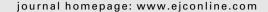


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Complementary and alternative treatment methods in children with cancer: A population-based retrospective survey on the prevalence of use in Germany

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ABSTRACT

Introduction: Few studies have been conducted to date on the prevalence of use of complementary and alternative treatment methods (CAMs) in paediatric oncology, and those that have been conducted are often not representative. We therefore decided to study a representative sample of children with cancer in the German population.

Patients and methods: The study took the form of a retrospective survey amongst all parents whose children were first diagnosed with a disease covered by the German Childhood Cancer Registry in 2001. The primary objectives of the survey were to establish the prevalence of use of CAM and the factors related to its use.

Results: Of the 1595 questionnaires sent out, 1063 (67%) could be evaluated. 35% of the responders had used CAM. The most frequently used methods were homeopathy, dietary supplements and anthroposophic medicine including mistletoe therapy. Factors which increased the probability of using CAM were the previous use of CAM, higher social status and poor prognosis of the child's disease. The most frequently named reasons for use of CAM were physical stabilisation, strengthening the immune system and improving the chance of cure. Whilst the sources of information about CAM were in most cases not doctors, 71% of users had nevertheless spoken to a doctor about using CAM. The effects of the CAM perceived by the parents were for the most part positive. 89% of the users reported that they would recommend CAM to other parents.

Conclusions: CAMs are administered alongside standard therapy to 35% of children with cancer in Germany, usually by the parents. Prospective studies on the effects and side-effects of the most frequently used methods are urgently needed, and paediatric oncologists should have sufficient knowledge of CAM to enable them to advise parents professionally and competently about these treatments, too.

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1. Introduction

Patients are showing an increasing interest in the use of complementary and alternative treatment methods (CAMs) in the treatment of acute and chronic diseases, 1,2 both in adults^{3,4} and in children⁵⁻⁷ and particularly in the Western industrial nations.8 Professional organisations such as medical societies and the WHO9-11 are also devoting increasing attention to traditional and complementary medicine in the scientific debate. In adult oncology CAM is used to a significant extent. 12,13 Depending on the population studied, the prevalence of use is well above 50% and in all populations a trend towards increasing prevalence of use over time can be seen. 17 Many of the CAMs used have not yet been scientifically studied or only to an insufficient extent. So far only a few smaller studies have been published on the prevalence of the use of CAM in children with cancer and factors related to its use. 18-26 With sometimes very different study populations and in the absence of a uniform definition of CAM there is considerable variation in the reported prevalences of CAM use and the related factors. The largest population based study published to date18 reported a prevalence of CAM use of 42% for British Columbia/Canada. There are practically no representative data available on the prevalence of CAM use in Europe. Only Molassiotis and colleagues¹⁴ have reported a prevalence of 33% in the United Kingdom. To date there are no figures on CAM use in children with cancer in Germany. In view of the general increase in the prevalence of CAM and the fact that very little is known about the effects and side-effects of these methods there is an urgent need for better investigation of these treatment strategies.

As the first step we now present the first nationwide, registry-based, population-based retrospective survey of the prevalence of CAMs use in children with cancer, the types of therapies used and the factors related to its use.

The data obtained in our survey provide a basis for subsequent prospective studies on the use particularly of the more frequently used CAM methods in paediatric oncology. They can also serve as a source of information for paediatric oncologists around the world as an opening for frank and competent dialogue with parents of children with cancer on the subject of CAM.

Patients and methods

2.1. Selection of patients

The survey was conducted from 1st of January to 15th September 2004. All families with a child under the age of 15 years who was first diagnosed with a disease defined in the International Childhood Cancer Classification (ICCC)²⁷ or with myelodysplastic syndrome (MDS), severe aplastic anaemia (SAA) or Langerhans cell histiocytosis (LCH) between 1st of January and 31st December 2001 and registered in the German Childhood Cancer Registry (GCCR), were eligible for inclusion. Approximately 95% of all cases of childhood cancer are registered in the GCCR, children are registered by name with the consent of parents or guardians. Exclusion criteria were death

within the first 8 weeks after diagnosis and development of a second cancer. There were two reasons for choosing a period of diagnosis lying about 3 years before the survey. On the one hand, we wanted to minimise distortion of the results by gaps and inaccuracies of memory. At the same time we wanted to ensure that the survey covered a significant number of recurrences (and use of CAM in this context).

The survey was conducted in coordination with all the German hospitals which had treated children with leukaemia and cancer in the year 2001 and had reported to the GCCR. The hospitals were permitted to exclude individual patients from the survey (stating reasons if possible). The selected families were sent the questionnaire by mail.

2.2. Content of the survey

Complementary or alternative treatments were defined as all the treatments not currently considered standard or largely accepted experimental methods. Similar definitions were also used by most of the other study groups (e.g. 18). The WHO defines CAM as follows:²⁸ 'a comprehensive term used to refer both to traditional medical systems such as traditional Chinese medicine (TCM), Indian Ayurveda and Arabic Unani medicine and to various forms of indigenous medicine.'

CAM is defined by the NCI as follows:²⁹ 'Forms of treatment that are used in addition to (complementary) or instead of (alternative) standard treatments. These practices generally are not considered standard medical approaches. Standard treatments go through a long and careful research process to prove that they are safe and effective, but less is known about most types of CAMs. CAM may include dietary supplements, megadose vitamins, herbal preparations, special teas, acupuncture, massage therapy, magnet therapy, spiritual healing and meditation.' The NIH also provides definitions of the different types of CAM.³⁰

The list of alternative and complementary treatment methods given in the questionnaire was as comprehensive as possible in order to obtain as realistic as possible a picture of the different methods used. The German language questionnaire for parents was developed taking into account the data published on this topic to date, on the basis of our own clinical experience and on the basis of the experience obtained from a pilot survey. To the analysis of the data, we used the categories generally employed in the international literature. 32,30

2.3. Study procedure

The study was approved by the ethics committee of the University of Witten/Herdecke, Germany and was done in accordance with the declaration of Helsinki.

The parents were assured in the letter accompanying the questionnaire that the information they gave would not be passed on to the treating hospital or the treating physician on an individual level or in a form that would enable it to be traced back to them personally. A single written reminder was sent after 4–6 weeks if no response had been received by then. If families had moved to an unknown address, the GCCR attempted to trace them through the registry office.

The questionnaires returned were made anonymous and saved electronically (Microsoft Access 2000) only if consent had been given.

2.4. Statistical analysis

As this was not an analytical cross-sectional study the results are presented mainly in the form of descriptive statistics, i.e. percentages, in view of the mainly categorical data collected. In the case of important information, the precision was also estimated in the form of a 95% confidence interval. The comparisons between subgroups and associations are also largely descriptive in nature, the *p*-values are given as an indication of the strength of the association.

In some cases, a multiple logistic regression model was used to examine the influence of several factors at once, for example, the influence on the probability of using CAM.

Further methodological details on the performance of the study have already been published elsewhere.³³

3. Results

3.1. Patient characteristics

Eighty of the Eighty one German hospitals which had reported cases to the GCCR during the period in question,

consented in principle to include their patients in the survey. A total of 79 patients were excluded by the hospitals from the survey (the most frequently given reasons were, in decreasing order of frequency: death of the patient, language problems and patient had left Germany). Of the 1768 patients registered in the GCCR in the year 2001 (time of first diagnosis) who met the inclusion criteria, 1595 families were sent the questionnaires. Altogether 1063 questionnaires (67%) could be evaluated (Fig. 1). These are referred to in the following as 'study participants'. The 525 families who actively or passively declined participation are referred to as 'non-participants'.

As the GCCR contains basic data (age at diagnosis, sex, diagnosis, course) of all patients to whom questionnaires were sent, these data can be used for a comparison between participants and non-participants. The multiple analysis showed no significant differences with regard to age, sex and age at diagnosis and history of recurrence. Parents of children who had died before the survey participated significantly less often in the survey, parents of children with a relapse before the survey took part significantly more often. It should be kept in mind that parents of children who died early (8 weeks after diagnosis) had not been approached at all. In most cases, the questionnaires were completed by one parent (57%), in some cases by both (36%) and in a few cases by a third party (2%) or with the help of a third party

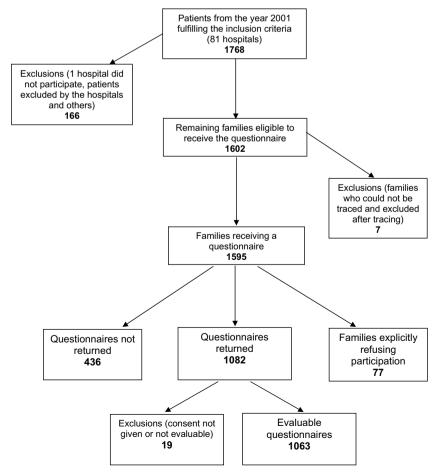


Fig. 1 - Description of sample.

(5%). The mothers were involved in completing the questionnaires in 92% of the cases, whilst the fathers were only involved in 45% of cases (data not shown).

3.2. Family characteristics

When asked whether anyone in their family had used CAM before their child developed cancer, 396 (37%) replied 'yes'. Of these 396 former users, 255 (64%) stated that they had used CAM 'sometimes' and 115 (29%) 'often'.

3.3. CAM users

Of the 1063 families who responded, 367 (35%, 95% CI [31.7%; 37.4%]) stated that they had used CAM in the course of their child's illness (referred to in the following as 'users').

The most frequent reasons given by the parents for the use of CAM were 'physical stabilisation' and 'to strengthen the immune system', 'to improve the chance of cure', 'to help cope with the side-effects of the conventional medicine', 'to feel we had done everything possible' (Table 1). The reasons for non-use of CAM were lack of information (29%), so as not to additionally burden the child (18%), too little known about interactions (15%), doctor had advised against it (13%) and CAM is ineffective (8%).

In reply to the question of whether they had been convinced before its use that CAM would have a positive influence on the course of the child's disease, 63% of the users responded that they were 'absolutely' or 'fairly sure', 27% were 'doubtful'.

An exploratory multivariate analysis showed that the following factors had a significant influence on the probability of CAM use (in order of importance): earlier experience of CAM (OR = 4.72, p < 0.0001), diagnosis with poor prognosis (OR = 1.63, p = 0.0013) (Table 2), child died before the survey (OR = 1.97, p = 0.0063) and higher social status (OR = 1.44,

Table 1 – Reasons for CAM use according to the frequency of indication (n = 367 users; a list of possible reasons was given; respondents could indicate more than 1 reason)

| 'Why did you use CAM?' | Percentage of users |
|---|---------------------|
| For physical stabilisation | 69.7 |
| To strengthen the immune system | 66.2 |
| To improve the chance of cure | 55.0 |
| To help cope with the side-effects of | 47.9 |
| chemotherapy/radiation therapy/surgery | |
| To feel we had done everything possible | 44.9 |
| To prevent recurrence of the disease or | 36.5 |
| development of a second cancer | |
| For psychological stabilisation | 35.1 |
| For detoxification | 29.9 |
| To relieve concomitant symptoms of the | 29.4 |
| disease (e.g. pain) | |
| For relaxation | 17.4 |
| Other reasons | 8.7 |
| Because of lack of confidence in the | 8.1 |
| treatments of conventional/orthodox | |
| medicine | |

Table 2 – CAM use as a function of prognosis $N^{\rm b}$ Percentage of users

| | IN | Percentage of users |
|-----------------------------------|-----|---------------------|
| Diagnosis with expected | 787 | 31.4 |
| 5-year survival ^a ≥70% | | |
| Diagnosis with expected | 219 | 46.6 |
| 5-year survival <70% | | |

Source: 2004 Annual Report of the German Childhood Cancer Registry. Table A1.1

- a Expected 5-year survival of the cases over the diagnostic period 1994–2003 according to the 12 ICCC classes.
- b N=1006, as MDS, LCH and SAA do not belong to the 12 ICCC classes.

p=0.1264). When the child had a relapse before the survey, CAM was reported significantly more frequently too (OR 1.67 95%CI [1.19, 2.35]), but this factor is highly correlated with prognosis of the disease group and the individual probability of death before the survey. Age at diagnosis and sex of the child were not relevant for the decision for using or against using CAM. All social status related factors, such as nationality, religion, health insurance, education and income were significant in the univariate analyses with a higher probability of CAM use in Germans, protestants, privately insured families, higher education and higher income.

One hundred and eighty seven of the users (51%) did not apply for reimbursement of the costs of the CAM to their health insurance. Of the 147 users who did apply for reimbursement by the health insurance only 48% had the costs reimbursed in full, 25% in part and 25% not at all. In those cases in which the costs were not or only partly reimbursed by the health insurance, the costs for the use of CAM were under 500 euros in most cases and, apart from a few exceptions, did not exceed 5000 euros.

3.4. Factors related to use

In the large majority of cases, the users learnt of the possibility of using CAM from family or friends. As further sources of information, doctors and the media were cited to an approximately equal extent whilst 'health care providers other than doctors', e.g. registered healers [Heilpraktiker], came second after family and friends (Table 3).

Table 3 – Sources of information about the possibility of CAM use according to frequency of indication (n = 367 users; a list of possible sources was given; respondents could indicate more than one source)

| 'From whom did you learn about the possibility of using CAM?' | Number | Percentage of users |
|---|----------------|----------------------|
| Family or friends Health care providers other than doctors | 258 127 | 70.3 34.6 |
| Media Doctors Other | 97 96 52 | 26.4 26.2 14.2 |

Seventy one percent of the families reported that they had spoken to a doctor (GP, paediatrician, paediatric oncologist) about using CAM; of these, 220 had spoken to their paediatric oncologist, 100 to their paediatrician and 61 to their GP (more than one answer was permitted). Use of CAM was recommended most often by GPs (Table 4). The CAM was prescribed by a doctor in 45% of the cases and by another health care provider (mainly registered healers) in 41% of cases. Self-medication also played a significant role (19%).

3.5. Treatment methods used

Table 5 shows the ten most frequently used CAMs. A further 50 CAMs were named by fewer than 30 users, respectively. A median of 3 different treatment methods was used per patient (range 1–15). When asked for the three 'most important' CAM methods used, 37% of the users named homeopathy, 22% named anthroposophic medicine including mistletoe therapy and 21% named dietary supplements. All other CAMs were designated the 'most important' by less than 10% of the users.

Table 6 shows the methods used grouped according to the CAM categories published by the NIH.³⁰ Sixty nine percent of the treatment methods used could be placed in the category Whole Medical Systems and 53% in the category Biologically Based Practices.

The child's age, the severity of the illness and the social status had no significant influence on the type of CAM used.

In most cases, CAM was used at the same time when the conventional treatment was performed by the paediatric oncologist. Only 14% of the users had only used CAM after the end of the conventional therapy. Most patients/families who used CAM showed commitment to treatment for a period of, on average, more than one year. Most of them already began to use the CAMs immediately after the diagnosis or not more than 3–6 months after the diagnosis. Only a few parents began to use CAM additionally immediately after the diagnosis of a recurrence (months 1 and 2).

3.6. Perceived effect

In addition to the question about the desired effect of the CAM use, the parents were also asked about the subjectively perceived effect of the respective CAM used. The following were named in the descending order of frequency:

- Strengthening of the immune system (mistletoe therapy, dietary supplements, dietary modification, phytotherapy, selenium and vitamin C).
- 2. The child became 'physically more stable' (homeopathy, anthroposophic medicine and reiki).
- 3. Psychological stabilisation (laying on hands).

Ninety one percent of the CAM users who had had positive expectations also perceived a positive effect of the method. However, 68% of parents who had been doubtful before the beginning of the CAM also reported a positive influence on the course of the disease.

In addition to the question about the more general effectiveness of the CAMs used, the parents were also asked to as-

sess the influence on the course of their child's disease. For all 10 of the most frequently used CAMs 'improvement' or 'marked improvement' was reported in more than 50% of the cases. It stood out that one third or more of the respondents were not able to assess the influence on the course of the disease (don't know) for mistletoe, reiki, selenium and vitamin C.

Four percent of the users reported adverse effects. Data on discontinuation of treatment because of side-effects, rates of hospitalisation and deaths were not asked for.

Eighty nine percent of the CAM users said they would advise other parents to use CAM in comparable situations. In response to the question of which CAMs they would recommend to other families the frequency distribution of the therapies named was similar to that of CAM use.

All patients received conventional therapy as well as the complementary therapy. Because we had no information from the so-called 'treatment refusers', we cannot say anything about their use of alternative therapies.

4. Discussion

This is the most extensive as well as the first populationbased study on the prevalence of use of CAM in paediatric oncology. Only one small study from Canada¹⁸ with 44 interviewees was based on a cancer registry. The prevalence of CAM use in our survey population was 35%. The very narrow confidence interval [31.7%; 37.4%] and the high statistical power of the study on account of the sample size can be taken to indicate that the figure found for the prevalence of use is very reliable. The likelihood of under reporting of CAM use can be regarded as small as the parents were assured that the hospital that had treated their child would only have access to the data in anonymous form. In contrast to our procedure, in all the studies published to date the survey was performed by a team from the formerly treating hospital. Other European studies conducted in the last 10 years report similar prevalences of use: 31% in the Netherlands, 21 33% in the United Kingdom¹⁴ and 40% in Finland.²³ However these were single-centre studies with small numbers of participants (<100). A recent study in 88 patients in Turkey³⁴ reports a prevalence of use of 49%. Canadian studies show slightly higher prevalence rates of 36%, ¹⁸ 42% ¹⁹ and 49%. ²² This difference is probably at least partly due to different medical-cultural traditions in Europe and North America.²⁶ The CAM use rate we found here for children with cancer is well below the rates reported for the general paediatric population in Europe: Madsen³⁵ found a prevalence of use of 53% in a general paediatric population in Denmark, Hughes and colleagues³⁶ reported 43% users in a population of children with atopic dermatitis.

We were able to confirm the significantly higher rate of CAM use in patients with relapse reported by Grootenhuis.²¹ We were not able to confirm the significant correlation between increasing duration of the cancer and increasing probability of CAM use described by Molassiotis.¹⁴

There was no statistically significant association between the type of CAM used and the patient's diagnosis. In the majority of the studies published to date parents of children

Table 4 – Reactions of doctors experienced by parents when they brought up the subject of possible CAM use (n = 260 users who spoke to one or more doctors about using CAM; respondents could indicate more than one response)

| Reactions of the respective doctors | General practitioner ($n = 61$) | Paediatrician (N = 100) | Paediatric oncologist (N = 220) |
|-------------------------------------|-----------------------------------|-------------------------|---------------------------------|
| Advised parents to go ahead | 33 (54.1%) | 29 (29.0%) | 27 (12.3%) |
| Indifferent | 26 (42.6%) | 64 (64.0%) | 141 (64.1%) |
| Advised against its use | 2 (3.3%) | 7 (7.0%) | 52 (23.6%) |

who had died were excluded altogether. In our survey, these parents were also invited to participate but did answer significantly less often than parents whose children were still alive at the time of the survey (data not shown).

4.1. Treatment methods used

If we compare the treatment methods named most often in our study with those in other European studies we find an inconsistent picture. Homeopathy (therapy with serially diluted remedies) and anthroposophic medicine (therapy with anthroposophic partly highly diluted medicine and non-medical therapies) were used by 72% and making these by far the most frequently used methods. Similar results were found by Grootenhuis²¹ in the Netherlands, whilst in a small Finnish study²³ mainly dietary supplements were used. In a small English survey¹⁴ (n = 16 users) homeopathy was only mentioned by one user. Studies from other cultural contexts show a completely different spectrum.^{25,26} In the North American studies^{18-20,37} (United States of America and Canada) there is also an inconsistent picture, although in principle spiritual and non-pharmacological methods play a clearly greater numerical role compared with autonomous medical systems such as homeopathy. In spite of the large size of the sample studied by us, we were not able to identify any different patterns of use for the different diagnostic groups studied (data not shown).

4.2. Reasons for use/desired effects

Physical stabilisation, strengthening the immune system and improving the chance of cure were the reasons the users gave most often for the use of CAM, a finding which partly matches

Table 5 – The 10 most frequently named CAMs (n = 367 users; a list of possible methods was given; respondents could indicate more than one method)

| Treatment method | Percent |
|--------------------------------|---------|
| Homeopathy | 45.2 |
| Dietary supplements (including | 35.4 |
| vitamins and trace elements) | |
| Anthroposophic medicine | 26.7 |
| (including mistletoe therapy) | |
| Dietary modification | 12.3 |
| Bach flower remedies | 10.1 |
| Laying on hands | 10.1 |
| Reiki | 10.1 |
| Phytotherapy | 9.3 |
| Megavitamins | 9.0 |
| Massage | 8.7 |

that of other authors. ^{18,25,37} Only 8% of the users gave dissatisfaction with conventional treatment as the reason for using CAM. Spigelblatt³⁸ on the other hand, reported dissatisfaction with conventional treatment as the primary motivating factor for use of CAM.

The interest of parents/patients in CAM in paediatric oncology is considerably greater than the prevalence of its use. This observation matches the findings reported by two Canadian groups. ^{18,19} Many parents (both users and nonusers) expressed a wish for better and more reliable information on the subject of CAM from the treating doctors. The sources of information about CAM were only in exceptional cases doctors, whilst the large majority of users obtained their information from family and friends and the lay press, a result similar to that reported by other authors. ^{20,37} Only one English study¹⁴ reported advice from 'health care professionals' in 67% of cases.

4.3. Patterns of communication

While some authors^{25,26,39} report that CAM use was rarely discussed with a doctor, particularly with the treating paediatric oncologist, 71% of the CAM users in our survey reported that they had spoken about it with a physician. Similar results were found by Bold¹⁸ in his study. Most often parents spoke to their treating paediatric oncologist about CAM use. He was mostly indifferent in his reaction, in comparison to the general practitioners, who advised families to go ahead with CAM use. This finding shows the need for further information for the treating physicians on CAM. It should also enable us to expand our knowledge about interactions between conventional and complementary methods.

4.4. Perceived effect/side-effects

The observation by the parents of a positive effect of CAM on the course of the disease is largely in line with the findings of

Table 6 – All treatment methods indicated according to NIH categories (n = 367 users; respondents could indicate more than one method)

| NIH treatment categories (more than one method could be indicated) | Number |
|---|--|
| Biologically based practices Energy medicine Manipulative and body-based practices Mind-body medicine Whole medical systems | 193 (52.6%) 118 (32.2%) 81 (22.1%) 107 (29.2%) 254 (69.2%) |

other groups which looked at this question. 24,25,37 In view of the fundamentally positive attitude of the CAM users towards the treatment methods used the low side-effect rate of 4% cannot be regarded as an indication of the actual frequency of side-effects of the CAMs used. Harmful side-effects in CAM-use are described, especially in inadequately regulated herbal medicines. One systematic literature review⁴¹ reports in narrative and tabular form of anecdotal adverse events in CAM use in paediatric patients. In a prospective observational cohort study including 163 paediatric patients with chronic conditions using anthroposophic medicine Hamre and colleagues⁴² could find only a few and not harmful adverse drug reactions. More than 80% of the CAM users in a Canadian province interviewed in 2001¹⁸ said they would recommend CAMs to other parents. The corresponding figure found by us for the German population was 89%. The results presented by us can be regarded as having particularly high validity for Germany as the interviewees and the users constitute a representative selection of patients based on the complete patient population of one year in the entire country. Both regional differences within one country 18,19,22 and institutional differences 14,23 regarding traditions of use could be ruled out by the population based approach chosen by us. This is also one of the few studies which covers all childhood cancers over the entire age range and in the frequency of their natural occurrence. The decision to conduct our survey 36-48 months after first diagnosis meant that we were also able to obtain information about changing patterns of use in the course of the illness, an aspect that has received little attention to date. Here we found particularly that the decision to use CAM, which is influenced to some extent by sociocultural and disease specific factors, was made very early.

A CAM use rate of 35% in German paediatric oncology is one argument more for the need that paediatric oncologists should communicate actively with their patients and their families on a potential CAM use. This calls for appropriate education and information and ties in with a desire expressed by many doctors. ⁴⁰ For a competent assessment and advice on this topic (64% of the paediatric oncologists could not advice the families when appealed to CAM; see Table 6) we urgently need methodologically well planned clinical trials on often used CAMs.

To our knowledge there is only one published randomised trial on CAM use in paediatric oncology. ⁴³ Moreover, as almost all CAM users in our survey were treated conventionally in the context of cooperative group clinical trials, the influence of CAM use on the results of cooperative clinical trials also needs to be examined.

Conflict of interest statements

Alfred Laengler has got honoraria for lectures held for anthroposophic pharmaceutical companies (WELEDA, Helixor).

Claudia Spix: no conflict of interest.

Georg Seifert is running a clinical study sponsored by anthroposophic pharmaceutical companies (Wala, WELEDA, Helixor).

Sven Gottschling: no conflict of interest. Norbert Graf: no conflict of interest. Peter Kaatsch: no conflict of interest.

Authors contributions

Alfred Laengler designed the study, was involved in the conception of the questionnaire, did the data analysis, interpretation and wrote the manuscript.

Claudia Spix was involved in the study and questionnaire conception, data management and did the statistical analysis. She participated in writing the manuscript.

Georg Seifert was involved in the study conception and data analysis. He participated in writing the manuscript.

Sven Gottschling was involved in the study and questionnaire conception and data analysis. He participated in writing the manuscript.

Norbert Graf was involved in the study conception and analysis. He participated in writing the manuscript.

Peter Kaatsch was involved in the study-design and questionnaire conception and data analysis. He participated in writing the manuscript.

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