

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

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29

30 ABSTRACT

31 This study examined the prevalence and correlates of use of complementary and alternative
32 medicine (CAM) among a sample of children with autism spectrum disorder (ASD) < 7 years
33 in 18 European countries (N=1,680). Forty seven percent of parents reported having tried
34 any CAM approach in the past 6 months. Diets and supplements were used by 25% of the
35 sample and mind-body practices by 24%; other unconventional approaches were used by
36 25% of the families; and a minority of parents reported having tried any invasive or
37 potentially harmful approach (2%). Parents in Eastern Europe reported significantly higher
38 rates of CAM use. In the total sample, children with lower verbal ability and children
39 concurrently using prescribed medications were more likely to be receiving diets or
40 supplements. Concurrent use of high levels of conventional psychosocial intervention was
41 significantly associated with use of mind-body practices. Higher parental educational level
42 also increased the likelihood of both use of diets and supplements and use of mind-body
43 practices. *Conclusion:* The high prevalence of CAM use among a sample of young children
44 with ASD is an indication that parents need to be supported in the choice of treatments early
45 on in the assessment process, particularly in some parts of Europe.

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Introduction

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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.

73 The efficacy of CAM treatment is controversial, but for most of these approaches
74 there simply is not enough evidence to evaluate them [23]. For example, while gluten- and
75 casein-free diets are widely used and reported to be efficacious by parents [40], to date only
76 two RCTs have tested their efficacy, yielding mixed results that prevent any recommendation
77 of these exclusion diets as standard treatments [19,8]. Omega-3 fatty acids are increasingly
78 used in ASD despite lack of understanding on which might be the optimal dosage and
79 insufficient evidence of efficacy [18]. Moreover, while CAM is often used in combination
80 with medication, little is known about potential aversive effects of the interaction between
81 drugs and supplements, which requires careful monitoring [20]. There is some positive
82 evidence for some CAM approaches, such as horse-riding [16] and massage [34]. A
83 Cochrane review of auditory integration training, a costly and theoretically ill-specified
84 treatment, did not find sufficient evidence to support its use [35].

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

98 correlates of use of the two main classes of CAM: diets and supplements and mind-body
99 practices.

100 Methods

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

104 *Survey*

105 The present study focuses on a set of questions on use of CAM that was part of a
106 wider-scope survey on use of interventions in Europe [33, in press]. The survey was open for
107 completion for 45 days. A total of 1,680 families with a child with ASD aged 7 or younger in
108 18 countries completed the online survey: Belgium, Czech Republic, Denmark, Finland,
109 France, Germany, Hungary, Iceland, Ireland, Italy, Netherlands, Norway, Poland, Portugal,
110 Romania, Spain, The Former Yugoslav Republic of Macedonia and the United Kingdom.
111 Participants were recruited via national parents' associations who advertised the link on their
112 websites, with the exception of parents in The Former Yugoslav Republic of Macedonia who
113 were recruited through the Paediatric Clinic of Skopje in absence of a national parents'
114 association and completed a paper version of the survey. Before launching the survey, the
115 questionnaire was piloted with parents from the UK (N=8) and Italy (N=2); as a result of the
116 pilot, the possibility to select a generic intervention if the nature of the approach was not
117 known to the parent was further highlighted in the initial instructions. Participant
118 characteristics are summarised in Table 1.

119 *Parent characteristics:* General background information on respondents was
120 gathered: relationship to child (mother/father/other) and educational level (below high school

121 diploma, high school diploma, bachelor/degree, postgraduate). The educational level was
122 collapsed for analysis into the following two categories: low educational level (up to high
123 school diploma, 37%) and high educational level (degree and postgraduate, 63%). To
124 comply with the relevant legislation on cross-national sharing of sensitive personal data in
125 some of the participating countries, parents were asked to report on the country of residency
126 but data on nationality and ethnicity were not collected.

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

134 *Use of conventional therapies and prescription medication:* Parents were asked to
135 report on current use of conventional behavioural, developmental and psychosocial
136 intervention (such as applied behavioural analysis, occupational therapy, speech and language
137 therapy...) and medication. A total of 1,529 parents (91%) reported using at least one
138 conventional intervention. The number of conventional interventions used ranged from 1 to 7
139 ($M=2.39$, $SD=1.43$; IQR: 1-3); more detailed results are reported in [33, in press]. For the
140 purposes of this analysis, we classified the sample for level of use of conventional treatments.
141 Three levels of use were defined based on the distribution of number of interventions used:
142 no use (0 therapies used; 9%), medium level of use (use of 1-3 therapies; 70.5%) and high
143 level of use (use of 4 or more therapies; 20.5%). Parents reported using at least one
144 medication in 19.7% of cases in the total sample. Use of medication was dichotomised for
145 this analysis into a “use of any medication” binary variable.

146 CAM: A list of CAM approaches was drawn from the literature. Parents were asked
147 to endorse all the approaches that they had used with their child in the previous 6 months.
148 The CAM approaches, listed alphabetically in the form, were successively classified into four
149 categories for the purpose of statistical analysis: the three categories proposed by the
150 NCCAM (diets and supplements; mind and body practices; other unconventional approaches)
151 and a fourth category of “invasive, disproven or potentially unsafe CAM” (including
152 chelation, hyperbaric oxygen therapy and packing) which was added [following 1].

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154 *Data analysis*

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

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

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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

193 approaches was significantly higher in Eastern Europe (43%) than in Western (24%, $p < .001$),
194 Northern (12%, $p < .001$) and Southern Europe (19%, $p < .001$). Reported use in Western and
195 Southern Europe was also significantly higher than in Northern Europe ($p < .001$ and $p = .006$).
196 A small minority of parents ($n = 40$, 2.4%) reported using any invasive, disproven or
197 potentially unsafe CAM (chelation, hyperbaric chamber and packing). Rate of use of such
198 approaches was significantly higher in Eastern Europe (5%) than in Western (0.8%, $p < .001$),
199 Northern (1.5%, $p = .006$) and Southern Europe (2.5%, $p = .037$). The rate in Southern Europe
200 was also significantly higher than the rate in Western Europe ($p = .034$). The total number of
201 different CAM approaches used for those parents who used any CAM approaches ranged
202 from 1 to 12 with a mean of 2.15 ($SD = 1.55$, IQR: 1-3) in the total sample. A significant
203 effect of European region was found on number of CAM approaches used, $F(3, 785) = 9.72$,
204 $p < .001$, $\omega = .18$. Post hoc comparisons indicated that the mean number of approaches used
205 with children living in Eastern Europe ($M = 2.60$, $SD = 1.87$, IQR: 1-3) was significantly
206 higher than the mean number of approaches used with children living in Western Europe (M
207 $= 1.92$, $SD = 1.40$, IQR: 1-2; $p < .001$), Northern Europe ($M = 2.06$, $SD = 1.22$, IQR: 1-3;
208 $p = .004$) and Southern Europe ($M = 1.93$, $SD = 1.42$, IQR: 1-2; $p < .001$).

209 ----- Table 2 about here -----

210 *Predictors of CAM use*

211 Logistic regression models were performed on the total sample with use of any
212 diets/supplements and use of any mind-body practice as outcome variables. Table 3 reports
213 the odds ratios and 95% CIs for the predictors of each logistic regression model. For all
214 models, the χ^2 statistics were significant (all $p < .001$) and the Hosmer & Lemeshow's
215 goodness-of-fit tests [17] were not significant (hence indicating well-fitting models). The
216 Nagelskerke's R^2 [27] were low (range .03-.08), which is an indication that several other

217 relevant variables had not been included in the model. For each predictor, the effects
218 reported below are intended to be over and above the effect of all other variables included in
219 the model.

220 ----- Table 3 -----

221 *Use of any diets/supplements*

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

226 *Use of any mind-body practices*

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

232 *Discussion*

233 This study is the first to report on use of CAM in young children with autism in
234 Europe. We found that overall 47% of parents reported using at least one type of CAM or
235 other unconventional treatment in the previous 6 months. Rates of use were homogeneous
236 across Europe with the exception of significantly higher rates in Eastern Europe (66%).
237 Prevalence data from US samples obtained from reviews of patients charts vary from 30-50%
238 [21,32,1] to 70-90% [14,15]. In the total sample, parents reported using diets or supplements
239 in 24% of cases. Previous reports of use of diets ranged 27%-42% [11,13,15], but

240 comparisons are made difficult by the different level of detail across studies. A similar
241 proportion of parents in our total sample reported using mind-body practices (24%). Rates
242 from previous studies ranged 20-30% [15,14], but comparison should be made with caution
243 as different definitions were used or CAM approaches were considered individually rather
244 than as a class.

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

257 Among the other unconventional treatments included in the survey, it is relevant to
258 note the high prevalence of reported use of pet therapy (14%). Pet-therapy is a generic term
259 that encompasses both the use of "assistance" pets (i.e., placement of a pet in the family) and
260 the use of "therapy" pets by a therapist at home or in other settings; it is not possible to know
261 whether in our sample parents were endorsing the former or the latter. Higher figures (24%)
262 have been reported before [5].

263 There were significant regional differences in the rates of use of the four over-arching
264 categories of CAM, with consistently higher rates in Eastern Europe than in the rest of
265 Europe. This might be due to lack of access to evidence-based information in those
266 countries, possibly as a residual consequence of the historical divide on health policies in
267 Europe [24] or to cultural differences in attitudes of professionals and community members
268 that are only beginning to be explored [41].

269 We were interested in identifying correlates of use of CAM in Europe. As CAM is
270 comprised of a plethora of different types of “treatments”, we investigated correlates of use
271 of the two main classes of approaches, selected for their conceptual relevance and relative
272 homogeneity: diets and supplements and mind-body practices. No gender differences were
273 found for use of diets and supplements. There was a tendency for more mind-body practices
274 to be used with girls than with boys, but this finding should be interpreted with caution as the
275 females in the sample were only a minority (n=291, 18%). In our sample, non-verbal
276 children and children with single-words speech were more likely to being treated with diets
277 (30% increase in the probability of use), suggesting that parents of lower functioning children
278 may tend to look to a range of interventions to respond to more severe difficulties.
279 Additionally, over and above the effect of verbal ability, children using prescription
280 medication were also more likely to be treated with diets than children not using medication
281 (62% increase). Interestingly though, neither of these associations was found for use of
282 mind-body practices. This suggests that previous evidence of higher use of CAM in low
283 functioning children [32,14] might be specific to some CAM types. The association of use of
284 medication with use of diets but not mind-body practice might be due to the use of
285 supplements or alterations in the diet as an attempt to counter-balance potential side effects of
286 medications or to “boost” their efficacy [15]. Alternatively, the association could reflect
287 parental attitudes or beliefs (e.g., a generic belief in chemical/biological mechanisms) or the

288 willingness of the child to orally intake pills or tablets. Increased diet use in children
289 concurrently taking medications may also reflect an attempt to counteract the weight-gain
290 associated with many psychotropic medications, although we did not ask parents to report
291 *why* their child was on a diet, which should be done in future studies. In addition, we do not
292 have information on whether diets or supplements were medically prescribed as a treatment
293 for specific conditions (such as iron deficiency).

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

303 When the correlation of CAM use and use of conventional treatments has been
304 explored, it appears that availability and use of conventional treatments does not lessen use of
305 CAM. Indeed, CAM use has been found to be associated with receiving 20 or more hours
306 per week of conventional treatment [1]. Here, we explored the association between use of
307 conventional treatments and use of two specific classes of CAM. There was no association
308 between use of conventional treatment and use of diets: the use of such approaches might in
309 fact be more related to the use of medications, as suggested above. We found instead a large
310 dose-response effect of use of conventional treatments on use of mind-body practices with a
311 four-fold increase in the likelihood of concurrent CAM use for parents reporting already

312 using more than four conventional treatments for their child, but not for medium levels of
313 treatment (up to three interventions).

314 This finding suggests that use of mind-body practices is most strongly related with a
315 tendency to try a wide number of approaches; this might indicate that some parents, over and
316 above the effect of their child's level of functioning (measured as verbal ability) and of their
317 own educational level (which can be constructed as a proxy of their SES), tend to look for as
318 many therapies as possible, whether these be conventional treatments or CAM approaches.
319 Use of diets appeared to be most strongly associated with lower functioning of the child and
320 concurrent use of prescription medication.

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

329 *Strengths and limitations*

330 There are a number of strengths to the present study, including the large sample size
331 and the wide scope of the survey, which enquired about the use of a range of both CAM
332 approaches and conventional treatments for young children with autism in Europe.
333 Moreover, while previous research has looked at predictive factors for use of CAM
334 considering child and parent characteristics as individual factors or only adjusting for parental
335 education level, in our study we used multiple logistic regression to estimate the contribution

336 of each predictor having taken into account the influence of the other factors. These findings
337 can help to identify families potentially more likely to adopt CAM approaches, and this
338 information may be beneficial both to primary care providers in their role as clinical advisors,
339 and to researchers, for example when designing trials of CAM approaches.

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

353 The factors examined in the present study are only some of the many that might affect
354 the decision-making process underlying the choice of using CAM alongside (or alternative
355 to) conventional healthcare, which is still largely unexplained. For example, there is
356 preliminary evidence from a small sample of French parents (N=89) that personality
357 characteristics such as personal control and attribution of cause of autism affect the decision
358 to use CAM or not [2]. Parents' own use of CAM is likely to be a relevant factor but has
359 never been examined in the association with use of CAM in children. Further research on the
360 topic should include these and other factors, such as beliefs on ASD aetiology, to better

361 understand the phenomenon of use of CAM for children with autism. Finally, reliance on
362 parent report in absence of direct assessments places a limitation on these findings in relation
363 to severity of child symptoms and behavioural characteristics.

364 *Conclusions*

365 This was the first study to report on factors associated with use of CAM in a large
366 sample of young children with autism in Europe. While little is known on the efficacy (and
367 conversely, on the potential harm) of CAM approaches, a vast amount of uncontrolled
368 information is available on-line, putting parents at risk of embarking in sometimes costly and
369 often non-efficacious treatments. Rates of CAM use, including use of disproven or unsafe
370 approaches, were particularly high in Eastern Europe. The present study contributed to the
371 understanding of the factors associated to use of CAM and provided some evidence that
372 families that tend to use a wide range of conventional treatments might also be more likely to
373 be trying some CAM approaches. The reasons behind this are not fully understood, and may
374 reflect factors that were not captured by the present study. Nonetheless these findings, taken
375 together with the evidence of socio-economic barriers in access to treatment for autism
376 [22,33, in press], provide some insight into the lengths to which families may go in pursuit of
377 ways to help their child progress. The findings highlight the need to further advance research
378 funding and policy development for evidence-based early interventions for children with
379 ASD across Europe.

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