

Original Article

From disappointment to holistic ideals: a qualitative study on motives and experiences of using complementary and alternative medicine in Sweden

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Significance for public health

Recent studies indicate increased use of complementary and alternative medicine (CAM), both in general western populations and specific patient groups. Well-documented motives for choosing CAM are related to disappointment and failure of conventional health care. In addition, there are findings that demonstrate that certain basic values (such as individualism and holistic orientations) are related to the use of CAM. A better understanding of individual motives behind people's choice of CAM, and how this is related to their perception of the health care system, is important for policy makers and health care professionals alike. This study contributes to a qualitative understanding of experiences of choosing and using CAM and how motives may change over time. It also contributes with knowledge on how users combine CAM with conventional health care and deal with risks.

Abstract

Background. Recent studies indicate increased use of complementary and alternative medicine (CAM) in western societies, to ameliorate health problems. Even if there is substantial research on general patterns of use, there is limited knowledge on individual motives. This study contributes to a qualitative understanding of experiences of choosing and using CAM.

Design and methods. This study consists of in-depth interviews with 10 CAM users in Sweden. The participants represent different backgrounds and experiences of using CAM. The interviews have been analysed in accordance with content analysis.

Results. In analysing experiences of choosing and using CAM four main themes were identified: frustration and critique, values and ideology, individual responsibility, and combining treatments. In general, the participants were highly reflexive on issues concerning their health. They highlighted their own role and responsibility, combined a variety of treatments, and continuously dealt with questions on risks, even if they had relatively different approaches to if and when to use CAM. The results also show that motives may change over time. Even if initial choices were closely related to frustration and critique of conventional treatments (for example, by perceiving conventional health care as limited, not receiving proper diagnoses, or being critical to conventional drugs) was long-term use motivated by ideological characteristics of CAM (such as holistic and individualized treatments, and extensive interaction with practitioners).

Conclusions. Four main themes, concerning experiences of choosing and using CAM were identified. This study also supports the idea that initial motives for choosing CAM may differ from those explaining long-term use.

Introduction

Several studies indicate that increasing proportions of western pop-

ulations have used some kind of complementary or alternative medicine (CAM) recently, even if reported percentages vary as much as from 2.6% to 74.8%.¹⁻³ Common health issues for CAM utilization are back pain, depression, insomnia or trouble sleeping, severe headache and migraine, stomach or intestinal illness,² and some of the most frequently reported treatments are homeopathy, acupuncture, chiropractic manipulation, herbal medicine, and massage.¹⁻³ In general, women, middle aged people and those with higher education are most frequent users, and there are positive correlations between income and use of CAM.^{2,4} A number of recent studies on specific groups, such as women,⁵ children,^{6,7} cancer patients,⁸⁻¹¹ and infectious patients,^{12,13} indicate extensive use of CAM, not necessarily to cure specific conditions but to improve quality of life, increase energy levels, and boost immune systems.⁹⁻¹¹ Use of CAM can also serve as routines and rituals to establish certainty and control among critically ill patients.¹⁴

To explain this development, we probably need to take several factors into account.¹⁵ One theme of explanations is related to influences of postmodern values, growth of individualism, and increased consumerism in the area of health.^{16,17} It has been proposed that it is increasingly common to question traditional authorities, such as doctors and researchers, and to have confidence in individual, subjective, and bodily experiences, in postmodern societies.¹⁸ Many CAM users highlight their own role and self-authority in taking care of health and seeking different kind of treatments. As a result, what *feels right* or *works for me* may be considered at least as important as expertise knowledge.¹⁹⁻²⁴ To some extent this indicates a greater willingness to take risks among CAM users, compared to non-users,²⁵ although, their belief in self authority does not seem to hinder CAM users from seeking expert advice.²²

Another theme of explanations is related to individual experiences of conventional health care. Many CAM users have not been helped by conventional treatments, are concerned about adverse side effects, and/or is not satisfied with doctor/patient communication.^{26,27} Previous research also shows that relatively few people chose CAM as a first-line or exclusive treatment. Instead they use CAM along with conventional health care.^{28,29}

However, more detailed motives to use CAM, for specific needs or in specific situations, are relatively poorly understood.³⁰ Vincent and Furnham suggested it could be relevant to separate the reasons for beginning such treatments from the reasons of continuing them.²⁶ Even if treatments start off in frustration and disappointment with conventional medicine, other factors may explain why people continue. For example, a study by Sirois and Gick found that established CAM users had significantly more health issues,²⁷ such as chronic pain, than newer and more infrequent users. There are also studies suggesting more complex pattern of motives and background variables, depending on what CAM treatments we are looking at. The reasons to use acupuncture or chiropractic are not necessarily the same as for using Reiki healing. Or as Kelner and Wellman concluded: *An individual may see a physician for heart problems, a chiropractor for headaches, and a naturopath for fatigue.*²⁵

This article examines individual experiences of choosing and using CAM. What are the motives for choosing treatments outside conven-

tional medicine and/or public health care? How are these choices carried out in practice? What are the experiences of using CAM like in comparison with conventional medical treatments? And how does use develop over time?

Design and Methods

This study consists of in-depth interviews with 10 CAM users in Sweden. The goal was to include participants with different experiences of using CAM; new/established users, frequent/infrequent users. Another goal was to include participants from varying backgrounds, ages and genders. All except from one were identified and contacted with the help of local CAM practitioners. The remaining person was contacted via one of the other participants.

The interviews were approved by the regional ethical review board in Sweden, as part of the project *A last hope or an active choice? A study on use, integration, and organization of complementary and alternative medicine (CAM)* (DNR 2011-355-31). The interviews, which were performed in 2013-14, took 60-90 minutes each. To obtain complete, detailed accounts, the interviews were highly flexible. Experiences of CAM, motives for use, searches for information, trust/reliability, and comparisons with conventional medicine were recurring themes. The initial questions were also similar. However, the choice of words and details, as well as the order of the themes, were adapted to the specific content of each interview. All of the interviews were conducted in Swedish and digitally recorded.

To ensure a systematic analytical procedure was the material analysed in accordance with qualitative content analysis, in the Atlas.ti software. In the first phase, the focus was on identifying relevant meaning units and on coding manifest and latent content (what were the participants talking about?).³¹ This generated 270 codes, which ranged from descriptive ones, such as *acupuncture*, *pain*, and *treatment*, to more abstract ones, such as *holism* and *risks*. After the first round of coding, the material was reread and recoded. Some of the codes were attached to more excerpts, others were renamed or merged. In the third phase, four main themes were identified (frustration and critique, values and ideology, individual responsibility, and combining treatments). In practice, this was done by using *code families* and memos in the software. In this phase, attention was also paid to how the participant talked about their experiences. In this article, not all codes or themes from the analysis are included, only those relevant to the research questions stated above.

Quoted excerpts were translated to English in the last phase of the

analysis. As far as possible, the goal was to keep the translations close to the linguistic characteristics of the spoken language in the interviews. However, some adjustments to make the quotes comprehensible have been necessary. In the presentation below, the participants are anonymised and labelled from A to J.

Demographic characteristics of the participants

The participants have different characteristics. As shown in Table 1 are eight women and two men. A majority of them are middle-aged, even if the youngest is in her early 20s and the oldest is over 70 years old. Seven of them are working, one is a student and two are retirees. They also have varying experiences of CAM. All participants use, and have tried, several treatments. Some of them visit CAM practitioners regularly for treatment or relief of chronic illness. Others use CAM occasionally when they have specific problems or needs. A couple of the participants have mainly used one or two traditions, while others have tried and used many different kinds of CAM. In the interviews, the participants mostly told about their experience of visiting CAM practitioners. However, a couple of them also use self-help techniques (such as herbs, yoga, Qi Gong, massage, and dietary recommendations) regularly. The participants also differ when it comes to health status and self-identified needs. A couple of them have been diagnosed with chronic diseases or have had severe illnesses or injuries. Others have more common problems, such as migraine, lower back or neck pain, asthma and allergies, and describe themselves as basically healthy.

Results

Frustration and critique

Even though the participants have very different health statuses and identify various problems and needs, they share a general sense of frustration with conventional treatments. Almost all of them said that they have seen various kinds of healthcare practitioners and searched for diagnoses and effective treatments, but that they have failed or not met their expectations. Out of disappointment or frustration, they have searched for solutions outside the medical establishment.

Narrow and limited perspectives

One common source of frustration is the perception of conventional health care as too narrow and limited. Several of the participants experienced that it doesn't have the right tools to provide adequate or effective treatments or is based on limited perspectives as to the factors that

Table 1. Demographic characteristics of the participants.

Label	Gender	Age	Occupation	Main health issue	Main CAM use
A	F	51-60	Preschool teacher	Fibromyalgia, migraine, chronic pain	Osteopathy, TCM
B	F	61-70	Retired	Migraine, various forms of pain	Osteopathy, acupuncture
C	M	31-40	Journalist	Chronic knee and shoulder pain	Medical yoga
D	M	70+	Retired	Chronic back pain	Osteopathy, naprapathy
E	F	41-50	Educator	Asthma and allergies	Osteopathy, TCM
F	F	41-50	Nurse	Back and shoulder pain	Osteopathy, naprapathy
G	F	41-50	Social worker	Neck pain, headache	Osteopathy, shiatsu, yoga
H	F	41-50	Nurse	Back and shoulder pain	Naprapathy
I	F	51-60	Journalist	Asthma, high blood pressure	Naturopathy, acupuncture
J	F	20-30	Student	Health improvement	Homeopathy, naturopathy

CAM, complementary and alternative medicine; TCM, tradition Chinese medicine.

should be considered when diagnosing. Even though most of them emphasized that they think healthcare professionals, such as doctors, midwives, and physical therapists, are highly skilled, they pointed out specific diagnoses, problems and parts of the body about which knowledge, education and open minds are lacking. One of the men told about chronic lower back pain, which started as the result of a serious injury as a child. Over the years, he has seen several conventional healthcare professionals: *You can go and see them, but they cannot help. All they recommend is painkillers... and rest. When I worked, they offered doctor's certificates and painkillers. Sometimes you could get a routine for how to strengthen the muscles.* (D) To relieve acute pain, he has sought treatment from chiropractors, naprapaths, and osteopaths. In contrast, he described these treatments as physical, effective and focused on his specific needs. In several parts of the interview, he stressed that he has a great deal of trust in conventional health care and that he has been successfully treated for other problems, but that it is too limited when it comes to treating his back pain: *They don't have the education, or they don't want that kind of education. Or don't believe in it. But I think that there should be someone at an orthopaedic clinic with skills in chiropractic or osteopathy. They must know that those methods help people.* (D)

Some of the participants did not think it is worthwhile using conventional health care to treat conditions such as back, hip, or neck pain. One woman stressed the lack of appropriate methods: *It doesn't help. They can take samples and point out different things, but they can't help. I mean, what can they do?* (E) Several of the participants also experienced conventional health care as too focused on specific symptoms, such as pain, and isolated parts of the body, in contrast to more complex or holistic perspectives. One of them stated that there are good and skilled doctors but that they tend to focus too much on what hurts: *If that's where it hurts, that's where the doctors focus. Not on the whole picture. Not on how do you feel? Are you stressed out? What is it like?* (H) Some participants also identified their health problems as complex, in terms of several intervening diagnoses, which were not suitable for the standard treatments of conventional health care.

No accurate diagnoses

A couple of the participants expressed their frustration with not being accurately diagnosed by public health care as a motive to search for other options. For example, one woman described her problem with migraine: *It started like a normal cold, you know how it feels in the head...but it didn't go away. So I saw the family doctor and he prescribed some pills. [...] But nothing improved, and I called back. I went back to the doctor, I don't know how many times. I was sent to the neurologists and they examined me, X-rayed my neck. But they found nothing that could explain my pain.* (A) At the time of the interview, she had not received a diagnosis, but she thinks that she has to continue exploring various treatments for her health problems. Another participant told about similar experiences. After a work-related accident, in which she hurt her shoulder, she went to a public health clinic: *I was on sick leave. They examined me with ultrasound but found nothing. I was told it was psychosomatic but I was referred to a physiotherapist to exercise and try to fix my shoulder. But nothing helped.* (H) Later on she had two operations and follow-up rehabilitation from a physiotherapist, but the pain did not go away: *I really needed help. So, I had to see my naprapath many times. Get treatments. And also work on my exercises from the physiotherapist.* (H)

Drugs and medication

A related theme in the interviews is a general critique of conventional drugs and medications. Even though most participants acknowledged that it is sometimes necessary to take pills for serious conditions (such as hypertension, pneumonia, or sinusitis), they associate conventional drugs with adverse effects, dependency and treatment of symptoms. One participant told that a reason for exploring alternative treatments

was her experience of adverse effects: *I've taken so many pills over the years. My stomach is damaged. It hurts. I need to take medication for gastric ulcer all the time. But if I can avoid painkillers and all that by trying something else, I would prefer diet, herbal medicines, or alternative treatments.* (A) Another woman explicitly related her view of conventional medicine as narrow and limited to her scepticism to medications. Even though she said that she has a great family doctor, *Their tools are so limited. You are referred to a physical therapist, and if you are lucky, a good one. But otherwise it's all about medication. Pills. Maybe I need them to carry on. But something is wrong. Something has to be identified.* (B) According to her, drugs are normally used to treat symptoms, not to address the causes, by the public healthcare system. Another participant who often takes herbal remedies told that she generally avoids conventional drugs: *I think the body has a great capacity to heal. If you sleep and eat well, the body can help with most problems. But you can't be foolish about it. If you come down with pneumonia or nephrolithiasis, you need medical care.* (I) Several participants were particularly critical of routine prescription of conventional drugs. One of them told about his experience of public health care to treat his injured knees and shoulders. On the one hand, he felt satisfied by having seen a doctor, who could provide reliable answers and explanations for his problems. On the other hand, he felt disappointed because they usually prescribed drugs: *But then you think about how fast the appointment went. And what were the recommendations really? Painkillers. I have never seen a doctor without getting a prescription of painkillers. My shoulder is all out of whack and my knee is full of screws.* (C) Exploring alternative treatment is a way of avoiding medication, as well as receiving individualised treatment that addresses his specific conditions.

Different views

A related aspect is not sharing the medical view of available treatments or health status. One participant described her frustration: *I have been to doctors and they have examined me. They say it's fibromyalgia. Live with it.* (A) She explained that she accepts her diagnosis and the fact that she probably has to live with pain for the rest of her life but that she cannot agree to the focus on medication and painkillers. She is looking for relief and wellbeing outside the medical establishment, for example by seeing an osteopath regularly. She has also explored other treatments, such as acupuncture and herbal remedies with varying degrees of success. Since she has severe pain and hardly gets out of bed during some periods, she must continue to look for treatments: *Is this something for me or not? At least I tried.* (A) Another participant described her experience of being diagnosed with asthma as an adult. The doctor told her to take medication: *And I thought, no! I am not going to take medication for the rest of my life. My attitude was that I wouldn't do it. Not cortisone and all that.* (E) As a result, she started to search for alternative treatments and ended up with traditional Chinese medicine, which has helped her a lot with both asthma and other health issues. Another participant said she had the impression that some problems, such as back pain, are more or less neglected by public health care: *Back problems are very common, but sometimes it's like... I am tall and I work in the health care sector so I should live with it.* (F) From her point of view, no solutions are offered for these kinds of problems by conventional health care, only management of symptoms.

Values and ideology

Several motives for using CAM are related to frustration and disappointment with conventional medicine. However, in the interviews it is possible to detect a transition of motives. What was important to the participants in initial contact with CAM is not necessarily the same as what valued in the long run – after trying, using, and comparing various CAM treatments. Motives that explain why the participants contin-

ue to use a specific kind of CAM treatment, or to explore additional CAM options, are largely related to values and ideology.

Holism

All participants emphasized various aspects of holism as one of the main motives to use CAM. Problems are not treated in isolation and the *whole person* is incorporated in the treatments. One participant explained why she continually uses osteopathy: *We need balance. And that's something I like about osteopaths, they think the same way. They don't isolate an elbow or a neck. Because then nothing happens. They consider the totality.* (G) In another sequence of the interview, she compared her experiences of yoga and osteopathy with conventional health care: *If I go to a physiotherapist and say that my elbow hurts, they will isolate it. Do bicep curls! Lock the muscle here!* (G) Another participant contrasted differing approaches to the body by public health care and naprapathy: *If my lower back hurts, the source of the problem might be located in the neck. The doctors don't see that. Or they don't buy the explanation. When I see my naprapath, he treats my whole body.* (H) This practical dimension of holism is a recurrent theme in the interviews. Several of the participants emphasized that their whole bodies are treated when receiving CAM and that this is something they appreciate. For example, one of the men described his experiences of osteopathic treatments: *She starts with my feet and works through my whole body. Up to my scalp, my head. Various trigger points. My lower back and my legs. And things happen, I can feel it.* (D)

In some of the interviews, it is clear that the holistic perspective incorporates both body and mind; from physical sensations to psychological and spiritual dimensions. One woman explained why she prefers holistic treatments, such as homeopathy, herbal remedies and acupuncture: *I really believe in this. If you don't feel okay, there is always some kind of inner explanation as well. Some part of your soul. Something that's not okay.* (J) According to her, both physical and psychological factors must be addressed to achieve good health. Other participants stressed that they are just interested in physical treatment, even if they are fully aware of other dimensions in CAM traditions. One said: *I think it is great when they bring in a holistic perspective, at least concerning the body. But I'm not sure I like it when they start getting into spirituality. I don't want that. One auuum is enough. Then I stop listening.* (C) Another participant who sees a naprapath regularly, and appreciates holistic treatments, was clear that she would not use some CAM traditions, such as homeopathy or acupuncture, since she thinks they deal too much with psychological or spiritual factors. She explained, *Naprapaths and chiropractors work with muscles and nerves. But an acupuncturist, or someone using Chinesology, is more focused on changing the mind. They are on another path. I might be wrong, but I don't want that.* (H)

Individualism

Other motives are related to individualism. A basic view among the participants is that people have unique needs, qualities and conditions. What works for one person may not necessarily work for the next. Some participants stated their ideas about individualism very explicitly. For example, one woman told about her experiences of cancer treatments and her ideal scenario, in which patients would have the opportunity to choose among various treatments, both conventional and alternative: *I think we are very different as human beings. Maybe I don't have the same needs as someone else with the same condition. I wish we had the opportunity to choose if we get really sick. Do you want to strengthen your body with osteopathy, not only medication? Conventional medicine is good, but there are other aspects of the body that need to be dealt with.* (E) Another participant said, *I believe every person finds the way that is best for her or him. Or the practice. For one person it might be hiking in Mexico and meeting a magician who can sort out your problems. For*

someone else, it is chemotherapy. Or interaction of various treatments. (J) Yet another participant compared herself to her best friend, who had similar problems with asthma: *We went to the same doctor, and she is still on conventional drugs. She has also seen a traditional Chinese therapist but it didn't help. I think we respond in different ways depending on the kind of person we are. I respond well to most treatments.* (E) Several stressed that various types of CAM treatments have been beneficial to them to relive problems and addressing needs. But even though they often recommend treatments and practitioners, they emphasised the importance of individual conditions.

The individualistic approach is also found at a practical level in actual treatments. Most participants pointed out that they appreciate individual adjustments by the practitioner. For example, one of them told about his first encounter with medical yoga. He has a history of severe knee and shoulder injuries and struggles with chronic pain: *The second time the main instructor was there. She fully focused on me so that I wouldn't hurt my knee. There are many sitting positions, and my knee is full of metal and screws. I know that some yoga positions are bad for the knee, but I can complement them with physiotherapy and aquatics. But I also know that some yoga exercises are really good for me, and she helps me with them.* (C) In a similar manner another participant told about her first appointment with an osteopath and the trust she felt because of the individual approach: *I felt it immediately, what it was all about. She knew what kind of difficulties I had and what I could manage. She didn't suggest anything that I couldn't handle.* (B) A third participant described her regular appointments with a doctor who is also a homeopath to get personal advice about what supplements and homeopathic remedies to take. The recommendations are continually adjusted to her specific needs: *Three months ago I got a mixture of flowers and homeopathic remedies to improve my concentration. To relax. Six months ago it was something else. It depends on what you are experiencing and feeling.* (J) Another aspect of individualism is that most participants described how they pieced together individual combinations of treatments, conventional or otherwise, for various needs. One participant expressed her general attitude to using various treatments: *I believe in combining treatments. Physical exercise. And if you have acute problems, see a naprapath or whatever you prefer.* (F) Some participants also stressed that it is important to be careful so that various treatments do not interact negatively and to tell practitioners about the different combinations. For example, one of the women who had tried and used many different treatments explained: *You cannot try everything at the same time. You have to give each treatment time. I am seeing a physiotherapist at the same time as I am seeing an osteopath. Only for my shoulders. But both of them know about it.* (A)

Interaction

Another set of motives for using CAM in the long run is related to interaction with practitioners. Most participants compared their encounters with conventional healthcare professionals to CAM practitioners, whom they often preferred. However, they also emphasized that public health care and private alternatives are subject to different conditions. When they visit a CAM practitioner, they usually pay for a certain amount of time, while the family doctor has only a few minutes to spend with them. A couple of them described their experiences as follows: *The doctors in public health care have ten minutes with each patient, fifteen at most. If they spend more time, their whole day will be ruined.* (B) *You realize that there is no time to finish what you are talking about because the doctor turns to the computer and starts to read the patient chart.* (C) *Had to work harder to keep their patients since there is no guarantee that they will come back: If you are a CAM practitioner, you care more about your patients. At the public health centre, it doesn't matter. They are overwhelmed anyway. Even if I leave, there are 27 people in the waiting room.* (A) However, it is clear from the interviews that interaction is not only about practical matters, such as time and

availability, but about how they are dealt with as individuals. Several of the participants emphasized factors such as interest, respect, and interacting on equal terms. One woman explained: *I think the encounter is important. That the practitioner I am going to is interested in me as a patient and as a person. And that could have to do with finances as well, that it is important for them because of the income. In the public health care... it doesn't matter if I go there, their finances are the same.* (F) Another one described: *If I go see an acupuncturist, it is not very stressful. We are on more of an equal footing. Yes, that's the right word for it. I see someone I can talk to and be understood by. Seeing a doctor is more about being nervous and sitting in a waiting room. Then you go in to the doctor's office and talk about what is wrong. They sit there and read the patient chart. You wonder, what is there? What have they written? What are they thinking about me? And they are performing their examination and need to come up with a quick solution. So there is a huge difference.* (I) This theme clearly overlaps with the one about individualism. Some of the participants told that CAM practitioners are usually more committed and interested in their specific problems and conditions than conventional healthcare professionals. They take time to read additional literature and consult colleagues in order to find individual treatments. This is in contrast to conventional health care, which most participants described as more standardized.

Natural treatments

As indicated in the previous section, most participants associate conventional health care with drugs, pills and medication. This is in contrast to CAM treatments, which are viewed as natural and gentle. Some participants emphasized that they prefer naturopathic remedies or herbs because they are gentler. One of them said, *I have tried herbs. Some have worked, others not. But it is not like taking penicillin, which makes a big difference after three days. It takes longer. I don't know whether it is like that just for me, but that's how it works. The ingredients aren't as powerful as conventional drugs. They are gentler on the body.* (A) Another participant explained that she prefers natural remedies even though she has to take drugs at times: *I try to avoid conventional drugs. People at work used to ask me if I had painkillers. But I never do. Maybe they think so because I am married to a doctor. But I do have a stash of remedies, so when people ask me, I say yes, I have this. I have garlic pills and buckthorn.* (I)

Individual responsibility

All of the participants told about their own role and responsibility when it comes to health issues. When facing health problems or being dissatisfied with conventional care, they found it logical to actively search for solutions, even if they generally involved different kinds of costs.

Openness

The view of individual responsibility is based on general openness to trying and exploring various treatments, sometimes with relatively limited information about specific CAM traditions, practical aspects of treatments or practitioners. One participant told about her general openness to exploring treatments outside public health care, despite the fact that she is working as a nurse: *I am a nurse, but I have always been open to alternatives. If painkillers don't help, go to a naprapath! Or to a physical therapist! I have never been afraid of such things.* (H) Another compared herself to her husband, who is a doctor: *I don't need scientific proof. I don't need an article in a journal. I am simply more open-minded. And if I see that something doesn't work, I drop it.* (I) The participants also described how they share information and are inspired by family, friends, and co-workers. Most of them also stressed the importance of recommendations: *I talk to everyone... have you seen anyone? Do you have any ideas about who I can see? I can ask anyone I know, or ask if I hear someone talk about something, I was here or there.*

Is that something for me?. (A) I am in touch with a lot of people and hear about their experiences and who they met. So a lot of information is spread by word of mouth. That's how it works. And if you experience that you are not being helped by conventional health care, or that there are long waits, it is easy to look for alternatives. (F) Some participants also mentioned other sources of information and guidance, such as books and magazines.

Negative experiences

Being willing to try and explore various treatments also opens the door to treatments that the participants do not like for some reason. All of them told about negative experiences, from treatments that showed no results to fraudulent practitioners. Some of the accounts were relatively brief, like: *I've tried massage, I've tried naprapathy, I've tried homeopathy, with very different results. I've tried all sorts of things. And I can tell that the practitioners have very different skills.* (B). Others gave more detailed descriptions on what had gone wrong. For example, two participants told about their experiences of using acupuncture for the treatment of specific problems. One of them didn't get any positive results: *I tried acupuncture, but it didn't work at all. One practitioner pricked my fingers. Not the whole body, or the head, as the others did. But nothing happened.* (A) The other participant described her positive experience of acupuncture, but said that her practitioner cannot address all health issues: *She tried to help me with allergies and they got better for a while, but then they came back. She tried several times, but it wasn't really successful. I see that some things work and others don't. And then I think you have to move on and look for other options.* (B) However, most participants interpreted having less successful or negative experiences as individual and expected. The treatment was not *right* for them, or the practitioner did not have enough experience or a manner that they appreciated. For example, one participant told about a shiatsu practitioner who wanted to use acupuncture, even though she explicitly stated that she did not want that kind of treatment: *But he did it anyway. He thought I wouldn't find out. But you simply don't do that. It is such a violation of my dignity. But he sat there, held my hand, and asked me if we couldn't try needles. I turned him down, but then he pricked me anyway.* (G) She lost trust in the practitioner and refused to go back even though she still consider him to be highly skilled and enjoy the tradition in general. Other participants reached similar conclusions, that there will always be *bad practitioners*, as with any profession, including doctors, but that they are open about other options.

Risks

From the interviews it is clear that the participants continuously deal with questions about risks. In general, conventional health care is associated with characteristics such as control, safety, skills and scientific standards, even though they also identified negative aspects and limitations. Similarly, CAM is generally associated with both positive characteristics, such as gentle, safe and holistic treatments, and negative ones, such as lack of control and malpractice. As presented above, the participants are generally willing to try and explore different kinds of treatments – and to take some risks. A crucial aspect, indicated in several quotes, is whether they perceive a condition as serious or not. If so, they tend to choose conventional health care. Or as a couple of participants expressed themselves: *Sometimes there is no choice. If I have a heart attack, I need to go to the ER. I don't think about any alternatives. CAM treatments are more for when it is manageable, when there are various options.* (B) *Public health care can take care of acute situations in a different way than alternative medicine.* (G) However, several participants indicated that it is difficult to make a clear distinction about what to choose and under what circumstances. Dealing with life-threatening and acute conditions is one thing, whereas less dramatic situations open the door to more complex choices and individual

preferences. One woman said, *Good question. What is serious or not? My allergies are serious. If I can't breathe, I will die.* (I) Several participants also explained that they could not use treatment that might be harmful. One of them told about negative experiences of zone therapy: *I reacted really strongly to that, and I think if you have severe pain, and they treat it...they could trigger it. So, I don't think I would use it again. [...] I don't dare.* (A) The last aspect, fear of staying out of conventional treatments, was mentioned by several participants. Even if there are alternative treatments of interest, they chose conventional ones because of the perceived risks. For example, one man told about his use of conventional drugs for hypertension: *I have to. I cannot just let my blood pressure rise, it's not good. It could have tremendous consequences, like a stroke.* (D) However, later on in the interview he discussed the possibility of using natural remedies if it could be done under safer circumstances: *It is difficult to go to a naturopathy store and try things out on your own. I would be afraid to do that. I could consider it to be experimental, but under other circumstances, with strict supervision by doctors.* (D)

Combining treatments

As indicated in previous sections, all participants combine various types of health care, conventional and otherwise, within and outside the public health care system. However, even though they have relatively similar motives when they choose and use CAM, there are notable differences in their general approaches. Some participants are clear about the fact that conventional medicine, in the public healthcare system, is their first choice. They normally go to the local health centre or family doctor for flu, infection or a sore knee or. These participants described conventional medicine as reliable, safe, scientific, cheap, and relatively accessible. CAM was described as an additional option, to be used when conventional medicine fails or is considered too limited. One participant told: *If I have a choice, I go to the public health centre and get help.* (C) Over time he has started to explore complementary treatments, such as naprapathy, osteopathy and medical yoga, which he finds beneficial to his health issues. But he also stressed that CAM treatments are very costly and that there are many expectations from family and friends to use conventional health care: *There is some pressure, like last time I saw a doctor. My girlfriend told me to go. It is more or less free. And maybe there is something I cannot find out by myself. Something that just a doctor can see.* (C) The last notion, that doctors have exclusive diagnostic skills, as well as access to advanced technology (such as radiology and laboratories), was mentioned by several participants. Some of them also told that they use conventional health care to get prescriptions and doctor's certificates: *I go to the health centre if I absolutely need drugs. Or if I have a serious infection that won't go away.* (B) In contrast, other participants explained that they avoid conventional health care and prefer CAM treatments, even if they sometimes found it necessary: *I prefer to stay out of public health care as much as possible if I'm not really sick. If a need an X-ray, of course I need to call a public health centre. But if I feel a bit unbalanced, I call an osteopath. Or if I'm having some other problem that I think she is more able to help me with. Better than a physical therapist.* (G) *I choose alternative treatments in the first place. I used to discuss it with my husband. You cannot go on like this, he said, you have to see a doctor. Why? Why should I see the family doctor? I said. They can do tests. They can but it doesn't help very much.* (E)

Discussion

One of the most striking aspects in the interviews is how reflexive the participants are about health issues. They are willing to assume a lot of personal responsibility – and to devote interest, knowledge, time and money to find health care that suits their needs and preferences.

Their choices are continually adjusted, changed, and reflected upon. Choices of CAM are not fixed or constant – not even for those participants who in most situations prefer CAM to conventional healthcare. Specific choices depend on specific circumstances (such as self identified needs, previous experiences, monetary costs, and perceived risks).²⁵ Even though the participants consult different kind of people (from health care professionals to family and friends) they seem to have great trust in their own capability to decide whether or not a treatment is working for them.

Many motives described by the participants are expected from previous research. However, one of the contributions with this study is that it supports the idea that it could be relevant to separate initial motives from long term ones.²⁶ This study also, as indicated above, supports the idea that motives depend on specific circumstances.²⁵ From the interviews, initial motives are closely related to failures and disappointment of conventional medicine. The participants told about experiences of not receiving accurate diagnoses or efficient treatments. They also described conventional health care as limited and too focused on isolated problems and specific parts of the body. A related motive is negative experience and critique of conventional drugs, medication and routine prescriptions. Furthermore, conventional health care is associated with management of symptoms, often with drugs, in contrast to resolving underlying problems. When the participants described continued, long-term use of CAM, other motives were in focus: values and ideology. They emphasized various aspects of holism and individualism, for example the experience of being treated as a whole person and getting individually adjusted treatments, as important reasons to come back. They also stressed extensive personal interaction with practitioners, as a contributing factor. Positive experiences of CAM also seem to open the door to more extensive use for other health issues. In other words, even though use of CAM started off in frustration with conventional health care, ideology may help explain why the participants continue to use and further explore CAM. However, all the participants use CAM more or less as a complement to conventional health care. All of them also acknowledged that there are issues, problems and situations when it is necessary to use conventional health care even though they might prefer CAM. In general, they have a great deal of trust in doctors and other healthcare professionals even when they cannot provide help or cure.

These results could easily be interpreted as a consumistic perspective on health,³² in which the patient or user takes responsibility not only for searching, choosing, and evaluating treatments but also for financing them. They develop expertise knowledge on health issues and act in accordance with that knowledge.³³ However, it is important to acknowledge the complexity in the interviews. All the participants question aspects of conventional health care and highlight their own role and responsibility. At the same time, they combine conventional treatments with CAM and express great trust in conventional medicine and health care professionals, especially in the treatment of serious conditions. Neither are they just positive about CAM. Freedom to choose opens up for risks – and at least some of them seem to prefer more integration of CAM in public health care and safer arrangements.

Even if this study is restricted to the Swedish context, and includes a small number of participants, is it reasonable to expect that many of the results are possible to transfer or apply on larger populations of CAM users and other national contexts,^{34,35} because of the variation in the sample and the richness in the material. However, an important limitation is that the participants relate their experiences to the Swedish public health care system, regulated by national laws but also characterized by large state subsidies. Most CAM treatments in Sweden are located in the private sector and fully paid by the users, even if there are examples of integrative medicine. As a consequence, most CAM treatments are much more expensive than conventional treatments. It is also important to recognize that this small group of participants doesn't include those who omit CAM completely after initial con-

tacts – or never would consider trying.

Conclusions

The general aim of this article was to examine individual experiences of choosing and using CAM. Moreover, it was also to answer questions about why people choose treatments outside conventional medicine and/or public health care, how choices are carried out in practice, how use of CAM is experienced compared to conventional treatments, and how use develop over time. In analysing experiences of choosing and using CAM four main themes were identified: frustration and critique, values and ideology, individual responsibility, and combining treatments. In general, the participants were highly reflexive on issues concerning their health. They highlighted their own role and responsibility and were willing to take some risks. They combined a variety of treatments, both conventional and CAM, even if they had relatively different approaches to if and when to choose CAM and/or conventional treatments. It was also possible to detect changes over time. Even if initial choices were closely related to disappointment, failure, and critique of conventional health care (for example, by perceiving conventional health care as narrow and limited, not being accurately diagnosed, or being critical to conventional drugs and routine prescriptions), long-term use was motivated by ideological characteristics of CAM treatments (such as holistic and individualized treatments, and extensive interaction with practitioners).

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