



---

## **PhD thesis**

Lasse Skovgaard

# Use and users of Complementary and Alternative Medicine among people with Multiple Sclerosis in Denmark

- a Sequential Mixed Methods Study

**Resumé og abstract**

## Resumé

**Baggrund:** Internationale undersøgelser har vist, at brug af komplementær og alternativ medicin (KAM), defineret som behandlingssystemer, praksisser og produkter, der generelt ikke anses som værende en del af konventionel medicin, er udbredt blandt mennesker med Multiple Sclerose (MS). Internationale studier har desuden vist, at motiverne for at bruge KAM er mangfoldige, at kvinder er mere tilbøjelige til at bruge KAM end mænd, og at brug af KAM er associeret med høj uddannelse, høj indkomst, lav selv-vurderet helbredstilstand og lang sygdomsperiode. Forskningsresultaterne er dog ikke fuldt konsistente, hvad angår disse tendenser, og viden om brug og brugere af KAM blandt mennesker med MS i en dansk kontekst er meget begrænset.

**Mål:** Afhandlingens overordnede forskningsmål er at undersøge brug og brugere af KAM blandt mennesker med MS i Danmark gennem et mixed methods forskningsdesign. De specifikke forskningsmål er at undersøge a) prævalensen af brug af forskellige KAM-modaliteter og prævalensen af adressering af forskellige formål med brug af KAM i de fem nordiske lande, b) forskelle i deskriptive karakteristikker af KAM-brugere og ikke-brugere blandt mennesker med MS i Danmark, c) forskelle i deskriptive karakteristikker af udvalgte undergrupper af KAM-brugere blandt mennesker med MS i Danmark, d) opfattelser af risiko for negative interaktioner forbundet med brug af konventionel, farmakologisk medicin kombineret med urtemedicin i en udvalgt gruppe af mennesker med MS i Danmark, som kombinerer disse to typer behandlinger og d) opfattelser af behandlings-mekanismer blandt mennesker med MS i Danmark, der bruger KAM eksklusivt. På baggrund af disse fem specifikke forskningsmål er studiets overordnede forskningsmål at undersøge, hvordan og hvorfor mennesker med MS i Danmark inkluderer KAM i håndteringen af deres liv med kronisk sygdom samt at diskutere muligheder og udfordringer forbundet med denne brug.

**Metoder:** Studiet er baseret på et sekventielt mixed methods design, der kombinerer en internetbaseret spørgeskemaundersøgelse med to kvalitative interviewstudier. 6850 mennesker med MS fra de fem nordiske lande (heraf 3500 fra Danmark) blev inviteret til at deltage i spørgeskemaundersøgelsen. Den gennemsnitlige svarprocent var 56,1. Komparative analyser blev gennemført ved fortolkning af odds ratio, og statistisk signifikans blev fortolket via konfidensintervaller. Statistiske analyser blev gennemført på baggrund af såvel det samlede, nordiske datamateriale (n=3795) som specifikt det danske datamateriale (n=1865). To særlige problemstillinger vedrørende respondenternes KAM-brug (dels opfattelser af risiko for negative interaktioner blandt KAM-brugere, der kombinerer konventionel, farmakologisk medicin med

urtemedicin og dels opfattelser af behandlings-mekanismer blandt KAM-brugere, der ikke benytter konventionel behandling) blev udvalgt til nærmere undersøgelse på basis af analyserne af de danske spørgeskemadata, og to kvalitative interviewundersøgelser blev gennemført. Programteori blev benyttet som overordnet analytisk tilgang i interviewundersøgelserne, og meningskondensering blev benyttet i analysen af interviewdata.

**Resultater:** Studiets resultater viser, at blandt de danske respondenter havde hver anden brugt KAM indenfor de seneste tolv måneder. KAM bliver oftest benyttet til ikke-specifikke/forebyggende formål. Komparative analyser af det nordiske datamateriale viser, at prævalensen af KAM-brug er på samme niveau blandt respondenter i alle fem lande (gennemsnittet var 53,0%), og at KAM oftest er blevet brugt til ikke-specifikke/forebyggende formål blandt respondenter i alle fem lande. I det samlede billede adskiller de danske respondenter sig ikke fra respondenterne i de øvrige nordiske lande; dog findes forskelle vedrørende brug af specifikke KAM-modaliteter og vedrørende eksklusiv brug af KAM. Komparative analyser af deskriptive karakteristikker af KAM-brugere og ikke-brugere blandt de danske respondenter viser, at KAM-brugere oftere er kvinder, oftere er under 40 år og oftere har videregående uddannelse. Komparative analyser af det danske datamateriale viser desuden, at der er få forskelle i deskriptive karakteristikker mellem udvalgte undergrupper af KAM-brugere, men at nærmere studier er relevante vedrørende to specifikke problemstillinger i to undergrupper: 1) opfattelser af risiko for negative interaktioner blandt KAM-brugere, som havde kombineret urtemedicin og konventionel, farmakologisk medicin og 2) opfattelser af behandlings-mekanismer blandt KAM-brugere som havde brugt KAM eksklusivt, deriblandt havde fravalgt sygdoms-modificerende behandling af deres MS. De to kvalitative interviewstudier viser, 1) at informanterne - bestående af KAM-brugere, som har kombineret urtemedicin og konventionel, farmakologisk medicin - generelt anser en sådan kombination som sikker på baggrund af det naturbaserede aspekt ved urtemedicin, og 2) at dette at bruge KAM eksklusivt ikke nødvendigvis repræsenterer en principiel afvisning af konventionel medicin, men fremstår som resultatet af den informanternes samlede vurdering, baseret på overbevisninger og erfaringer koblet til positive og negative effekter af forskellige typer af behandlinger.

Visse forbehold vedrørende generaliserbarheden af studiets resultater skal tages i betragtning; repræsentativiteten af de svenske, norske, finske og islandske samples indebærer en række udfordringer og repræsentativitetsanalyserne er begrænset til to variable (køn og alder).

**Konklusion:** Afhandlingens resultater indikerer, at brug af KAM er udbredt blandt mennesker med MS i Danmark såvel som i de øvrige nordiske lande. Studiets resultater indikerer desuden, at denne brug grundlæggende afspejler en forebyggende og autonom tilgang til behandling, og at

brugernes valg vedrørende KAM kan afspejle en række personlige overbevisninger uden nødvendigvis at være udtryk for en mistillid til det konventionelle sundhedssystem.

**Perspektiver:** Afhandlingens resultater understreger vigtigheden af, at sundhedsprofessionelle har en forståelse for patienters forskellige motiver for – og erfaringer med – at bruge forskellige typer af behandlinger. Således peger afhandlingens resultater også på vigtigheden af at styrke og kvalificere kommunikationen mellem patienter og sundhedsprofessionelle, hvad angår patienternes brug af KAM. Gensidig læring patienter og sundhedsprofessionelle imellem samt behandlingsmæssig sikkerhed er centrale aspekter i denne kommunikation.

## Summary

**Background:** It is known that Complementary and Alternative Medicine (CAM), defined as a group of medical and health care systems, practices, and products that are not generally considered part of conventional medicine, is popular among people with Multiple Sclerosis (MS) and that use is widespread. Studies have shown that motives for using CAM among people with MS are manifold, that more women than men use CAM, and that CAM use tends to be associated with high education, high income, low self-assessed state of health and long disease duration. However, these data are not totally consistent, and there is very limited knowledge about use and users of CAM among people with MS in a Danish context.

**Aims:** The overall research aim of this PhD study was to explore use and users of CAM among people with MS in Denmark by combining quantitative and qualitative research methods in a mixed methods design. The specific objectives of the study were to investigate a) the prevalence of CAM use and motives connected to CAM use among people with MS in Denmark as well as in the four other Nordic countries (Paper I), b) differences in descriptive characteristics of CAM users and non-users among people with MS in Denmark (Paper II), c) differences in descriptive characteristics of subgroups of CAM users among people with MS in Denmark (Paper III), d) beliefs on risks of negative interactions between herbal medicine and conventional drug therapy within a selected group of people with MS in Denmark who combine these two types of treatments (Paper IV) and e) perceptions of treatments mechanisms among people with MS in Denmark who use CAM exclusively. On the basis of these five specific research objectives, the overall aim of the thesis is to investigate how and why people with MS in Denmark include CAM in managing their life with a chronic disease and to discuss their experiences and beliefs linked to CAM use.

**Methods:** A mixed methods research design was applied, combining an internet based survey with two qualitative in-depth interview studies. A total of 6850 people with MS from the five Nordic countries (of these 3500 from Denmark) were invited to participate in the survey. The average response rate was 56.1%. Comparative analyses were performed, using odds ratios and determining significance by interpretation of confidence intervals, on the basis of the total Nordic data material (n=3795) as well as on the basis of the Danish data material (n=1865). Based on analyses of the Danish survey data, two specific issues regarding the use of CAM were selected for further investigation and two qualitative interview studies were performed, using program theory and meaning categorization as analytical tools.

**Results:** The results indicated that among the Danish respondents, every second one had used CAM within the past twelve months. CAM treatments were most often used for non-specific/preventive purposes. Comparative analyses of the Nordic survey data showed that prevalence of CAM use among respondents was consistent within the five Nordic countries (average prevalence was 53.0%) and that CAM was most often used for non-specific/preventive purposes among respondents in all five countries. Overall, the Danish respondents did not differ from the other Nordic respondents, although some differences were found regarding the use of specific CAM modalities and regarding the prevalence of exclusive CAM use. Analyses of the Danish survey data showed that among the respondents, CAM users were more often women, of young age and of high education than CAM non-users. Analyses of the Danish survey data also indicated that there were few differences between selected subgroups of CAM users, but that further qualitative studies were relevant regarding two specific issues in two subgroups: 1) beliefs on risks of negative interactions among users who combined herbal medicine and conventional drug therapies and 2) perceptions of treatment mechanisms among CAM users who used CAM exclusively, including having foregone use of disease-modifying drugs for MS. The two qualitative interview studies showed 1) that the informants, who were users of herbal medicine and conventional drug therapies in combination, generally considered such combination treatment to be safe due to the natural aspect of herbal medicine and 2) that the choice of using CAM exclusively did not seem to represent a principled rejection of conventional medicine, but appeared to be the result of the informants' overall assessment, weighing beliefs and experiences regarding positive and negative impact of different types of treatments.

Some reservations to the generalizability of the study results should be made due to challenges of representativeness regarding the Swedish, Norwegian, Finnish and Icelandic survey samples as well as due to the limited number of variables included in the analyses of representativeness (gender and age).

**Conclusion:** The results of the present mixed methods study indicate that the use of CAM among people with MS is widespread in Denmark as well as in the other Nordic countries. The results furthermore suggest that this use is generally embedded in a preventive, autonomous approach to treatment and that users' choices regarding CAM may be related to many personal factors and do not necessarily represent a distrust of the medical system.

**Perspectives:** The results of the study point to the relevance of health care professionals engaging in understanding patients' different motives for – and experiences with - using different types of treatments. Thereby, the results of the study also point to the importance of enhancing

and qualifying communication between patients and representatives of conventional health care systems regarding the patients' use of CAM, both with the aim of mutual learning and for reasons of safety.

## Short abstract

**Background:** It is known that Complementary and Alternative Medicine (CAM) is popular among people with Multiple Sclerosis (MS) and that use is widespread. However, very limited knowledge exists about use and users of CAM among people with MS in a Danish context.

**Aims:** The overall aim of the thesis is to investigate how and why people with MS in Denmark include CAM in managing their life with a chronic disease and to discuss their experiences and beliefs linked to CAM use.

**Methods:** A mixed methods research design was applied, combining an internet based survey with two qualitative in-depth interview studies. A total of 6850 people with MS from the five Nordic countries, of these 3500 from Denmark, were invited to participate in the survey. The average response rate was 56.1%. Based on analyses of the Danish survey data, two specific issues regarding the use of CAM were selected for further investigation and two qualitative interview studies were performed (n=17, n=11), using program theory and meaning categorization as analytical tools.

**Results:** The results of the study indicate that the use of CAM among people with MS is widespread in Denmark as well as in the other Nordic countries. The results furthermore suggest that this use is generally embedded in a preventative, autonomous approach to treatment and that the users' choices regarding CAM may be related to many personal factors and do not necessarily represent a distrust of the medical system.

**Perspectives:** The results of the study point to the relevance of health care professionals engaging in understanding patients' different motives for – and experiences with - using different types of treatments. Thereby, the results of the study also point to the importance of enhancing and qualifying communication between patients and representatives of conventional health care systems regarding the patients' use of CAM, both with the aim of mutual learning and for reasons of safety.