

Anthroposophic Medicine in Paediatric Oncology in Germany: Results of a Population-Based Retrospective Parental Survey

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Background. Anthroposophic medicine (AM) is frequently utilised in German-speaking countries as a complementary and alternative medicine (CAM) treatment approach. **Procedure.** This study presents results of a retrospective parental questionnaire comparing responses of AM-users and users of other CAM in paediatric oncology in Germany. The differences between these two groups are investigated with respect to usage, associated demographic characteristics and previous experience with CAM. **Results.** Ninety-eight patients (27%) of the 367 CAM-users were exposed to anthroposophic treatments or therapies. Treatment duration amounted to a median 619 days for AM and 225 days for other CAM treatments. Most parents with previous experience of AM also used AM for treatment of their child's cancer disease. AM-users had a higher social

status. Physicians played a relevant role for users of AM both in procuring information (24% vs. 11%; $P < 0.001$) and in prescribing medicines and therapies (73.0% vs. 34.9%; $P < 0.001$) compared to users of other CAM. AM-users communicate more frequently with their physicians about the use of CAM treatments (89.8% vs. 63.9%) and recommend CAM more often than other CAM-users (95.9% vs. 87%). **Conclusions.** AM plays a major role in paediatric oncology in Germany. Patients using AM sustain treatment and therapies considerably longer than patients using other CAM treatments. Furthermore, most families who had used AM before their child was diagnosed with cancer also used AM for the treatment of their child's cancer. Compared to other CAM treatments, patient satisfaction with AM appears to be very high. *Pediatr Blood Cancer* © 2010 Wiley-Liss, Inc.

Key words: cancer; children; eurythmy therapy; mistletoe preparations; population-based registry

INTRODUCTION

Complementary and alternative medicine (CAM) is frequently used in treating acute and chronic diseases in Germany and also worldwide. This applies equally to adults [1–3] and children [4–7]. Data concerning frequency of CAM-use, particularly in paediatric oncology, has been published mostly in the form of small, single-centre studies [8–17]. The current study is part of the largest and to date the only population-based survey of CAM-use in paediatric oncology. Results of the general questionnaire previously published, showed that 35% of 1,063 patients whose parents responded to the survey used CAM (of 1,595 patients surveyed) [18]. A multifactorial analysis showed that the following factors influenced the probability of CAM use: earlier experience of CAM (OR = 4.72, $P < 0.0001$), diagnosis with poor prognosis (OR = 1.63, $P = 0.0013$), child died before the survey (OR = 1.97, $P = 0.0063$) and higher social status (OR = 1.44, $P = 0.1264$).

Anthroposophic medicine (AM) may be used as an extension to conventional medicine or a replacement. The spectrum of therapeutic modalities offered by AM range from customised remedies derived from minerals, plants and animals to various artistic therapies, rhythmical massage, eurythmy therapy [19] (specific body movements with accompanying meditative aspects, carried out in conjunction with guided imagery), external treatments (compresses, oils and ointments, baths), medical consultations and counselling (partly psychotherapeutic), and anthroposophically extended nursing and care. These modalities aim to stimulate and strengthen the patient's own healing forces and are practiced by physicians, therapists, and nurses. AM physicians are trained in both AM and conventional medicine [20].

In German-speaking countries, that is, Germany, Austria, and Switzerland, AM plays a major role in general medical practice [21], especially in adult cancer patients (mistletoe therapy in particular) [22,23], but also in children [24]. While AM and mistletoe therapy, along with other CAM treatments are used in clinical oncology in Germany, no studies of the use of AM in paediatric oncology have

been published to date. This retrospective representative population-based survey investigates the differences in CAM-usage behaviour, associated circumstances and previous experience of CAM between the group of AM-users and a group using other CAM treatments only in paediatric oncology.

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PATIENTS AND METHODS

The study survey was mailed to parents of paediatric cancer patients in 2004 in collaboration with the Deutsche Kinderkrebsregister (GCCR) (German Childhood Cancer Registry). The study population included all parents whose children were under the age of 15 years and had been diagnosed in 2001 with one of the diseases registered and systematically recorded by the GCCR. At least 95% of all German cases of childhood cancer are registered in the GCCR. Exclusion criteria for the survey were death within the first 8 weeks after diagnosis and development of a second cancer. The survey was conducted in coordination with all German hospitals which had treated children with cancer in the year 2001 and had reported to the GCCR. The hospitals were permitted to exclude individual patients from the survey with stating reasons. The questionnaires were sent by mail. The CAM methods were listed in the questionnaire as comprehensively as possible to obtain a representative sample of the different methods used. The German language questionnaire for parents was developed on the basis of data published on this topic to date, our own clinical experience and the experience obtained from a pilot survey [25].

The questionnaire presented a list of 69 CAM treatments and therapies in alphabetic order including anthroposophic–homeopathic medicines [20], eurythmy therapy [19] and mistletoe therapy [26]. Data for general CAM use has been previously published [18]. This article reports responses from CAM-users who employed one or more of the three anthroposophic categories (anthroposophic medicine users [AM-user]). The differences between the AM-user group and the other CAM-user group (i.e., non-anthroposophic, complementary or alternative medicine users only [NAM-users]), are examined with respect to CAM-use behaviour, associated circumstances and previous experience of CAM.

All patients had received conventional treatment as well as the specified complementary treatments or therapies. Because we did not collect information from patients/families who declined treatment, we are unable to comment on their use of CAM. The study was approved by the ethics committee of the University of Witten/Herdecke, Germany and carried out in accordance with the World Medical Association Declaration of Helsinki (www.wma.net/e/policy/pdf/17c.pdf).

Statistical Analysis

This was not an analytical study and therefore results are primarily presented in the form of descriptive statistics, that is, percentages relating to the mostly categorical data collected. The basic proportions were supplemented by binomial 95% confidence intervals reflecting the precision of the estimate. The main measure is the comparison of percentages between the groups. Some of the more relevant differences of AM-users and NAM-users were tested by the χ^2 -test for homogeneity or by *t*-test in tables. These tests should also be viewed as exploratory in nature, not confirmatory.

RESULTS

CAM-Use

One thousand and sixty-three out of 1,595 families who were sent the questionnaire responded. Of the 1,063 families who responded, 367 (35%, 95% CI [31.7%; 37.4%]) stated that they had used

TABLE I. The ‘Most Important’ CAM Treatment Methods from the Users’ Viewpoint*

CAM treatment methods	Number (%)
Homeopathy	137 (37.3)
Mistletoe therapy	53 (14.4)
Anthroposophic–homeopathic medications (except for mistletoe therapy)	46 (12.5)
Food supplements	43 (11.7)
Reiki	27 (7.4)
Dietary changes	26 (7.1)
Laying on of hands	22 (6.0)
Medicines of plant origin (phytotherapy)	21 (5.7)
Selenium	21 (5.7)
Vitamin C	21 (5.7)
Massage	19 (5.2)
Other	19 (5.2)
Spiritual healer	18 (4.9)
Ayurveda, e.g., H15 (incense)	16 (4.4)
High dosage vitamins	16 (4.4)
Bach flower remedies	15 (4.1)
Acupuncture	14 (3.8)
Bioresonance	13 (3.5)
Kinesiology	13 (3.5)
Osteopathy	12 (3.3)
‘Biochemistry according to Schüssler’	11 (3.0)
‘Energy work’	11 (3.0)
Music therapy	11 (3.0)
Eurythmy therapy	6 (2.0)

*The table includes treatment methods listed at least 10 times plus eurythmy therapy (n = 367 CAM-users; multiple answers possible). Anthroposophic treatments in bold.

CAM during the course of their child’s illness. Of these 367 CAM-users, 67 (18%) used anthroposophic–homeopathic medication, 59 children (16%) received mistletoe therapy and 11 children (3%) participated in eurythmy therapy. After accounting for multiple answers, 98 patients (27%) of all patients who employed CAM used AM. When asked about the most important CAM treatment used, 53 respondents (14%) named mistletoe therapy, 46 (13%) cited anthroposophic–homeopathic medicines and 6 (2%) eurythmy therapy (Table I).

The average duration of use was 619 days for anthroposophic–homeopathic medicines, 555 days for mistletoe therapy and 418 days for eurythmy therapy ($P = 0.03$). The average duration of use for all other CAM treatments amounted to 275 days. These might be underestimations because in many families long-term treatments may have been on-going at the time of filling in the questionnaire. Therefore the duration for some treatments may be longer than our data suggest. An evaluation of the frequency of individual usage determined by diagnostic groups showed no particular clustering of AM-use in specific diagnosis groups.

Three hundred and ninety-six of the respondents (37%) had previous experience with CAM. This previous experience most commonly related to homeopathy (n = 252 or 64%; multiple answers possible). Previous experience with anthroposophic–homeopathic medicines, eurythmy therapy and/or mistletoe therapy were specified by 65 families (16%).

Thirty-two out of 55 families who had previous experience of anthroposophic medicine turned to AM when their child became ill with cancer. The total AM-user group includes 34 other families

TABLE II. Previous Experience of CAM* (n = 1,063 Questionnaire Participants)

Previous experience	CAM-users (n = 367)		CAM-non-users (%), n = 696
	AM-users (%), n = 98	NAM-users (%), n = 269	
Previous experience with AM	32 (32.7)	8 (3.9)	15 (2.2)
Previous experience with CAM but no previous experience with AM.	34 (34.7)	153 (59.6)	154 (22.1)
No previous experience of CAM	32 (32.7)	104 (38.7)	517 (74.3)
No answer given	0 (0.0)	4 (1.5)	10 (1.4)

P < 0.0001

*In the family before a child was diagnosed with cancer.

TABLE III. Reasons for CAM-Use

	AM-user (%), N = 98	NAM-user (%), N = 269
For physical stabilisation	71 (72.5)	185 (68.8)
To strengthen the immune system	71 (72.5)	172 (63.9)
To improve the chance of cure	62 (63.3)	140 (52.0)
To help cope with the side-effects of chemotherapy/radiation therapy/surgery	46 (46.9)	130 (48.3)
To feel we had done everything possible	52 (53.1)	113 (42.0)
To prevent recurrence of the disease or development of a second cancer	48 (49.0)	86 (32.0)
For psychological stabilisation	32 (32.7)	97 (36.1)
For detoxification	29 (29.6)	81 (30.1)
To relieve concomitant symptoms of the disease (e.g., pain)	26 (26.5)	82 (30.5)
For relaxation	11 (11.2)	53 (19.7)
Other reasons	9 (9.2)	23 (8.6)
Because of lack of confidence in the treatments of conventional/orthodox medicine	11 (11.2)	19 (7.1)

who had previous CAM experience but no previous experience of AM, and a further 32 families who had no previous CAM experience (Table II).

The items prognosis of the primary disease and death of child prior to the survey resulted in similar responses between the AM-user group and the NAM-user group. Within the AM-user group families with high socioeconomic status (67% for anthroposophic-homeopathic medicines and 70% for mistletoe therapy) were significantly more common than in the total group of CAM-users (52%).

Associated Circumstances for CAM-Use

There were no significant differences between AM-users and NAM-users regarding parents' motivation for CAM use (Table

III). Linking sources of information about CAM to the category physicians showed that physicians played a significantly different role as a source of information for AM-users than for NAM-users: 39.8% (AM-users) versus 21.9% (NAM-users) (*P* < 0.001; Table IV).

The majority of AM-users (73%) received the prescription for treatment from a physician (in contrast to 34.9% of NAM-users). Other professionals played a role for AM-users in 45.9% and for CAM-users in 39.8%. On the other hand, relatives, friends, and other parents played no major role for AM-users in comparison to NAM-users (24.5% vs. 40.5%; Table V; all these differences are statistically significant with *P* < 0.0001). In addition, 39 out of 98 AM-user families were additionally advised by a Heilpraktiker (state registered, non-MD healthcare provider of CAM in Germany, Austria, and Switzerland).

TABLE IV. Sources of Information About CAM (n = 367 CAM-Users; Multiple Answers Possible)

Source of information	AM-users (%), n = 98	NAM-users (%), n = 269
Friends	52 (53.1)	117 (43.5)
Other parents in the same situation	41 (41.8)	82 (30.5)
Physicians ^a	39 (39.8)	59 (21.9)
The media (television, radio, magazines, internet etc.)	28 (28.5)	69 (25.7)
Heilpraktiker ^b ; other complementary/alternative therapist	25 (25.5)	69 (25.7)
Family member	18 (18.3)	61 (22.7)
Medical personnel (nurse, therapist, etc.)	9 (9.1)	29 (10.8)
Other	11 (11.2)	41 (15.2)

^aAttending physician or other physicians; ^bHeilpraktiker: state registered, non-physician healthcare provider of CAM in Germany, Austria, and Switzerland.

TABLE V. CAM-Prescribers (n = 367 CAM-Users; Multiple Answers Possible)

Prescribed/advised by whom?	AM-users (%), n = 98	NAM-users (%), n = 269
Physicians ^a	72 (73.0)	88 (34.9)
Heilpraktiker	39 (39.8)	90 (33.5)
Other persons	12 (12.2)	60 (22.3)
Self-medication	12 (12.2)	58 (21.6)
Therapist for specific naturopathic treatments	12 (12.2)	26 (9.7)
Other medical specialist/consultant	11 (11.2)	17 (6.3)
	<i>P</i> < 0.0001	

^aGeneral medical practitioner; hospital-based physician who treated the child (paediatric oncology); other hospital-based physician; paediatrician in private practice.

TABLE VI. Time-Point of CAM-Use

	AM-user (%), N = 98	NAM-user (%), N = 269
Together with conventional therapy in first line therapy	49 (50)	143 (53.2)
After end of conventional therapy or during a continuation therapy	36 (36.7)	89 (33.1)
After end of continuation therapy	14 (14.3)	51 (19)
When all conventional therapy failed	16 (16.3)	18 (7)
Together with conventional therapy in relapse therapy	13 (13.3)	20 (7.4)

The time point at which CAM was first administered during the course of illness was the same in both groups (Table VI). In most cases CAM was used concurrently with conventional treatment given by the paediatric oncologist. Only 14% of the CAM-users started CAM-treatment after the end of conventional treatment.

Communication Behaviour

Eighty-eight out of 98 AM-using families (89.8%) spoke with a physician about the use of CAM for their child's treatment, while less than two-thirds of NAM-users (63.9%) had spoken with a physician about using CAM (Table VII). The response of the consulted physician (advised use, took note of, advised against) was different between general medical practitioners attending to AM-users and those attending to NAM-users but did not reach statistical significance: use of CAM was advised by 65.2% physicians of AM-users in contrast to 47.4% of NAM-users physicians. Physicians took note of treatments without comment in 47.4% of NAM and 34.8% AM-users. These differences were not statistically different due to small numbers (Table VII).

The responses of paediatricians of AM-users and NAM-users were also not significantly different (*P* = 0.72). Within the hospital-based physician category there was no significant difference between hospital-based physicians of AM-users to recommended

use more often than in physicians consulted by NAM-users (15.5% vs. 10.7%; *P* = 0.60).

Anticipated Effects and Experienced Effects

Basic convictions regarding the effectiveness of CAM were similar in AM-users and NAM-users (*P* = 0.44); before starting CAM treatment, 67% of AM-users and 71% of NAM-users, respectively, were absolutely convinced or fairly sure that CAM would have a positive effect on their child's health. The proportion of parents who had doubts was 33% in the AM-user group and 29% in the NAM-user group (n.s.).

No differences between the AM-users and NAM-users were evident in the results of the question concerning parents' assessment of the experienced effects of CAM on their child's illness. In response to the question on side effects, 4.4% of all CAM-users reported most unspecific side effects (n = 16 of 358 CAM-users who answered this question; multiple answers were possible). There were no statistical differences between AM-users and NAM-users in this respect.

The overall positive attitude, both with regards to hoped-for and experienced effects, of all CAM-users is also expressed by parents' willingness to advise other parents in a similar situation to use CAM, especially the AM-users: 89.4% of all CAM-users (95.9% of AM-users and 87% of NAM-users; *P* = 0.05) would recommend CAM.

TABLE VII. Physician's Response (n = 367 CAM-Users)

Response of the physician at the time	General practitioner (n = 61)		Paediatrician (n = 100)		Hospital-based physician (n = 220)	
	23 AM-users, No. (%)	38 NAM-users, No. (%)	43 AM-users, No. (%)	57 NAM-users, No. (%)	71 AM-users, No. (%)	149 NAM-users, No. (%)
Advised use	15 (65.2)	18 (47.4)	13 (30.2)	16 (28.1)	11 (15.5)	16 (10.7)
Took note of	8 (34.8)	18 (47.4)	28 (65.1)	36 (63.2)	44 (62.0)	97 (65.1)
Advised against	0 (0.0)	2 (5.3)	2 (4.7)	5 (8.8)	16 (22.5)	36 (24.2)
	<i>P</i> = 0.27		<i>P</i> = 0.72		<i>P</i> = 0.60	

TABLE VIII. CAM Treatments Recommended by CAM-Users (n = 367 CAM-Users)

Treatment method	Rank distribution according to frequency (N)	
	AM-users, n = 98 (Rank)	NAM-users, n = 269 (Rank)
Mistletoe therapy	43 (1)	5 (28)
Anthroposophic–homeopathic medicines (except for mistletoe therapy)	40 (2)	2 (35)
Homeopathy	25 (3)	97 (1)
Art therapy	9 (4)	7 (25)
Food supplements	9 (4)	26 (2)
Music therapy	8 (6)	12 (15)
Dietary change	7 (7)	19 (3)
Laying on of hands	6 (8)	16 (9)
Kinesiology	6 (8)	14 (9)
Acupuncture	5 (10)	7 (22)
Eurythmy therapy	5 (10)	0

The treatment methods most frequently recommended by AM-users, that is, mistletoe therapy (rank 1) and anthroposophic–homeopathic medicines (rank 2) play a marginal role for the NAM-users with respect to recommending these treatments (rank 28 and 35). On the other hand, homeopathy is frequently recommended by both groups (rank 3 for AM-users and rank 1 for NAM-users) (Table VIII).

DISCUSSION

These data were derived from the most extensive and the first population-based study available investigating the prevalence of CAM use in paediatric oncology. The specific use of AM in paediatric oncology has not been investigated in any published study to date. Furthermore, we do not know of any similar studies that compare AM-users with CAM-users in general. In our survey population, the prevalence of CAM use in paediatric oncology in Germany was 35%. Of these at least 27% used AM. The actual number of AM-users may be higher because parents often are unable to distinguish between homeopathy and AM. This means that some of the children whose parents specified homeopathy may have received AM.

Furthermore, there are specific anthroposophic non-medicinal treatment methods, such as music therapy or rhythmical massage, which were not investigated in this study and therefore are not included in the total number of AM-users.

A key factor that influenced the probability of CAM use among children with cancer was existing familiarity with CAM treatment methods before the child became ill with cancer. Thirty-seven percent of all questionnaire respondents had previous experience of CAM; this figure is somewhat lower than that of the general German population [27,28]. On the other hand, 67% of AM-users had previous experience of CAM. It is noteworthy that about two-thirds of families who had previous experience of AM also used AM when their child became ill with cancer. Sixty percent of NAM-users had previous CAM experience. Of the respondents who said they did not use CAM for their child's treatment, 24% had previous experience of CAM but only 2% had previous experience of AM and these were significant differences. Previous experience of AM appears to motivate parents to use AM as an adjuvant treatment in the case of their child becoming ill with cancer von Rohr et al. [29] showed that adult patients with cancer engaging in anthroposophic therapies have both

previous experience of AM and a strong connection to AM. In a study of patient satisfaction in anthroposophic and conventional medical practices in Switzerland, Esch et al. [22] described high patient satisfaction with respect to the effectiveness of AM treatment and other expectations surrounding the treatment. AM-users have a high degree of trust in the physician–patient relationship. In the present study 89.8% of AM-users had spoken with a physician about the use of CAM while only about two-thirds (63.9%) of NAM-users had done so. A study of anthroposophic and conventional general medical practices has shown that adult patients intentionally seek out anthroposophic practices because of the specific forms of treatment and therapy [30]. The patients emphasise the quality of treatment experienced and, in particular, their satisfaction with the information provided by their physician [31]. Parents may similarly seek out AM practices for their children.

Given the CAM-users' generally positive level of expectation of CAM, the high degree of recommendation to parents in a similar situation is not surprising. However, a difference between AM-users and NAM-users is also evident here: 95.9% of AM-users and 87% of NAM-users recommend CAM to others. This may reflect the above-mentioned connection to AM.

The higher socioeconomic status of AM-users compared to other CAM-users and users of exclusively conventional medicine described in this study has also been described in several adult–patient studies [22,26,32]. While AM-users tend to have a closer relationship with the physician with respect to both procuring information and prescription behaviour, in 39% of the cases a Heilpraktiker was involved in the prescription. This finding may be a reflection of a lack of AM-trained physicians in some areas of Germany, or a need for additional support felt by AM-orientated patients. This result is also surprising, however, because AM aims to build on conventional medicine and extend it, whereas, in Germany, Heilpraktiker do not receive training in conventional medicine comparable to trained and licensed physicians. The results of this study suggest that there is a need for physicians treating children with cancer to actively inquire about CAM use and especially AM treatment by other health professionals, and to maintain open communication.

CONCLUSIONS

In addition to homeopathy, AM as an independent form of treatment is used frequently in paediatric oncology in Germany. Patients

using AM are engaged in treatment and therapies considerably longer than patients using other CAM approaches. Furthermore, most families who had used AM before their child became ill also used AM for the treatment of their child's cancer. Patient satisfaction with AM appears to be very high. Only a few small reports regarding the use of AM in paediatric oncology have been published [33–35]; given this and the results of the study in terms of the use of AM, there is a concerning need to carry out prospective controlled clinical studies of the safety and efficacy of AM in paediatric cancer.

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