

Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

Research in Autism Spectrum Disorders

journal homepage: www.elsevier.com/locate/rasd

Alternative treatments for autism: Prevalence and predictors

Kim M. Jonkman^{a,*}, Elisa Back^b, Wouter G. Staal^{c,d}, Lotte Benard^a, Daniël M. van der Doelen^e, Sander Begeer^a

^a Department of Clinical, Neuro and Developmental Psychology, Vrije Universiteit Amsterdam, Amsterdam Public Health Research Institute, the Netherlands

^b Department of Psychology, Kingston University London, UK

^c Faculty of Social Sciences, Leiden University, the Netherlands

^d Department of Psychiatry, Radboud University Medical Centre, Nijmegen, the Netherlands

^e Karakter Child and Adolescent Psychiatry, University Centre, Nijmegen, the Netherlands

ARTICLE INFO

Keywords:

Autism spectrum disorder
Complementary and alternative medicine
Complementary health approaches

ABSTRACT

Autism is a heterogeneous neurodevelopmental disorder for which a large variety of treatments are offered, including alternative treatments. Vaccine-related treatments (treatments falsely claiming to cure autism by addressing its alleged cause: routine childhood vaccines such as MMR) continue to be offered worldwide, despite widespread evidence against the effectiveness and even possible harm related to these treatments. We analysed the use of alternative treatments in two studies: a survey study (N = 1989, autistic adults and parents/legal representatives of individuals with autism) and a clinical care study (N = 4520, patient files from a treatment center for autism). Both studies found a relatively high frequency of alternative treatments (23.0–30.7%) – in children even 46.4% –, mostly in combination with mainstream treatment. In the survey study vaccine-related treatments were used by 3.2% of all individuals with autism (and 6.7% of autistic children), and alternative treatment use was predicted by co-occurring diagnoses, younger age of diagnosis and mainstream treatment use. In the clinical care study, patients who had received treatment from a homeo-/osteopath more often had highly educated parents from Dutch/Western background and were more often enrolled in special education. Alternative treatments are widely used and should be included in treatment guidelines. Parents, practitioners and individuals with autism should be both advised and warned about the benefits and risks of these treatments. More research is needed to better understand the choice for and effect of alternative treatments for autism, and mainstream care should be improved.

1. Introduction

Alternative treatments for autism: prevalence and predictors.

Autism Spectrum Disorder (ASD, autism from hereon) is a heterogeneous neurodevelopmental disorder that occurs in around 1% of the population and often co-occurs with other disorders or difficulties ([American Psychiatric Association, 2013](#); [Lord et al., 2020](#)). Many alternative treatments - this term is used to describe treatments that fall outside of conventional mainstream care - are offered for autism. Some of them claim to cure autism by addressing its alleged cause: vaccines and other toxic substances. Despite abundant

* Correspondence to: Department of Clinical, Neuro and Developmental Psychology, Vrije Universiteit Amsterdam, the Netherlands.
E-mail address: k.m.jonkman@student.vu.nl (K.M. Jonkman).

<https://doi.org/10.1016/j.rasd.2022.102046>

Received 14 March 2022; Received in revised form 30 August 2022; Accepted 8 September 2022

Available online 16 September 2022

1750-9467/© 2022 The Author(s). Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

evidence for the contrary, autism is still falsely linked to routine childhood vaccinations such as the MMR-vaccine. Many alternative treatments for autism are offered worldwide, some of which spread misinformation about vaccinations and the possibility of curing autism. In this study we analysed the use of alternative and vaccine-related treatments among autistic individuals.

Autism is the result of both genetic and environmental factors (Lord et al., 2020). There is no cure for autism (nor is this a desired objective according to many (Bagatell, 2010; Barnes & McCabe, 2012)), but autistic individuals can greatly benefit from appropriate treatment and support. Most treatments focus on reducing and learning to deal with the core autism symptoms and alleviating additional problems (Fuentes et al., 2020). In young children, treatments aim to stimulate social initiative and communication. In older children and adults, treatment mostly focusses on specific problems, social skills, regulating behaviour or dealing with sensory stimuli. Medication can be used to treat co-occurring problems like aggression and irritability (Mayes et al., 2020). Conventional treatments for autism are described in several guidelines (see the Dutch Youth Institute (Nederlands Jeugd Instituut NJI, 2017), the Dutch mental health care quality standards (GGZ Standaarden, 2020), the European society of child and adolescent psychiatry (ESCAP; Fuentes et al., 2020), the British National Institute for Health and Care Excellence (National Institute for Health and Care Excellence (NICE), 2013) and the Centers for Disease Control and Prevention (Centers for Disease Control and Prevention (CDC), 2019); also see Jonkman et al., 2022), their advice is based on scientific evidence, general practice and the theoretical framework underlying the treatment approach.

In addition to these conventional treatments, many unconventional treatments for autism are offered outside of mainstream care. These are sometimes referred to as complementary and alternative medicine or complementary health approaches. We will refer to these as alternative treatments. These alternative treatments may vary from dietary and supplement-based treatments (Trudeau et al., 2019) to cranial-sacral therapy and neurofeedback (Patten et al., 2013) or homeopathic remedies. Some of these alternative treatments for autism are described in the guidelines as treatments that should *not* be used because they have shown to be harmful (e.g., holding therapy or facilitated communication; NJI, 2017) or because there is no evidence for their effectiveness (e.g., diets and neurofeedback; Fuentes et al., 2020). Many others are not mentioned in the treatment guidelines but are, in practice, offered by alternative and homeopathic practitioners to help with autism and related symptoms, sometimes even incorrectly suggesting that they can cure autism.

Autistic individuals use alternative treatments relatively often (Höfer et al., 2017), which is understandable as alternative treatments are often used for chronic or non-treatable conditions (Höfer et al., 2017). The extent to which alternative treatments could be harmful may vary, from innocent diets and vitamin supplements or massages, to dangerous treatments like holding therapy (Mercer, 2014). One particularly disputable element of some alternative treatments involves the idea that autism is caused by vaccinations and other toxic substances. The myth that autism is caused by routine childhood vaccinations (such as the MMR-vaccine) has been around since the 1990 s (Larson et al., 2011) and is still circulating, especially on social media (Jang et al., 2019), even though countless studies have shown that there is no link between autism and vaccinations (Taylor et al., 2014). This myth spreads misinformation and increases vaccine hesitancy (Bonnievie et al., 2021) and was recently linked with COVID-19 vaccines (Pullan & Dey, 2021).

The vaccination myth has also been used as a theoretical foundation for treatments, such as CEASE-therapy. CEASE stands for Complete Elimination of Autism Spectrum Expression, (<http://www.cease-therapy.com/cease-therapy/>). CEASE practitioners claim that the treatment can (partially) cure autism through the use of isotherapy (a homeopathic method that uses a dilution of the toxic substance, in this case a vaccine, to erase its effects on the body). CEASE practitioners often combine isotherapy with supplements, diets or homeopathic remedies. Other names for similar treatments include homeopathic detox therapy, isopathy and homeopathic prophylaxis. We will refer to these treatments as ‘vaccine-related treatments’.

Individuals with autism and important stakeholders in the Netherlands have recently drawn attention to the topic of alternative treatments for autism and the need for more research (KRO-NCRV, 2020). Given the relatively high frequency of alternative treatments in autistic children and adolescents (Höfer et al., 2017), it is important to investigate what treatments are being used and by whom. Several studies have shown that alternative treatments are used more in children with a higher (parental) education level (Höfer et al., 2017; Keene et al., 2019; Wang et al., 2018), parents who use these treatments themselves (Doering et al., 2013; Singendonk et al., 2013), children with co-occurring medical condition (Wang et al., 2018) and by females (Keene et al., 2019; Singendonk et al., 2013; Wang et al., 2018). The role of age and ethnicity is unclear (Höfer et al., 2017).

We investigated (1) the frequency and types of alternative and vaccine-related treatments, and (2) differences in demographic characteristics and use of mainstream treatment (age, sex, parental level of education, ethnicity, comorbidity, intellectual disability, attending special education, age of diagnosis and number of mainstream treatments used) between individuals who do and do not use alternative and vaccine-related treatments. We expect individuals who use alternative treatments to more often have highly educated parents, to more often have a comorbid diagnosis and to more often be female. To answer these questions, we carried out two separate studies. The first study uses national survey data and the second study includes data from participants in a regional clinical care setting.

2. Study 1

2.1. Methods

2.1.1. Participants

Participants included individuals who took part in our survey ($n = 1989$, mean age = 36.54% and 46.1% males). Participants were invited to complete the questionnaire through the newsletter from the Dutch Association of Autism (NVA) and through the yearly questionnaire of the Netherlands Autism Register (NAR), a free, online longitudinal database including demographic information, family and living situation, treatment use and standardised questionnaires. Participation was voluntary but participants were required

to have an autism diagnosis based on the DSM-IV-TR or DSM-5. People were allowed to participate in the questionnaire if they: 1) were an adult (16+) with autism, 2) were a parent of a child younger than 16 years old with autism or 3) were the legal representative of an adult with autism. In total 2290 individuals (from both the NAR and the NVA, see Fig. 1) responded to the questionnaire. After incomplete questionnaires and individuals without an official diagnosis were filtered out, 1989 participants were included (see Fig. 1). The individuals who were excluded because their questionnaire was incomplete, did not differ significantly in demographic characteristics from the included participants. The majority of the participants were adults with autism. Table 1 shows the demographic information of the participants.

2.1.2. Materials

Treatment use and demographic information was obtained using an online questionnaire. The questionnaire included questions about the role of the person who completed the questionnaire (a person with autism, a parent of a child with autism or a legal representative of someone with autism), age (in years and months), sex, maternal and paternal level of education (categorized as high, middle and low based on Dutch guidelines (Centraal Bureau voor de Statistiek CBS, 2020)), ethnicity ("which ethnic group do you consider yourself to be part of?"), comorbidity (participants could choose from 22 options of common co-occurring diagnoses like ADHD, epilepsy and anxiety disorders), intellectual disability (IQ lower than 70) and age of diagnosis (in years and months). Furthermore, participants were asked about their treatment use including mainstream treatments (e.g. pivotal response treatment, physiotherapy or psycho-education), mainstream medication (e.g. risperidone, aripiprazole or methylphenidate), and alternative treatments and how long ago these were used. Alternative treatments included among others food or diet-based treatments, treatments with (homeopathic) remedies, treatment aimed at stimulating the brain, treatments focused on energy and the subconscious and treatments with animals (see Appendix A for all treatments included in the questionnaire). These treatments were included based on previous input from participants and other representative stakeholders about (alternative) treatments that are on offer for or used by individuals with autism. All variables are self-reported, reported by parents of children under 16 or legal representatives of someone with autism. The questionnaire was developed in co-creation with representative stakeholders (autistic adults, parents and legal representatives of children or adults with autism). The questionnaire was also piloted and tested by a panel of stakeholders and could be completed in 30 minutes.

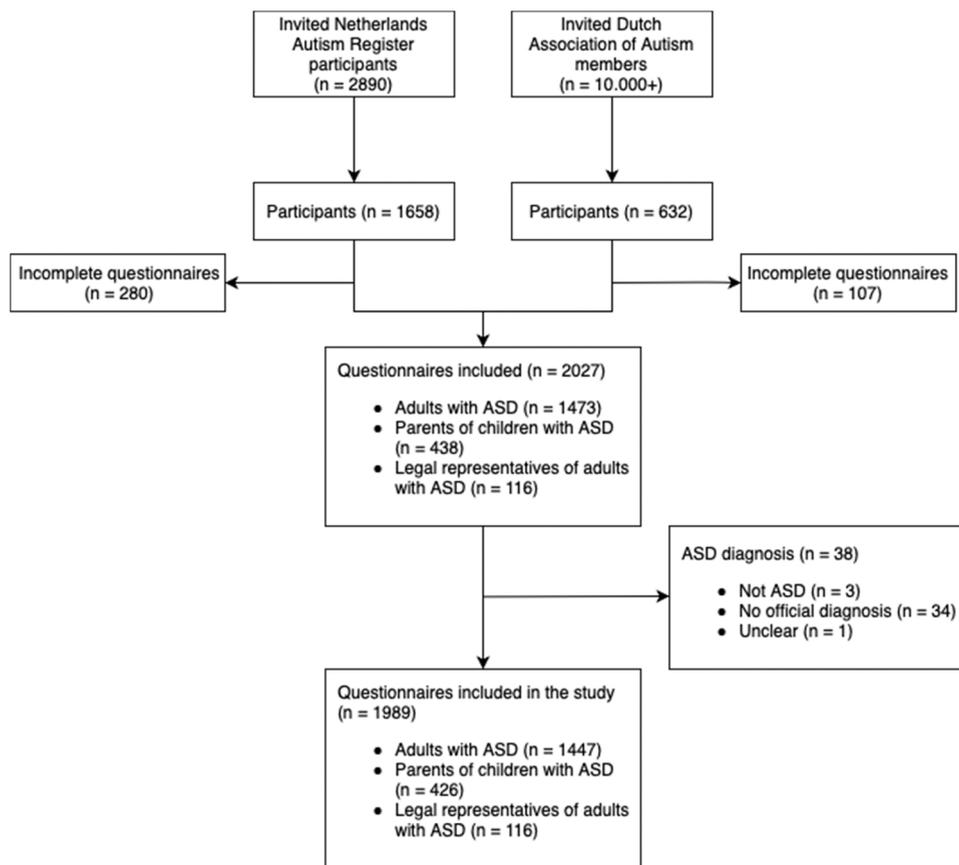


Fig. 1. Flowchart of participants in Study 1.

Table 1
Demographic information from the participants in Study 1.

Variables	
Age	
Mean (SD)	36.54 (18.37)
Range	4.00–84.00
Role of the participant	
Self-report	72.8%
Reported by parent	21.4%
Reported by legal representative	5.8%
Sex	
Male	46.1%
Female	53.9%
Intellectual disability	
IQ < 70	8.5%
Parental education level	
Low	38.8% (M) 31.0% (P)
Middle	26.1% (M) 25.7% (P)
High	35.1% (M) 43.3% (P)
Ethnicity	
Dutch	93.1%
Age of diagnosis	
Mean (SD)	29.02 (18.49)
Comorbidity present	
At least one other diagnosis	50.9%

Note. M = maternal level of education, P = paternal level of education

2.1.3. Procedure

The questionnaire was distributed to all participants of the Netherlands Autism Register (NAR; <https://www.nederlandsautismeregister.nl/english/>) through email and on the website. A separate public questionnaire was made for individuals with autism who were not participants of the NAR. This questionnaire was distributed through the email-newsletter of the Dutch Association of Autism (NVA; www.autisme.nl) and all their social media channels.

2.1.4. Statistical analyses

Participants who reported using CEASE therapy, (homeopathic) detox therapy, isotherapy, or homeopathic prophylaxis or a vaccine detox treatment were put in the vaccine-related treatment group. All 'other' alternative treatments that were filled in were manually checked and, if they clearly described one of the answer options already included in the questionnaire, moved to the corresponding answer option. A binary logistic regression was used to predict the use of alternative treatments using the predictors age, sex, maternal level of education, paternal level of education, ethnicity (dichotomous Dutch or non-Dutch), comorbidity (dichotomous comorbidity present or not), intellectual disability (dichotomous), age of diagnosis and number of mainstream treatments used. Within the group that used alternative treatments, the use of vaccine-related treatment was predicted using a binary logistic regression with the same predictors.

2.1.5. Ethical considerations

This study was approved by the Standing Committee of Science and Ethics (VCWE) of the Vrije Universiteit Amsterdam (VCWE-2020–041R1, amendment 2021: VCWE-2021–018R1).

2.2. Results

Out of all the participants, 30.7% reported using alternative treatments, it was even more common amongst autistic children, with almost half of the children (46.4%) using alternative treatments. Vaccine-related treatments were used by 3.2%, amongst children this

Table 2
Prevalence of the use of different types of treatments in Study 1.

	Full sample (n = 1989)	Children (<18 y.o.) (n = 450)
Alternative treatment	30.7%	46.4%
Vaccine-related	3.2%	6.7%
Exclusively alternative treatments	2.8%	4.4%
Mainstream treatments	88.1%	86.7%
Mainstream interventions	75.0%	72.2%
Mainstream medication	65.0%	62.4%
Exclusively mainstream treatments	60.1%	44.6%
Combination mainstream and alternative treatments	27.9%	42.0%
No treatments	9.2%	8.9%

was 6.7%. Vaccine-related treatments were used in the past 5 (42.2%) or 10 years (65.6%), by individuals diagnosed between 1991 and 2020. There were no indications that the use of vaccine-related treatments decreased over time.

With respect to the participants using alternative treatments, 91% used them in combination with mainstream treatments (see Table 2). The most commonly used alternative treatments were sensory integration therapy (9.2%), therapy with horses (5.4%) and vitamin therapy or supplements (4.7%; Table 3). Individuals who had a co-occurring diagnosis were more likely to have used alternative treatments ($OR = 1.39$). Those who used alternative treatments were diagnosed at younger ages ($OR = .97$) and had used more mainstream treatments ($OR = 1.15$). Within the group of people who used alternative treatments there were no significant predictors for the use of vaccine-related treatments (Table 4). There was no indication of multicollinearity (for all predictors: $VIF < 10$).

2.3. Discussion

We found a high overall frequency of alternative treatments (30.7%). Alternative treatments were often used in combination with mainstream care. The use of alternative treatments was more common among autistic children (46.4%). Vaccine-related treatments were used by 3.2% of all participants, and by 6.7% of children. Co-occurring diagnoses, younger age of diagnosis and a higher number of mainstream interventions predicted alternative treatment use. No specific predictors for the use of vaccine-related treatments were found.

Our results indicate that individuals who use alternative treatments might have a higher burden; they are diagnosed younger, have co-occurring diagnoses and use more mainstream treatments. It could be suggested that mainstream treatments are not sufficient or effective enough for autistic individuals with more severe and additional problems. Interestingly, intellectual disability was not predictive of alternative treatment use. This could have been due to the number of predictors in our model. As IQ or intellectual disability are rarely mentioned in previous studies on the use of alternative treatments in autism (e.g. Akins et al., 2014; Höfer et al., 2017), more research is needed to determine whether intellectual disability is related to the use of alternative treatments.

Table 3
Prevalence of alternative treatments in Study 1.

Treatment	n	%
Sensory integration therapy	183	9.2
Hippotherapy / therapy with horses)	108	5.4
Vitamin therapy or supplements like multivitamines, minerals, L-carnosine, L-carnitine, omega 3 fatty acids, ascorbic acid, magnesium or zinc	93	4.7
Back flower remedies	87	4.4
Acupuncture or acupressure	79	4
A gluten free or casein-free diet	68	3.4
Another elimination diet or a diet that avoids certain food	66	3.3
Cranial osteopathy (or craniosacral therapy)	55	2.8
Neurofeedback or neurotherapy	53	2.7
Reiki treatment	52	2.6
*Homeopathic prophylaxis or a vaccine detox treatment	49	2.5
Therapy with a dog	42	2.1
Aura or chakra therapy	40	2
Regression or reincarnation therapy, or any other therapy based on hypnosis	23	1.2
Son-Rise program / Kaufman-method / Option-method	18	0.9
A treatment with other medicines, for example antibiotics or antihistamines	18	0.9
Qigongmassage	17	0.9
Facilitated communication / supported typing	13	0.7
Auditory integration therapy (AIT)	11	0.6
Electro-acupuncture or biophoton therapy	11	0.6
*CEASE therapy	10	0.5
* (Homeopathic) detox-therapy (HDT)	9	0.5
SensiTherapy	8	0.4
Brain Stimulating Method (BSM)	7	0.4
Therapy with another animal (not horse, dog or dolphin)	7	0.4
Neuro-emotional integration (NEI)	5	0.3
Dolphin therapy	5	0.3
Holding therapy	4	0.2
Another treatment based on the administration of hormones (secretin), immunoglobulins or chelators	4	0.2
MMS therapy (Mineral Miracle Supplement)	4	0.2
*Isopathy therapy / isotherapy	3	0.2
Packing (cold, wet compresses)	3	0.2
Tomatis listening therapy	3	0.2
Doman-Delcato technique (psychomotor patterning)	2	0.1
Jin Shin Jyutsu	2	0.1
Hyperbaric oxygen therapy (HBOT)	1	0.1
Van Soest therapy (hierarchy of the senses)	1	0.1
Other A	67	3.4
Other B	17	0.9
Other C	7	0.4

Notes. *a vaccine-related treatments

Table 4
Binary logistic regressions to predict use of alternative and vaccine-related treatment in Study 1.

Predictor	Alternative					Vaccine-related				
	B	SE	Wald	P	OR	B	SE	Wald	p	OR
Age	0.01	0.01	0.46	0.498	1.01	0.01	0.02	0.33	0.569	1.01
Sex	0.12	0.14	0.82	0.366	1.13	0.36	0.39	0.84	0.359	1.43
Maternal education	0.01	0.10	0.2	0.901	1.01	0.11	0.27	0.16	0.690	1.11
Paternal education	0.05	0.09	0.28	0.595	1.05	0.212	0.246	0.743	0.389	1.24
Ethnicity	-0.04	0.29	0.02	0.888	0.96	-0.54	0.68	0.63	0.429	0.59
Co-occurring diagnosis	0.33	0.13	6.16	0.013	1.39*	0.16	0.35	0.21	0.650	1.17
Intellectual disability	0.49	0.26	3.63	0.057	1.63	-0.33	0.53	0.39	0.533	0.26
Age of diagnosis	-0.03	0.01	10.84	0.001	.97**	-0.04	0.03	2.19	0.139	0.96
Number of mainstream treatments	0.14	0.03	23.09	0.000	1.15**	-0.07	0.07	0.82	0.367	0.94
Chi-square	125.23**					11.59				

Note. *p < 0.05 * *p < 0.01.

Even though there is no link between vaccines and autism, our results show that vaccine-related treatments are still used by autistic individuals. In addition to the lack of scientific evidence, claims made by these practitioners also affect the public confidence in vaccinations including the COVID-19 vaccine (Bonnievie et al., 2021; Pullan & Dey, 2021). Treatments like this often promise to cure autism, something that is not only impossible according to science so far (Lord et al., 2021) but also unwanted according to a growing group of individuals with autism and researchers (Bagatell, 2010; Barnes & McCabe, 2012). Given that vaccine-related treatments are still used by autistic individuals despite the negative effects they can have, a warning in the treatment guidelines for autism would be appropriate.

Despite insufficient evidence (CDC, 2019; Fuentes et al., 2020; NICE, 2013; NJI, 2017) sensory integration therapy was the most used alternative treatment, confirming other finding on the popularity of this therapy, which ranges from 18% to 53% (Höfer et al., 2017). Sensory integration is not always considered as an alternative treatment, one study even claims that a sensory integration intervention meets all the requirements for an evidence-based practice (Schoen et al., 2019). In any case, there seems to be a discrepancy between the advice from the guidelines and the actual use of this treatment.

Furthermore, survey participants are likely to have high motivation and engagement, these individuals might also be more interested in exploring autism treatment options, which could have led to an overestimation of alternative treatment use (Höfer et al., 2017).

3. Study 2

Autism studies that sample through online (social media) channels are at risk of sampling bias, including reversed sex ratio (more women than men), higher education levels, less participants with an intellectual disability and a later age of diagnosis compared to samples from a population study (Rødgaard et al., 2022). Some of these biases can be seen in the sample from Study 1. While the NAR recruitment methods are broader than social media, we conducted a second study using a sample from clinical care to investigate (1) the frequency of alternative treatment use within mainstream care and (2) the differences in demographic characteristics (age, sex, parental level of education, ethnicity, comorbidity, intellectual disability, attending special education and age of diagnosis) between

Table 5
Demographic information from the participants in Study 2.

Variables	
Age	
Mean (SD)	13.65 (5.14)
Range	2.32–71.44
Sex	
Male	70.6%
Female	29.4%
Intellectual disability	
IQ < 70	9.0%
Parental education level	
Low	20.0% (M) 15.7% (P)
Middle	43.9% (M) 42.2% (P)
High	32.9% (M) 33.3% (P)
Ethnicity	
Dutch	82.8%
Age of diagnosis	
Mean (SD)	2.33 (1.30)
Comorbidity present	
At least one other diagnosis	33.1%

Note. M = maternal level of education, P = paternal level of education.

individuals who do and do not use alternative treatments.

3.1. Methods

3.1.1. Participants

Participants were recruited through a treatment centre ($n = 4520$, mean age = 13.65% and 70.6% males). This included 4520 patient files from a treatment centre for child and youth psychiatry with several locations in The Netherlands. Patient files were included if the patient was registered at the treatment centre between 2017 and 28th of May 2021 and had an official diagnosis of autism based on the DSM. All included patients received outpatient care. Children up to the age of 18 can be registered at the treatment centre, but it is possible that treatment continues until the patient is in their twenties. Table 5 shows the demographic information of the participants.

3.1.2. Materials

Data about the use of alternative treatments given by a homeopath or osteopath was available within the patient files from the treatment centre. This was based on a questionnaire that was completed by (parents of) patients upon registration at the treatment centre. The question that was used to determine the use of these alternative treatments was "Have you used any of these health care providers?". Individuals who had received treatment from an "osteopath" or "homeopath" (two of the answer options, other options included psychologist, dietician or speech therapist, among others) were considered to have used alternative treatments. Demographic variables that were available within the patient files to predict treatment use were: age (in years and months), sex, maternal and paternal level of education (categorized as high, middle and low based on Dutch guidelines (Centraal Bureau voor de Statistiek [CBS], 2020), ethnicity (non-Dutch if at least one parent was born in another country), comorbidity, patient's education (special or mainstream education), intellectual disability (IQ lower than 70) and age of diagnosis (in years and months).

3.1.3. Procedure

The gathering and analyses of the patient files was carried out by the internal data manager from the treatment centre who used the data that was available in the database to carry out the specified analyses.

3.1.4. Statistical analyses

A binary logistic regression was used to predict the use of alternative treatments (from a homeopath or osteopath) using the predictors age, sex, maternal level of education, paternal level of education, ethnicity, comorbidity, patient's education (dichotomous special or mainstream education), intellectual disability and age of diagnosis.

3.1.5. Ethical considerations

This study was approved by the internal review committee and Board of Directors of Karakter, and by the Standing Committee of Science and Ethics (VCWE) of the Vrije Universiteit Amsterdam (VCWE-2020-041R1, amendment 2021: VCWE-2021-018R1).

3.2. Results

Within the current sample, 23.0% of the patients reported having used alternative treatments from a homeopath or osteopath. Higher paternal education increased the chance of someone using alternative treatments ($OR = 1.23$). Individuals who used alternative treatments also more often attended special education ($OR = 1.42$) or were Dutch ($OR = 2.65$). Table 6 shows the results of the binary logistic regression. Post hoc analyses on ethnicity revealed that the group that was least likely to use alternative treatment were those with non-Western mothers ($OR = .24$, $p = .022$).

Table 6
Binary logistic regressions to predict use of alternative treatment in Study 2.

	B	SE	Wald	p	OR
Age	-0.01	0.01	0.76	0.385	0.99
Sex	-0.12	0.14	0.41	0.411	0.89
Maternal education	0.03	0.09	0.14	0.714	1.03
Paternal education	0.21	0.10	4.65	0.031	1.23*
Ethnicity	0.97	0.28	12.57	0.000	2.65**
Co-occurring diagnosis	-0.06	0.16	0.13	0.721	0.95
Intellectual disability	-0.00	0.22	0.00	0.987	1.00
Age of diagnosis	0.01	0.05	0.01	0.905	1.01
Special education	0.35	0.13	6.94	0.008	1.42**
Chi-square	28.513 * *				

Note. * $p < 0.05$ ** $p < 0.01$.

3.3. Discussion

About a quarter of the patients in clinical care reported having used alternative treatments. We found that individuals in mainstream care who chose treatments from homeopaths and osteopaths were more often Dutch/Western, highly educated and attended special education.

Children in special education most likely have more co-occurring problems and lower IQ, and thus might need additional care. Perhaps parents with a migration background are less likely to seek alternative treatments when already receiving mainstream care. On the other hand, Dutch parents might be more familiar with the mainstream care system and might be more confident to seek additional treatments. Results from previous studies varied (Höfer et al., 2017), but given the high odds ratio of ethnicity in the current study, it is likely that ethnicity influenced alternative treatment use, though more research is needed to understand how and why. Higher parental education predicted alternative treatments use in previous studies (Höfer et al., 2017; Keene et al., 2019; Wang et al., 2018), which we confirmed in this study. It seems that individuals with a higher socioeconomic status (Dutch/Western and highly educated) tend to more often use alternative treatments when also receiving mainstream care.

While the recruitment method of this study has eliminated the biases of online sampling (reversed sex ratio, fewer participants with intellectual impairment, later age of diagnosis), patients in clinical care tend to have their own bias towards more (severe) or different problems which could affect the use of alternative treatments (Levy et al., 2003). Recruitment procedures did not allow administering the survey from Study 1 in the current sample. It was assumed that treatments provided by an osteopath or homeopath were alternative. Both osteopathy and homeopathy are not considered as mainstream care in the Netherlands. However, specific details about the treatments received were not available in this study. Both this study's recruitment method and the definition of alternative treatments could have affected the prevalence of alternative treatment found in this study (Höfer et al., 2017). Our results could therefore over- or underestimate alternative treatment use within mainstream care.

4. General discussion

Combining both studies, we found a persistent use of alternative treatments in autistic individuals, including disputed vaccine-related treatments. It is imperative that more information about alternative and vaccine-related treatments is made available in treatment guidelines. Parents, practitioners and individuals with autism should be both advised and warned about the risks of alternative treatments. Furthermore, alternative treatments are mostly used by autistic individuals with more severe and additional problems and often in combination with mainstream care (Study 1). Amongst patients in mainstream care, Dutch/Western and highly educated individuals more often used alternative treatments (Study 2). Combined, our results suggest that there is something lacking in mainstream care for individuals with autism. More research should be carried out to determine why people turn to alternative treatments, and mainstream care should be improved to ensure that autistic individuals, and especially those with additional problems, receive all the support and care they need.

The definition of 'alternative treatments' is prone to discussion (Höfer et al., 2017). We have categorised treatments based on the autism guidelines from the Netherlands, UK, Europe and the USA (CDC, 2019; Fuentes et al., 2020; GGZ Standaarden, 2020; NICE, 2013; NJI 2017). However, as can be seen with sensory integration therapy, some might consider the treatments that we labelled as alternative to be mainstream. This raises the question whether treatments are no longer considered to be 'alternative' when more evidence becomes available for their effectiveness. For example, therapy with animals including horse therapy is usually considered to be alternative. However, recently a study found that a horse-riding intervention had an effect on autistic children's social functioning (Harris & Williams, 2017). This is why we suggest to specifically define alternative treatments as unconventional treatments that are not recommended in the current guidelines.

Findings from the current studies could be limited to the Dutch cultural setting as all participants live in the Netherlands. Different approaches to the diagnosis and treatment of autism in different countries could affect the rate of alternative treatment use. Future research on (alternative) treatments will benefit from international perspectives, comparing samples from different and more non-Western countries. Additionally, further research should focus on why individuals with autism or their parents decide to use alternative treatments and what effect the treatments have.

CRedit authorship contribution statement

Kim M. Jonkman: Conceptualization, Methodology, Formal analysis, Writing – original draft, Writing – review & editing, Visualization, Supervision, Project administration. **Elisa Back:** Conceptualization, Methodology, Writing – review & editing, Funding acquisition. **Wouter G. Staal:** Conceptualization, Resources, Writing – review & editing. **Lotte Benard:** Methodology, Software, Data curation, Investigation, Visualization. **Daniël M. van der Doelen:** Data curation, Formal analysis, Investigation, Writing – review & editing. **Sander Begeer:** Conceptualization, Methodology, Validation, Writing – review & editing, Supervision, Project administration, Funding acquisition.

Acknowledgements

The current studies were the result of a school project by Elijah Delsink, a 17-year-old autistic person, who relentlessly fights to reduce misinformation and increase inclusivity for autistic individuals. Results from these studies have partially been published in Jonkman et al. (2021). This study was funded by a ZonMW Research grant (The Netherlands) [63634000], by the Senior Research

Advancement Fund/Research Development Allowance, School of Law, Social and Behavioural Sciences, Faculty of Business and Social Sciences, Kingston University(United Kingdom) and by funding from the Dutch Ministry of Health, Welfare and Sport (VWS) 16–4067-26061. We have no known conflict of interest to disclose.

Appendix A. Study 1 treatment answer options in the questionnaire

Mainstream treatments:

- Clinical daycare or outpatient day clinics
- Conversation groups
- Creative therapy or music therapy
- Early intensive interventions (e.g., early intensive behaviour interventions, applied behaviour analysis, pivotal response treatment, discrete trial teaching, psychiatric intensive treatment)
- Family therapy (e.g., multi system therapy, functional family therapy)
- Hometraining or other coaching/guiding treatments in the home situation (e.g., intensive orthopedagogical family treatment, practical pedagogical family treatment, video interaction guidance, parent-child interaction therapy, Floortime)
- Individual conversations with a psychologist or psychiatrist (e.g., psychotherapy, CBT, EMDR)
- Mindfulness
- Parent training or guidance
- Physiotherapy or other motor therapies (e.g., occupational therapy, psychomotor therapy, sensory integration therapy)
- Play therapy
- Psycho-education for the parents, siblings or environment
- Psycho-education for the person with autism
- Social skills training and resilience treatment (e.g., theory of mind training, aggression regulation)
- Speech therapy

Medication:

- Abilify/aripiprazol(e)
- Amitriptyline
- Ativan/orfidal/lorazepam
- Avanza/axit/mirtaz/mirtazon/remeron/zispin/mirtazapine
- Cipramil/citalopram
- Concerta/methylfenidaat (methylphenidate)
- Depakine (valproic acid)
- Dexamfetamine (dextroamphetamine)
- Dipiperon/pipamperon(e)
- Dixarit/clonidine
- Fevarin/fluvoxamine
- Haloperidol/Haldol
- Lexapro/cipralext/escitalopram
- Medikinet/equasym/methylfenidaat (methylphenidate)
- Orap/pimozide
- Propranolol
- Prozac/fluoxetine
- Restoril/normison/temazepam
- Risperdal/risperidon(e)
- Ritalin/methylfenidaat (methylphenidate)
- Rivotril/clonazepam
- Seresta/oxazepam
- Seroquel/quetiapine
- Seroxat/paroxetine
- Strattera/atomoxetine
- Valium/diazepam
- Venlafaxine
- Wellbutrin (bupropion)
- Zoloft/sertraline
- Zyprexa/olanzapine

Alternative treatments:

- (Homeopathic) detox-therapy (HDT)
- A gluten free or casein-free diet
- A treatment with other medicines, for example antibiotics or antihistamines
- Acupuncture or acupressure
- Another elimination diet or a diet that avoids certain food
- Another treatment based on the administration of hormones (secretin), immunoglobulins or chelators
- Auditory integration therapy (AIT)
- Aura or chakra therapy
- Back flower remedies
- Brain Stimulating Method (BSM)
- CEASE therapy
- Cranial osteopathy (or craniosacral therapy)
- Dolphin therapy
- Doman-Delcato technique (psychomotor patterning)
- Electro-acupuncture or biophoton therapy
- Facilitated communication / supported typing
- Hippotherapy / therapy with horses)
- Holding therapy
- Homeopathic prophylaxis or a vaccine detox treatment
- Hyperbaric oxygen therapy (HBOT)
- Isopathy therapy / isotherapy
- Jin Shin Jyutsu
- MMS therapy (Mineral Miracle Supplement)
- Neuro-emotional integration (NEI)
- Neurofeedback or neurotherapy
- Packing (cold, wet compresses)
- Qigongmassage
- Regression or reincarnation therapy, or any other therapy based on hypnosis
- Reiki treatment
- SensiTherapy
- Sensory integration therapy
- Son-Rise program / Kaufman-method / Option-method
- Therapy with a dog
- Therapy with another animal (not horse, dog or dolphin)
- Tomatis listening therapy
- Van Soest therapy (hierarchy of the senses)
- Vitamin therapy or supplements like multivitamines, minerals, L-carnosine, L-carnitine, omega 3 fatty acids, ascorbic acid, magnesium or zinc
- Other...
- Other...
- Other...

References

- Akins, C. R. S., Krakowiak, P., Angkustsiri, K., Hertz-Picciotto, I., & Hansen, R. L. (2014). Utilization patterns of conventional and complementary/alternative treatments in children with autism spectrum disorders and developmental disabilities in a population-based study. *Journal of Developmental and Behavioral Pediatrics*, 35(1), 1–10. <https://doi.org/10.1097/DBP.0000000000000013>
- American Psychiatric Association, 2013, Diagnostic and statistical manual of mental disorders (5th ed.). <https://doi.org/10.1176/appi.books.9780890425596>.
- Bagatell, N. (2010). From cure to community: Transforming notions of autism. *Ethos*, 38(1), 33–55. <https://doi.org/10.1111/j.1548-1352.2009.01080.x>
- Barnes, R. E., & McCabe, H. (2012). Should we welcome a cure for autism? A survey of the arguments. *Medicine, Health Care and Philosophy*, 15(3), 255–269. <https://doi-org.vu-nl.idm.oclc.org/10.1007/s11019-011-9339-7>.
- Bonnevie, E., Gallegos-Jeffrey, A., Goldbarb, J., Byrd, B., & Smyser, J. (2021). Quantifying the rise of vaccine opposition on Twitter during the COVID-19 pandemic. *Journal of Communication in Healthcare*, 14(1), 12–19. <https://doi.org/10.1080/17538068.2020.1858222>
- Centers for Disease Control and Prevention (CDC), 2019, Treatment and intervention services for Autism Spectrum Disorder (<https://www.cdc.gov/ncbddd/autism/treatment.html>) Accessed 18 November 2020.
- Centraal Bureau voor de Statistiek (CBS), 2020, Standaard Onderwijsindeling 2016, (<https://www.cbs.nl/nl-nl/onze-diensten/methoden/classificaties/onderwijs-en-beroepen/standaard-onderwijsindeling-soi-/standaard-onderwijsindeling-2016>).
- Doering, J. H., Reuner, G., Kadish, N. E., Pietz, J., & Schubert-Bast, S. (2013). Pattern and predictors of complementary and alternative medicine (CAM) use among pediatric patients with epilepsy. *Epilepsy and Behavior*, 29(1), 41–46. <https://doi.org/10.1016/j.yebeh.2013.06.025>
- Fuentes, J., Hervás, A., & Howlin, P., 2020, ESCAP practice guidance for autism: a summary of evidence-based recommendations for diagnosis and treatment. *European Child and Adolescent Psychiatry*. <https://doi.org/10.1007/s00787-020-01587-4>.
- GGZ Standaarden, 2020, Zorgstandaard Autisme. (<https://www.ggzstandaarden.nl/zorgstandaarden/autisme>).

- Harris, A., & Williams, J. M. (2017). The impact of a horse riding intervention on the social functioning of children with autism spectrum disorder. *International Journal of Environmental Research and Public Health*, *14*(7), 776. <https://doi.org/10.3390/ijerph14070776>
- Höfer, J., Hoffmann, F., & Bachmann, C. (2017). Use of complementary and alternative medicine in children and adolescents with autism spectrum disorder: A systematic review. *Autism*, *21*(4), 387–402. <https://doi.org/10.1177/1362361316646559>
- Jang, S. M., McKeever, B. W., McKeever, R., & Kim, J. K. (2019). From social media to mainstream news: The information flow of the vaccine-autism controversy in the US, Canada, and the UK. *Health Communication*, *34*(1), 110–117. <https://doi.org/10.1080/10410236.2017.1384433>
- Jonkman, K. M., Back, E., & Begeer, S. (2022). Predicting intervention use in autistic children: demographic and autism-specific characteristics [Manuscript submitted for publication]. *Department of Clinical, Neuro and Developmental Psychology*. Vrije Universiteit Amsterdam, and Amsterdam Public Health Research Institute.
- Jonkman, K., Wevers, J., Benard, L., Staal, W., & Begeer, S., 2021, Alternatieve behandelingen en autisme. Omvang, ervaringen en kenmerken gebruikers. (<https://www.rijksoverheid.nl/documenten/rapporten/2021/06/30/nar-vws-alternatievebehandelingen-en-autisme>) Accessed 01 July 2021.
- Keene, M. R., Heslop, I. M., Sabesan, S. S., & Glass, B. D. (2019). Complementary and alternative medicine use in cancer: A systematic review. *Complementary Therapies in Clinical Practice*, *35*(January), 33–47. <https://doi.org/10.1016/j.ctcp.2019.01.004>
- KRO-NCRV, 2020, Februari 2, Scholier (16) met autisme kraakt antivax-beweging: 'Ze doen alsof autisme het nieuwe ebola is' [Student (16) with autism cracks antivax movement: 'They act as if autism is the new Ebola']. Pointer. (<https://pointer.kro-ncrv.nl/scholier-16-met-autisme-kraakt-antivax-beweging-ze-doen-alsof-autisme-het-nieuwe-ebola-is>).
- Larson, H. J., Cooper, L. Z., Eskola, J., Katz, S. L., & Ratzan, S. (2011). Addressing the vaccine confidence gap. *The Lancet*, *378*(9790), 526–535. [https://doi.org/10.1016/S0140-6736\(11\)60678-8](https://doi.org/10.1016/S0140-6736(11)60678-8)
- Levy, S. E., Mandell, D. S., Merhar, S., Ittenbach, R. F., & Pinto-Martin, J. A. (2003). Use of complementary and alternative medicine among children recently diagnosed with autistic spectrum disorder. *Journal of Developmental & Behavioral Pediatrics*, *24*(6), 418–423.
- Lord, C., Brugha, T. S., Charman, T., Cusack, J., Dumas, G., Frazier, T., Jones, E. J. H., Jones, R. M., Pickles, A., State, M. W., Taylor, J. L., & Veenstra-Van der Weele, J. (2020). Autism spectrum disorder. *Nature Reviews Disease Primers*, *6*(1). <https://doi.org/10.1038/s41572-019-0138-4>
- Lord, C., Charman, T., Havdahl, A., Carbone, P., Anagnostou, E., Boyd, B., Carr, T., de Vries, P. J., Dissanayake, C., Divan, G., Freitag, C. M., Gotelli, M. M., Kasari, C., Knapp, M., Mundy, P., Plank, A., Scahill, L., Servili, C., Shattuck, P., ... McCauley, J. B. (2021). The Lancet Commission on the future of care and clinical research in autism. *The Lancet*, *399*(10321), 271–334. [https://doi.org/10.1016/S0140-6736\(21\)01541-5](https://doi.org/10.1016/S0140-6736(21)01541-5)
- Mercer, J. (2014). International concerns about holding therapy. *Research on Social Work Practice*, *24*(2), 188–191. <https://doi.org/10.1177/1049731513497518>
- National Institute for Health and Care Excellence (NICE), 2013, Autism spectrum disorder in under 19s: support and management. (<https://www.nice.org.uk/guidance/cg170>) Accessed 18 November 2020.
- Nederlands Jeugd Instituut (NJI): Wat werkt bij ASS? K. van Rooijen en L. Rietveld (2017).
- Patten, E., Baranek, G. T., Watson, L. R., & Schultz, B. (2013). Child and family characteristics Influencing intervention choices in autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, *28*(3), 138–146. <https://doi.org/10.1177/1088357612468028>
- Pullan, S., & Dey, M. (2021). Vaccine hesitancy and anti-vaccination in the time of COVID-19: A Google Trends analysis. *Vaccine*, *39*(14), 1877–1881. <https://doi.org/10.1016/j.vaccine.2021.03.019>
- Rødgaard, E. M., Jensen, K., Miskowiak, K. W., & Mottron, L. (2022). Representativeness of autistic samples in studies recruiting through social media. *Autism Research*, *15*(8), 1447–1456. <https://doi.org/10.1002/aur.2777>
- Schoen, S. A., Lane, S. J., Mailloux, Z., May-Benson, T., Parham, L. D., Smith Roley, S., & Schaaf, R. C. (2019). A systematic review of ayres sensory integration intervention for children with autism. *Autism Research*, *12*(1), 6–19. <https://doi.org/10.1002/aur.2046>
- Singendonk, M., Kaspers, G. J., Naafs-Wilstra, M., Meeteren, A. S., Van, Loeffen, J., & Vlieger, A. (2013). High prevalence of complementary and alternative medicine use in the Dutch pediatric oncology population: A multicenter survey. *European Journal of Pediatrics*, *172*(1), 31–37. <https://doi.org/10.1007/s00431-012-1821-6>
- Taylor, L. E., Swerdfeger, A. L., & Eslick, G. D. (2014). Vaccines are not associated with autism: an evidence based meta-analysis of case-control and cohort studies. *Vaccine*, *32*(19), 3623–3629. <https://doi.org/10.1016/j.vaccine.2014.04.085>
- Trudeau, S. M., Madden, R. F., Parnell, J. A., Gibbard, W. B., & Shearer, J. (2019). Dietary and supplement based complementary and alternative medicine use in pediatric autism spectrum disorder. *Nutrients*, *11*(8), 1783. <https://doi.org/10.3390/nu11081783>
- Wang, C., Preisser, J., Chung, Y., & Li, K. (2018). Complementary and alternative medicine use among children with mental health issues: Results from the National Health Interview Survey. *BMC Complementary and Alternative Medicine*, *18*(1), 1–17. <https://doi.org/10.1186/s12906-018-2307-5>