehensive understanding

Our research question was what characterises courses of MS where patients using CAM experience unexpected improvements of their MS symptoms. We traced four health-related change processes in the empirical material that can lead to an understanding: the process of losing bodily competence; the process of developing responsibility; the process of taking control; and the process of choosing CAM. The processes weave into each other, and can develop and change over time. We found that the patients redefined their history, their living with MS, and the concept of treatment. They defined what they found useful in CAM. In these processes of change, CAM was seen as particularly important as a system of treatment able to frame and mobilise the patients’

own efforts in coping with their living with MS. The patients redefined the importance and meaning of the conventional health care. Their own efforts became dominant, and actions that could nourish and strengthen these efforts were chosen and constantly assessed. Supported by what they defined as useful in CAM, the patients in this study experienced improvements of their MS symptoms that they claimed they would not have achieved by using conventional treatments only.

Discussion

Theoretical understandings of the health-related change processes

We conducted an inductive, bottom-up analysis, theorising our empirical findings and interpretations of what characterises self-defined exceptional courses of MS in patients using CAM. We linked the four health-related change processes to theoretical concepts that create a foundation for analytical generalisation. Most MS research has focused on the physical impact of the disease and not on personal strategies for living a better life with MS (Kirkpatrick Pinson et al., 2009; Reynolds & Prior, 2003). Based on the main themes that emerged in our empirical analysis, we studied MS patients’ choice and use of CAM from a theoretical standpoint that could accommodate patients’ choice and use of CAM as a personal strategy for living a better life with MS. We found Antonovsky’s (1979, 1987) central theory of sense of coherence and the three components comprehensibility, manageability and meaningfulness to be an interesting sociological perspective to try out, together with Bourdieu’s (1977, 1986) concepts of capital. If a person believes there is no reason to persist and confront challenges, if the person experiences no sense of meaning, he will have less motivation to cope with stress and diseases. The concept of “sense of coherence” interacts with a person’s coping style, social network and financial assets (Antonovsky, 1979, 1987), ingredients in Bourdieu’s concepts of capital. Bourdieu (1977, 1986) distinguishes between three types of capital: economic, social and cultural. Economic capital can be defined as command over economic resources. Bourdieu (1986, p. 51) defines social capital as “the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalised relationships of mutual acquaintance and recognition”. The concept of cultural capital includes forms of knowledge, skills, education and advantages that individuals have, and which influence their position and power in different social contexts (Bourdieu, 1986).

Redefinition in exceptional courses of MS

In our analysis of the processes of losing bodily competence, developing responsibility, taking control and choosing CAM, we found the phenomenon of redefinition to be essential in our interpretations. According to Antonovsky (1979, 1987), the limits for what is meaningful are flexible. After having lived through the process of losing bodily competence that includes facing limitations in conventional health care, the MS patients during the three other identified health-related change processes redefine their history and lives with MS, the concept treatment and the importance and meaning of conventional health care. By redefinition the patients become able to extend their scope of action (Launsø, 1997) and develop new knowledge including knowledge of CAM. They individually define what is meaningful in their choice and use of CAM. The patients make use of their economic, social and cultural capital (Bourdieu, 1977, 1986) as a basis for reflection and choice in coping with their lives with MS.

The patients redefine their history and their lives with MS

Living with MS and treating MS symptoms includes contextual and historical aspects. The MS patients take the authority “home” and, based on their inner gyroscope (Riesman, Glazer, & Denney, 2001), guide themselves in coping with their courses of disease. The past and the future are interpreted based on a radical change in the present situation, and the elements of this trinity are connected to and constantly influencing each other. The patients work on taking responsibility thereby making changes in their way of thinking and acting (Rosenzweig & Thelen, 1998).

The patients redefine the concept of treatment and define what they find useful in CAM

The concept of treatment is not understood by the patients as just a single entity isolated from the recipient of an intervention and seen as determining the outcomes. The concept must also include the patients’ receptivity and readiness. The patients influence how an intervention is being integrated and used. They extend their scope of action and develop vigour based on their own efforts and achievements, their economic, social and cultural capital (Bourdieu, 1977, 1986). Included in the patients’ own efforts is the use of the Internet, social network, literature and the choice and use of CAM.

When the patients choose to use an alternative treatment outside the conventional health care

system, they are in a position to define the meaning of their use of CAM. The choice and use of CAM modalities and the choice of conventional doctors and CAM practitioners that include the patients’ own efforts can be perceived as “the turning point” in living a better life with MS. Patient with MS in this study value both their alternative practitioners and the alternative treatments, but their main focus is on CAM as a system of treatment able to frame and mobilise their own efforts in coping with their living with MS.

The patients redefine their position from recipient to explorer

The MS patients’ redefinitions in this study can be summarised as a redefinition of their position from Recipient to Explorer. The concept of recipient as we use it here, signals a passive use of interventions. The concept of explorer signals that the patients work on safeguarding their health and life situation in a new way. Riessman (2003) uses the concept of explorer quite similar to our use, analysing a patient with MS who is narrating the story about breaking the frame of his previous life. We have not found the concept used to describe a patient’s position in other studies.

The prerequisite to move from recipient to explorer is that patients redefine their positions as patients from a passive “recipient” position to an active “explorer” position. The patients expand their universe of knowledge and change their position within this universe from periphery to centre. The identified health-related change processes presuppose that the patients develop their capital (Bourdieu, 1977, 1986) regarding personal habits, patterns of thought and life patterns from their experience-based knowledge about living with MS. Early on in the course of MS, the patients and their doctor have a common perception of the doctor being positioned at the centre of the universe of knowledge related to the treatment of the patients’ MS. As time passes, we see that the patients’ universe of knowledge expands and the patients place themselves at the centre of this universe. As CAM and personal efforts take up more space, the patients place less emphasis on the medical doctors’ power of definition, and instead develop their scope of action.

The concept of explorer does not only imply actions. It is important to understand that the concept also entails all the social, cultural and economic capital (Bourdieu, 1977, 1986) needed for the patients to be able to take responsibility for and cope with their situation in a new way. Furthermore, it is important that the concept of explorer is understood neither as normative nor as a factor that

can be controlled and developed from the outside. Explorers are not ideal patients and their way of handling their disease is not static, but constantly developing. This development is not created by conventional health care providers or alternative practitioners, but by the explorers.

To move from recipient to explorer takes time and requires personal learning and efforts. As explorers, the patients take on a considerable responsibility and wish to be respected as independent authorities with the competences they have developed. The explorers make new demands on the conventional health care system by choosing the conventional and alternative practitioners they want and the treatments they consider being the best here and now in their life with MS. The conventional health care providers are now used according to the explorers' reflective consideration of what different treatments and providers can contribute to their tool kit. The tool kit and the universe of knowledge are constantly being tried out, investigated and re-assessed.

The explorers represent a plurality of heterogeneous claims to knowledge and actions in which science does not have a privileged place. The explorers search for knowledge that is meaningful in their everyday life with MS. Furthermore, the knowledge is selected and its relevance assessed in relation to the patients' scope of action and action capacity at a given time. Laypeople, in their differential engagement with biomedical knowledge, according to McClean and Shaw (2005), seek to adopt, mimic, critique or rewrite experts' positions. We can, in this sense, see the movement in late modernity towards expert knowledge as highly individualised knowledge (McClean & Shaw, 2005). The constellation of health identities around lay experiential models of health and the body can be understood to reflect the diversity of relations in a technology-driven, consumer-oriented and media-saturated society (Fox & Ward, 2006). The rise of CAM can be seen as evidence that elements of postmodern culture have arrived at the door of conventional health care (McQuaide, 2005).

The explorers' choice and use of CAM can be analysed both as a positive choice towards CAM (Foote-Ardah, 2003; Goldstein, 2003; Thorne et al., 2002) and as a negative choice towards the established health care system (Astin, 1998; Siapush, 1998). Patients' reasons for using CAM should be taken to account in the future both by decision-makers in public health care (Bodeker et al., 2007), and by alternative practitioners to optimise patients' treatment choices and the quality of treatment both within and outside the conventional health care system. Leckridge (2004) proposes a patient-centred

model of delivery of CAM and biomedical care, which shifts the power from therapists to patients and regulates products and services irrespective of CAM or biomedical definitions.

Unexpected courses of MS and coping

Our main focus in the further discussion is on different empirical and theoretical approaches to coping and MS. We also focus on CAM and chronic disease from a patient and public health perspective, and on methodological aspects of our study. In a study on MS and coping among users of CAM, Apel et al. (2007) used a quantitative design and found that MS patients using CAM were more active in their coping with their disease than patients who were not using CAM. Most of the earlier studies on MS and coping are based on QoL-questionnaires, and focus on optimising the information and intervention programmes in the conventional health care system (Bishop, Frain, & Tschopp, 2008; Lode et al., 2007; McCabe, Stokes, & McDonald, 2009; Montel & Bungener, 2007). It has been argued that qualitative research on MS and coping is necessary to complete the picture of the complexity, flexibility and evolution of the MS patients' coping strategies (Reynolds & Prior, 2003; Thorne et al., 2002). Earlier qualitative studies have shown successful coping through proactivity, perspective and control (Malcomson, Lowe-Strong, & Dunwoody, 2008; Miller, 1997), through preserving valued roles as, e.g., mother, and through finding new pursuits that express earlier skills and interests (Reynolds & Prior, 2003). We see common patterns in these studies and our study. We found that MS patients' coping strategies including the choice and use of CAM are based on history and context and can be very complex and interwoven. We will argue that our study in addition to Apel et al.'s (2007) quantitative study contribute with in-depth knowledge of what in CAM the MS patients find useful for coping with their disease.

In a recent qualitative study focusing on self-reported successful coping in spite of MS progression, Kirkpatrick Pinson et al. (2009) found that confronting the problem, effort or will towards change, and awareness seem to be very potent factors to create favourable conditions to help MS patients cope successfully when using conventional treatments. Also knowledge about MS and the value of having strong support from health care providers are important factors for the 10 women that report successful coping with MS (Kirkpatrick Pinson et al., 2009). There are obvious similarities and interesting differences between the central findings in our

and Kirkpatrick Pinson et al.'s study. A basic difference is the importance of strong support from the conventional health care system for successful coping that Kirkpatrick Pinson et al. found. The patients in our study, however, have often had negative experiences with conventional health care. Instead of coping successfully supported by the conventional health care system, the patients get support for coping with their MS symptoms from their social network, alternative practitioners and last but not least their own inner work. The patients in Kirkpatrick Pinson et al.'s study (2009) can be characterised as compliant patients who succeed within the conventional health care system, as opposed to the patients in our study who, based on their experiences with the conventional health care system and treatment choices based on these experiences, can be characterised as non-compliant patients. Regarding Kirkpatrick Pinson et al.'s (2009) operationalisation of successful coping for compliant MS patients within conventional health care we argue, based on our study, in favour of a theory of successful coping for non-compliant MS patients which includes the four identified health-related change processes, redefinition and repositioning from Recipient to Explorer. These MS patients take their authority home and activate their inner gyroscope (Riesman et al., 2001) which is the restarting point and guideline for these patients' exploring and coping. We argue that these MS patients have another and wider pool of experience and scope of action than the compliant MS patients because they position themselves as users of both conventional health care and CAM. Furthermore, we argue that there is a need for more research on MS and coping among patients using CAM, because these patients' coping strategies as we have seen in this study can be different from coping strategies among MS patients that are not using CAM.

Our study and the one by Kirkpatrick Pinson et al. (2009) can be seen as complementing each other because they explore coping among MS patients with different positions in relationship to the conventional health care system and the alternative treatment field. The two studies also contribute with different methodological accesses. Kirkpatrick Pinson et al. based their work on a general and abstract model for coping (the precursors of change-model), a theory of pre-defined conditions for coping with chronic disease which they tested on MS patients through interviews. In our theoretical understanding of unexpected courses of MS, the empirically identified health-related change processes are essential for our development of a theory of coping.

Chronic disease and the use of CAM

We find similarities in respect to our empirical findings and theoretical approaches in a number of other studies on chronic disease and the use of CAM. Studies on different groups of patients with chronic disease call attention to the importance of CAM as facilitating active coping behaviour and enhancing self/other awareness (Cartwright & Torr, 2005; Sollner et al., 2000) and to the meaning of CAM as a treatment system framing development of personal responsibility and control (Foote-Ardah, 2003; Goldstein, 2003; Thorne et al., 2002). There are also studies that point to problems in taking responsibility and control. Broom (2009) finds that although patients experience positive impacts of CAM engagement, like increased feeling of control, power and individual autonomy within therapeutic processes, they also experience problematic notions of self-healing and hyper-positivity, involving restrictive notions of self-discipline. Taking responsibility for the past (appearance of disease or symptoms) could result in a burdensome responsibility with its own potential risks for the patients' mental health and life quality (Pucci et al., 2004). The patients in our interview material reflect on such risks, but have not themselves experienced consequences like this from taking responsibility and control. Studies on patient-physician relations show, like we found in our study, that many MS patients have experienced conflicts in their communication with conventional health care providers regarding the diagnosis, explanation and treatment of the disease (Clayton, Rogers, & Stuijbergen, 1999; Miller, 1997; Thorne et al., 2004).

Furthermore, we have argued that researching and analysing patient experiences based on their history and lived context gives new information. Kelly-Powell (1997) found in her study that decisions to accept treatment are personalised to correspond with the patients' view of themselves within the context of their life stories. Thorne et al. (2003) explained how people with chronic disease come to rely heavily on a skill-base founded on personal experience with the disease within the context of their unique lives rather than standardised knowledge alone. Hughner and Kleine (2008) underline that the ways Western consumers once thought about health have changed and multiplied in a world with competing health paradigms. They conclude that we should not classify health care consumers as either conventional or alternative. This is in line with the pragmatic way the explorers try out and re-assess different conventional and alternative treatments and treatment providers. From a public health perspective, it has been argued that political and

scientific will and data are needed to support an agenda where treatment options would not be considered complementary or alternative, orthodox or conventional. All possible contributions should be evaluated for their promise, and harnessed for the good of the public's health (Bodeker et al., 2007).

Methodological aspects

The results are based on a self-selected material on patient-defined exceptional courses of MS in patients using CAM. We have hereby limited this study to extreme or deviant cases (Patton, 2002). The benefit of this sampling strategy is the unique information gained about unusual cases that have been assessed by the patients as exceptional courses of MS. A weakness can be the lack of generalisability. Patton (2002) argues that the logic of extreme group sampling is that extreme cases can be information-rich cases precisely because, by being unusual, they can illuminate both the unusual and the typical. This effect can for instance be recognised in our analysis of MS patients in the Registry as non-compliant patients coping with their MS through their choice and use of CAM, compared to compliant patients coping with their MS through conventional health care. Patton (2002) further emphasises that, in evaluation, lessons may be learned about unusual conditions or extreme outcomes that are relevant to improve more typical programmes. One of the backgrounds of this study was the need for more research on MS patients' choice of CAM and their experiences with use of CAM, both from a patient perspective and a public health perspective (Apel et al., 2007; Bodeker et al., 2007; Marrie et al., 2003; Nayak et al., 2003; Olsen 2009; Pucci et al., 2004).

In line with Flyvbjerg (2004) and Kvale (1996), we argue that social research should be problem-driven and not methodology-driven. We chose to explore our research question by constructing cases based on qualitative interviews and written documents, because we found such a design to enable comparison and complexity, and detail of the unusual case to be studied in-depth in a contextual perspective (Anaf et al., 2007; Stake, 1995; Weiss, 1994). Although a purpose was comparison and contrasting between cases (Yin, 2003), we here used the case study methodology particularly to understand the shared phenomenon of interest that can be discovered through the cases (Stake, 2005; Yin, 2003). We argue that a case study with its contextual perspective can provide new knowledge of patients' choice and use of CAM in regard to chronic and complex illnesses (Launsø & Rieper, 2006).

We found qualitative interviews to be a valuable source of information because we wanted to explore a phenomenon of which we had little earlier knowledge, and where patients' perspectives and experiences were the source to new knowledge (Minichiello et al., 1990). According to the communicative elements in the interview, we shall keep in mind that the patients might use their position as storytellers to regain lost status and taking centre stage, justifying their own actions (Riessman, 1990). The patients in the Registry state clearly that they comment morally and politically (Williams, 1984) on the limitations they have experienced in the conventional health care.

The internal validity in this study is ensured through approval of the case presentations by the particular patients, by the researchers reading through and analysing the data material of all MS patients in the Registry, applying theoretical approaches to this material and comparing with previous studies. The patient interviews were open-ended and focused on the patients' self-defined exceptional courses of disease. The interviewers had no treatment position within conventional health care or the alternative treatment field. Through running dialogues between the authors, we have ensured that tendencies to verify preconceived interpretations were expressed and processed through working with falsification of preconceived opinions.

In assessing quality of qualitative studies, we can ask whether the credibility of our claims made is supported by sufficient evidence (Seale, 2004). Qualitative methods can not provide us with causal explanations or provide causal links between use of CAM and health-related outcomes. We aimed at transferring knowledge as working hypotheses, which can be a valuable contribution to further research on topics of which we have little earlier knowledge (Gobo, 2008). Gobo (2004) argues for a theory of idiographic sampling to support empirical generalisation in case study research. We used document analysis of all MS patients in the Registry to create a sample of patients with unusual courses of MS after the use of CAM that reflected variation. We then explored similarities and differences from this sample in regard to our research question. We have compared information from the interviews with information from an amount of written documents of courses of MS from the Registry. The results have been presented to closed circles of patient associations, conventional health care providers, alternative practitioners, and researchers who recognise our empirical findings and the theoretical understanding of our findings. Based on this, we will claim that our empirical and theoretical interpretations may have some power as hypotheses. However, the results of

this study are tentative, and the hypotheses we present need to be further explored through different research designs to establish evident knowledge of treatment outcomes and what MS patients find useful in CAM.

Conclusion

The patients in this study can be perceived as modern boundary walkers, walking the boundaries between different treatment systems. The patients express that they have experienced unexpected improvements of MS symptoms that they relate to their own efforts, including their choice and use of CAM. We argue in favour of a theory of successful coping for non-compliant MS patients which includes health-related change processes leading to the choice and use of CAM, redefinition and repositioning from Recipient to Explorer. The concept of Explorer implies action, and entails all the social, cultural and economic capital needed for the patients to take responsibility for and cope with their situation. As explorers the patients influence how an intervention is chosen and used. Taking new and active positions, constantly assessing and re-assessing their choices of treatment, the explorers make new demands on both the conventional health care system and the alternative treatment field in terms of positions, communication, decision-making and knowledge. The public health care, CAM practitioners and conventional health care providers need to include knowledge of patients' reasons for using CAM and patient-experienced benefits and disadvantages from CAM use to safeguard and optimise chronically ill patients' treatment choices and well-being in the future.

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Notes

1. The Registry of Exceptional Courses of Disease has established collaboration with nine patient associations in Norway and Denmark: The Danish Cancer Society, the Danish ME/CFS Association, the Danish Multiple Sclerosis Society, the Danish Rheumatism Association, the Norwegian Asthma and Allergy Association, the Norwegian Cancer Society, the Norwegian ME Association, the Norwegian Multiple Sclerosis Society and the Norwegian Rheumatism Association.

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