Prevalence and Correlates of Use of Complementary and Alternative Medicine in Children with Autism Spectrum Disorder in Europe

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ABSTRACT

This study examined the prevalence and correlates of use of complementary and alternative medicine (CAM) among a sample of children with autism spectrum disorder (ASD) < 7 years in 18 European countries (N=1,680). Forty seven percent of parents reported having tried any CAM approach in the past 6 months. Diets and supplements were used by 25% of the sample and mind-body practices by 24%; other unconventional approaches were used by 25% of the families; and a minority of parents reported having tried any invasive or potentially harmful approach (2%). Parents in Eastern Europe reported significantly higher rates of CAM use. In the total sample, children with lower verbal ability and children concurrently using prescribed medications were more likely to be receiving diets or supplements. Concurrent use of high levels of conventional psychosocial intervention was significantly associated with use of mind-body practices. Higher parental educational level also increased the likelihood of both use of diets and supplements and use of mind-body practices. Conclusion: The high prevalence of CAM use among a sample of young children with ASD is an indication that parents need to be supported in the choice of treatments early on in the assessment process, particularly in some parts of Europe.
Introduction

Autism spectrum disorder (ASD) is a behaviourally defined disorder characterized by impairments in social communication abilities and the presence of restricted and repetitive behaviours and atypical sensory responses [3]. Despite the evidence that behavioural and social communication interventions can ameliorate symptoms and improve outcomes [29] it is not a condition for which a ‘cure’ is currently available. The uncertainty concerning the developmental outcomes, the limitations to existing treatments, and the lack of a simple cure have been indicated as possible reasons for the high prevalence of use of therapies based outside the domain of conventional medical and psychological practice by families of children with autism [21]. Such therapies, generally defined as complementary and alternative medicine (CAM), comprise a myriad of “interventions” that range from unproven and untested treatments to approaches that have been found to be harmful. The National Center for Complementary and Alternative Medicine (NCCAM) distinguishes the following broad areas of CAM: ‘natural products’ (often sold as dietary supplements), ‘mind and body practices’ (such as massage or sensory integration therapy) and a residual category of other complementary health approaches that do not fit neatly in the previous ones, such as homeopathy (http://nccam.nih.gov/). Research on CAM use broadly refers back to this classification, but additional meaningful categories of CAM such as “invasive or potentially unsafe approaches” [1] and other unconventional approaches that are not strictly classifiable as CAM (such as pet therapy) are also often included in such surveys. This, and the fact that the NCCAM classification has changed over time, have led to some inconsistency across studies.
The efficacy of CAM treatment is controversial, but for most of these approaches there simply is not enough evidence to evaluate them [23]. For example, while gluten- and casein-free diets are widely used and reported to be efficacious by parents [40], to date only two RCTs have tested their efficacy, yielding mixed results that prevent any recommendation of these exclusion diets as standard treatments [19,8]. Omega-3 fatty acids are increasingly used in ASD despite lack of understanding on which might be the optimal dosage and insufficient evidence of efficacy [18]. Moreover, while CAM is often used in combination with medication, little is known about potential aversive effects of the interaction between drugs and supplements, which requires careful monitoring [20]. There is some positive evidence for some CAM approaches, such as horse-riding [16] and massage [34]. A Cochrane review of auditory integration training, a costly and theoretically ill-specified treatment, did not find sufficient evidence to support its use [35].

In US based samples, there is some evidence that CAM use in children or young people with ASD is associated with greater functional difficulty [15,32,38], but this has not always been replicated [1]. A higher parental educational level and high levels of use of conventional therapy (>20 hours) have also been found to be associated with CAM use in children with ASD [1]. Cultural and systemic factors (such as families’ own recognition and beliefs around aetiology and course of symptoms as well as the actual availability of conventional therapy) might also play a role in the decision to use CAM [25]. Professionals’ opinions vary widely on the topic [31] and might be another source of influence on family choice. These aspects are likely to differ in different parts of the world [4], however with the exception of a non-systematic review based on professionals’ opinions [41] no studies to date report on the use of CAM in Europe. Moreover, different factors might play a different role in use of specific types of CAM, but this is only beginning to be addressed [32]. The present study aimed at describing the prevalence of use of CAM in Europe, as well as identifying the
correlates of use of the two main classes of CAM: diets and supplements and mind-body practices.

Methods

Ethical approval was given by the Research Ethics Committee of the Faculty of Children and Learning, Institute of Education, London, UK. Parents provided informed consent before completing the survey (IOE/ FPS 385).

Survey

The present study focuses on a set of questions on use of CAM that was part of a wider-scope survey on use of interventions in Europe [33, in press]. The survey was open for completion for 45 days. A total of 1,680 families with a child with ASD aged 7 or younger in 18 countries completed the online survey: Belgium, Czech Republic, Denmark, Finland, France, Germany, Hungary, Iceland, Ireland, Italy, Netherlands, Norway, Poland, Portugal, Romania, Spain, The Former Yugoslav Republic of Macedonia and the United Kingdom. Participants were recruited via national parents’ associations who advertised the link on their websites, with the exception of parents in The Former Yugoslav Republic of Macedonia who were recruited through the Paediatric Clinic of Skopje in absence of a national parents’ association and completed a paper version of the survey. Before launching the survey, the questionnaire was piloted with parents from the UK (N=8) and Italy (N=2); as a result of the pilot, the possibility to select a generic intervention if the nature of the approach was not known to the parent was further highlighted in the initial instructions. Participant characteristics are summarised in Table 1.

Parent characteristics: General background information on respondents was gathered: relationship to child (mother/father/other) and educational level (below high school
diploma, high school diploma, bachelor/degree, postgraduate). The educational level was collapsed for analysis into the following two categories: low educational level (up to high school diploma, 37%) and high educational level (degree and postgraduate, 63%). To comply with the relevant legislation on cross-national sharing of sensitive personal data in some of the participating countries, parents were asked to report on the country of residency but data on nationality and ethnicity were not collected.

Child characteristics: Information on the age of the child at survey completion was collected and dichotomised to reflect the age at which typically children start school in Europe (below age 5, 52% and 5 years and above, 48%). Child verbal ability was rated by parents selecting one of five options (does not talk; uses single words; uses two- or three-word phrases; uses sentences with four or more words; uses complex sentences). The options were collapsed into two categories for the purposes of analysis: low verbal ability (non-verbal or single words speech, 37%) and use of at least phrase speech (63%).

Use of conventional therapies and prescription medication: Parents were asked to report on current use of conventional behavioural, developmental and psychosocial intervention (such as applied behavioural analysis, occupational therapy, speech and language therapy…) and medication. A total of 1,529 parents (91%) reported using at least one conventional intervention. The number of conventional interventions used ranged from 1 to 7 (M=2.39, SD=1.43; IQR: 1-3); more detailed results are reported in [33, in press]. For the purposes of this analysis, we classified the sample for level of use of conventional treatments. Three levels of use were defined based on the distribution of number of interventions used: no use (0 therapies used; 9%), medium level of use (use of 1-3 therapies; 70.5%) and high level of use (use of 4 or more therapies; 20.5%). Parents reported using at least one medication in 19.7% of cases in the total sample. Use of medication was dichotomised for this analysis into a “use of any medication” binary variable.
A list of CAM approaches was drawn from the literature. Parents were asked to endorse all the approaches that they had used with their child in the previous 6 months. The CAM approaches, listed alphabetically in the form, were successively classified into four categories for the purpose of statistical analysis: the three categories proposed by the NCCAM (diets and supplements; mind and body practices; other unconventional approaches) and a fourth category of “invasive, disproven or potentially unsafe CAM” (including chelation, hyperbaric oxygen therapy and packing) which was added [following 1].

**Data analysis**

Descriptive statistics were used to report on use of each CAM approach, grouped in four over-arching categories. Prevalence of use of these categories was examined in the total sample and by European regions [37]: Western Europe (Belgium, France, Germany and Netherlands), Northern Europe (Denmark, Finland, Iceland, Ireland, Norway, United Kingdom), Eastern Europe (Czech Republic, Hungary, Poland, Romania) and Southern Europe (Italy, Macedonia, Portugal, Spain).

To investigate the association of child and parental characteristics with use of CAM, we conducted logistic regressions on the total sample for two primary outcomes: use of any diets or supplements and use of any body-mind practices. These categories were selected for the analysis on the basis of the following criteria: conceptual relevance, homogeneity of approaches included and frequency of use. In each model, the predictors were: child’s gender, verbal ability and age, parental educational level, use of any prescription medication, use of conventional therapies categorised into three dummy variables (no use of therapy, medium level of use, and high level of use; the first category was used as the reference).
Results

--- Table 1 about here -----

Frequency of CAM

Frequency of use of individual CAM approaches is reported in Table 2. A total of 789 respondents (47%) reported using at least one type of CAM. The rate of use of any CAM was significantly higher in Eastern (66%) than in Western (41%, p<.001), Northern (46%, p<.001) and Southern (40%, p<.001) Europe. The prevalence of use in Northern Europe was also significantly higher than in Southern Europe (p=.038). In the total sample, the most commonly used CAM approaches were diets and supplements (24.4% reported using any); use of vitamins was reported by 259 parents (15.4%) and gluten or casein free diets were reported by 227 (13.5%). The proportion of parents reporting using diets and supplements was significantly higher in Eastern Europe (38%) than in Western (17%, p<.001), Northern (28%, p=.003) and Southern Europe (20%, p<.001). Reported use in Northern Europe was also significantly higher than use in Western (p<.001) and Southern Europe (p=.007). Mind and body practices were reported by 395 respondents in the total sample (23.5%); among these, sensory integration therapy (13.6%) and massage (7.1%) were the most commonly used treatments. Parents in Eastern Europe also reported the highest rate of use of any mind-body practices (34%); this proportion was significantly higher than rates in Western (20%, p<.001), Northern (28%, p=.043) and Southern Europe (16%, p<.001). Reported use of mind-body practices in Northern Europe was also significantly higher than in Southern (p<.001) and Western Europe (<.006). A number of other unconventional approaches not included in the previously mentioned classes of CAM were reported in 24.5% of the total sample (n=514): among these, pet therapy (n= 233, 13.9%) and homeopathy (n=161, 9.6%) were the most widely used. The proportion of parents reporting using such
approaches was significantly higher in Eastern Europe (43%) than in Western (24%, p<.001), Northern (12%, p<.001) and Southern Europe (19%, p<.001). Reported use in Western and Southern Europe was also significantly higher than in Northern Europe (p<.001 and p=.006).

A small minority of parents (n=40, 2.4%) reported using any invasive, disproven or potentially unsafe CAM (chelation, hyperbaric chamber and packing). Rate of use of such approaches was significantly higher in Eastern Europe (5%) than in Western (0.8%, p<.001), Northern (1.5%, p=.006) and Southern Europe (2.5%, p=.037). The rate in Southern Europe was also significantly higher than the rate in Western Europe (p=.034).

The total number of different CAM approaches used for those parents who used any CAM approaches ranged from 1 to 12 with a mean of 2.15 (SD=1.55, IQR: 1-3) in the total sample. A significant effect of European region was found on number of CAM approaches used, F (3, 785) = 9.72, p<.001, ω=.18. Post hoc comparisons indicated that the mean number of approaches used with children living in Eastern Europe (M = 2.60, SD = 1.87, IQR: 1-3) was significantly higher than the mean number of approaches used with children living in Western Europe (M = 1.92, SD = 1.40, IQR: 1-2; p<.001), Northern Europe (M = 2.06, SD = 1.22, IQR: 1-3; p=.004) and Southern Europe (M = 1.93, SD = 1.42, IQR: 1-2; p<.001).

----- Table 2 about here -----
relevant variables had not been included in the model. For each predictor, the effects reported below are intended to be over and above the effect of all other variables included in the model.

----- Table 3 -----

*Use of any diets/supplements*

Use of any diets or supplements was significantly associated with low verbal ability in the children and higher parental educational level. Use of prescription medication increased the likelihood of using diets or supplements by 62%. Child’s gender and age and use of conventional therapy were not predictors of using diets or supplements.

*Use of any mind-body practices*

Mind and body practices were less likely to being used with boys than with girls. A higher parental educational level and high levels of use of conventional psychosocial interventions were associated with concurrent use of mind-and-body practices. Child’s age and verbal ability, use of medication and medium levels of use of conventional treatments were not associated with use of this category of CAM.

**Discussion**

This study is the first to report on use of CAM in young children with autism in Europe. We found that overall 47% of parents reported using at least one type of CAM or other unconventional treatment in the previous 6 months. Rates of use were homogeneous across Europe with the exception of significantly higher rates in Eastern Europe (66%). Prevalence data from US samples obtained from reviews of patients charts vary from 30-50% [21,32,1] to 70-90% [14,15]. In the total sample, parents reported using diets or supplements in 24% of cases. Previous reports of use of diets ranged 27%-42% [11,13,15], but
comparisons are made difficult by the different level of detail across studies. A similar proportion of parents in our total sample reported using mind-body practices (24%). Rates from previous studies ranged 20-30% [15,14], but comparison should be made with caution as different definitions were used or CAM approaches were considered individually rather than as a class.

We also enquired about some invasive or potentially harmful treatments: chelation, hyperbaric chamber and packing. Chelation is a medical procedure involving administering various chemical substances for the purpose of binding and then withdrawing specific metals from the person's body; its potential serious side effects (including death) and the lack of sound scientific rationale argue against its therapeutic use [6]. Hyperbaric oxygen therapy involves breathing oxygen in a pressurized chamber for the purpose of increasing the amount of oxygen in the blood; it is both ineffective [12] and unsafe (potential side effects include paralysis and air embolism). Packing involves wrapping the individual in towels previously wet in cold water to supposedly reinforce the individuals’ consciousness of their bodily limits; this practice, which appears to be a clear violation of human rights, has not been evaluated systematically [7]. In our sample, 40 parents (2%) reported using any of these treatments with their children.

Among the other unconventional treatments included in the survey, it is relevant to note the high prevalence of reported use of pet therapy (14%). Pet-therapy is a generic term that encompasses both the use of “assistance” pets (i.e., placement of a pet in the family) and the use of “therapy” pets by a therapist at home or in other settings; it is not possible to know whether in our sample parents were endorsing the former or the latter. Higher figures (24%) have been reported before [5].
There were significant regional differences in the rates of use of the four over-arching categories of CAM, with consistently higher rates in Eastern Europe than in the rest of Europe. This might be due to lack of access to evidence-based information in those countries, possibly as a residual consequence of the historical divide on health policies in Europe [24] or to cultural differences in attitudes of professionals and community members that are only beginning to be explored [41].

We were interested in identifying correlates of use of CAM in Europe. As CAM is comprised of a plethora of different types of “treatments”, we investigated correlates of use of the two main classes of approaches, selected for their conceptual relevance and relative homogeneity: diets and supplements and mind-body practices. No gender differences were found for use of diets and supplements. There was a tendency for more mind-body practices to be used with girls than with boys, but this finding should be interpreted with caution as the females in the sample were only a minority (n=291, 18%). In our sample, non-verbal children and children with single-words speech were more likely to being treated with diets (30% increase in the probability of use), suggesting that parents of lower functioning children may tend to look to a range of interventions to respond to more severe difficulties. Additionally, over and above the effect of verbal ability, children using prescription medication were also more likely to be treated with diets than children not using medication (62% increase). Interestingly though, neither of these associations was found for use of mind-body practices. This suggests that previous evidence of higher use of CAM in low functioning children [32,14] might be specific to some CAM types. The association of use of medication with use of diets but not mind-body practice might be due to the use of supplements or alterations in the diet as an attempt to counter-balance potential side effects of medications or to “boost” their efficacy [15]. Alternatively, the association could reflect parental attitudes or beliefs (e.g., a generic belief in chemical/biological mechanisms) or the
willingness of the child to orally intake pills or tablets. Increased diet use in children concurrently taking medications may also reflect an attempt to counteract the weight-gain associated with many psychotropic medications, although we did not ask parents to report why their child was on a diet, which should be done in future studies. In addition, we do not have information on whether diets or supplements were medically prescribed as a treatment for specific conditions (such as iron deficiency).

Parents with a high educational level have been consistently reported in previous studies to be more likely to use CAM than parents with a lower educational level [14,1] and in our study more educated parents were more likely to choose diets or supplements for their child as well as using mind-and body practices. Notably, the increase in the likelihood was higher for the mind-body practices (64%) than diets and supplements (35%). Mind-and-body practices are practitioner-delivered and their cost is on average almost double the cost of self-care therapies such as supplements [28], and this might explain why in our sample mind-and-body practices were significantly less used by parents with a lower SES (indexed by their educational level).

When the correlation of CAM use and use of conventional treatments has been explored, it appears that availability and use of conventional treatments does not lessen use of CAM. Indeed, CAM use has been found to be associated with receiving 20 or more hours per week of conventional treatment [1]. Here, we explored the association between use of conventional treatments and use of two specific classes of CAM. There was no association between use of conventional treatment and use of diets: the use of such approaches might in fact be more related to the use of medications, as suggested above. We found instead a large dose-response effect of use of conventional treatments on use of mind-body practices with a four-fold increase in the likelihood of concurrent CAM use for parents reporting already
using more than four conventional treatments for their child, but not for medium levels of
treatment (up to three interventions).

This finding suggests that use of mind-body practices is most strongly related with a
tendency to try a wide number of approaches; this might indicate that some parents, over and
above the effect of their child’s level of functioning (measured as verbal ability) and of their
own educational level (which can be constructed as a proxy of their SES), tend to look for as
many therapies as possible, whether these be conventional treatments or CAM approaches.

Use of diets appeared to be most strongly associated with lower functioning of the child and
concurrent use of prescription medication.

There is concern that desperate parents may resort to unsafe or disproven CAM
approaches and public agencies have been actively campaigning against them [10], but such
approaches were not in wide use in our sample. However, animal-assisted therapy, whose
efficacy is not yet established, is attracting increasing interest [30] and a considerable number
of parents reported using such approaches in our sample. These findings have implications
for clinicians and professionals involved in the care of children with ASD, in that they should
engage parents in frank discussions about CAM approaches, the available evidence and any
potential for adverse effects.

Strengths and limitations

There are a number of strengths to the present study, including the large sample size
and the wide scope of the survey, which enquired about the use of a range of both CAM
approaches and conventional treatments for young children with autism in Europe.

Moreover, while previous research has looked at predictive factors for use of CAM
considering child and parent characteristics as individual factors or only adjusting for parental
education level, in our study we used multiple logistic regression to estimate the contribution
of each predictor having taken into account the influence of the other factors. These findings can help to identify families potentially more likely to adopt CAM approaches, and this information may be beneficial both to primary care providers in their role as clinical advisors, and to researchers, for example when designing trials of CAM approaches.

Nevertheless, the findings should be seen in the context of some limitations. Firstly, we employed a recruitment method (online survey advertised via parents’ associations) that might have been prone to selection bias since parents involved in associations are more likely to have a relatively high income and educational level [26] and internet access is still a function of socio-demographic characteristics in Europe [39]. Our sample had in fact a higher than average education level [9]. However, while the recruitment strategy used necessarily prevents any claims of generalizability of our results to the European population, it has enabled us to reach a large number of families across Europe. Moreover, it has been argued that, given the controversy around use of CAM, an anonymous online survey might actually better protect against the potential risks of selection and reporting bias [36], than when parents are directly asked by clinicians (as happened in most other studies on the topic). Furthermore, we found that reported levels of CAM use in the present study were similar to previous studies in non-EU samples.

The factors examined in the present study are only some of the many that might affect the decision-making process underlying the choice of using CAM alongside (or alternative to) conventional healthcare, which is still largely unexplained. For example, there is preliminary evidence from a small sample of French parents (N=89) that personality characteristics such as personal control and attribution of cause of autism affect the decision to use CAM or not [2]. Parents’ own use of CAM is likely to be a relevant factor but has never been examined in the association with use of CAM in children. Further research on the topic should include these and other factors, such as beliefs on ASD aetiology, to better
understand the phenomenon of use of CAM for children with autism. Finally, reliance on parent report in absence of direct assessments places a limitation on these findings in relation to severity of child symptoms and behavioural characteristics.

Conclusions

This was the first study to report on factors associated with use of CAM in a large sample of young children with autism in Europe. While little is known on the efficacy (and conversely, on the potential harm) of CAM approaches, a vast amount of uncontrolled information is available on-line, putting parents at risk of embarking in sometimes costly and often non- efficacious treatments. Rates of CAM use, including use of disproven or unsafe approaches, were particularly high in Eastern Europe. The present study contributed to the understanding of the factors associated to use of CAM and provided some evidence that families that tend to use a wide range of conventional treatments might also be more likely to be trying some CAM approaches. The reasons behind this are not fully understood, and may reflect factors that were not captured by the present study. Nonetheless these findings, taken together with the evidence of socio-economic barriers in access to treatment for autism [22,33, in press], provide some insight into the lengths to which families may go in pursuit of ways to help their child progress. The findings highlight the need to further advance research funding and policy development for evidence-based early interventions for children with ASD across Europe.

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