

## Original Research Article

# Perceptions, attitudes and practices of physicians regarding use of complementary and alternative medicine in autism spectrum disorder

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### ABSTRACT

**Background:** Use of Complementary and Alternative Medicine (CAM) in children with Autism Spectrum Disorder (ASD) has been reported as highly prevalent in literature. Our objective was to assess the perceptions, attitudes and practices of Indian physicians regarding use of CAM in ASD.

**Methods:** An online survey was emailed to pediatricians, developmental pediatricians, pediatric neurologists and psychiatrists. We had 417 respondents, 78% being primary-care pediatricians. Descriptive analysis was conducted.

**Results:** Of 417 respondents, 75% physicians were unaware or minimally aware of the risks and benefits of CAM. 60% of pediatricians rarely or did not ask families about their use of CAM, and 57% felt that families too do not bring up CAM. 67% of pediatricians felt that less than 25% of their patients used CAM, though 50% regularly prescribed nutritional supplements to children with ASD. Pediatricians reported either not offering an opinion or referring to a specialist for questions about GFCF (83%), stem-cell transplant (69%), hyperbaric oxygen (71%) and ayurveda or homeopathic remedies (49%). Lack of ASD-specific intervention services, time, training and practice guidelines were perceived as barriers to care. 97% physicians desired autism training, while 81% also desired CAM training.

**Conclusions:** Most pediatricians perceive use of CAM in ASD to be lower than reported and do not discuss or opine on CAM modalities with families of children with ASD, possibly due to inadequate doctor-patient communication and limited awareness and knowledge about CAM in ASD, underscoring need for capacity building in this area.

**Keywords:** ASD, CAM, Integrative medicine, India, Pediatrician attitudes

### INTRODUCTION

Autism spectrum disorder (ASD) is the collective term for neurodevelopmental disorders characterized by qualitative impairments in social interaction and communication and a restricted range of activities and interests.<sup>1</sup> In the last few decades, the prevalence of ASD has increased dramatically. Recent CDC estimates show a prevalence rate of 18.5 per 1000 (1 in 54) children.<sup>2</sup> A recent meta-analysis of data from 9 Asian countries revealed a prevalence ranging from 0.06% in Iran, 2.64%

in Korea, with an overall prevalence of 0.36% in Asia.<sup>3</sup> Recent studies from India suggest a prevalence between 0.6 and 3.2%.<sup>4</sup>

The mainstay of management in ASD is behavioral and educational interventions, focusing on communication, social, and daily functioning skills.<sup>5</sup> Despite clear guidelines, literature shows that 52-88% of families of children with ASD often use one or many Complementary and Alternative Medicine modalities, also referred to as integrative medicine modalities, as an

adjunct to or in place of conventional therapies.<sup>6-8</sup> Complementary and Alternative Medicine (henceforth referred to as CAM) comprises health care approaches that are not typically a part of conventional medicine.<sup>9</sup> Commonly used categories of CAM are natural products like herbs, dietary supplements, probiotics (13-54%), mind and body practices (25-30%), and special diets (17-33%).<sup>10</sup> The use of CAM in ASD is widespread, especially in children with co-morbid intellectual disability, GI symptoms, seizures, and behavioral problems.<sup>11</sup> Though data about the use of CAM in developing countries is hard to access, existing literature suggests that 15-90% of families may be using CAM.<sup>12-15</sup> In these countries, the range of treatments for autism includes options available in the West alongside distinctly culture-specific interventions like acupuncture and Traditional Chinese Medicine in China, equine therapy along with dietary supplements in UAE, massages, hot springs, and religious activities in Malaysia and herbal and ayurvedic medicines in India.<sup>13-16</sup> In a study by Daley (2002), Indian families reported using a wide range of treatments for their children like acupuncture, acupressure, auditory-integrated therapy, ayurvedic medicine, behavior therapy, and magnetotherapy. Astrologers, faith healers, fakirs, and family gurus were also sought.<sup>17</sup>

There are diverse views on why parents appear to be using more CAM for their children with ASD. Families may choose CAM to promote health, treat co-existing gastrointestinal symptoms, seizure disorders, or behavior problems, to avoid side effects of conventional medicine, and with a hope for a cure.<sup>6,7,11,16</sup> Additionally, the surge in the use of the internet has dramatically increased the exposure of families to sophisticated marketing and promotion of treatments through testimonials, anecdotal pieces of evidence, and unproven claims which influences many vulnerable parents desperately seeking an effective treatment for their child.<sup>10,18,19</sup>

The prolific use of CAM by families is a matter of grave concern, primarily as most CAM interventions are not supported by clear evidence to back their claims, with a dearth of methodologically sound clinical trials and replication studies.<sup>5</sup> Certain CAM treatments have been repeatedly shown not to work (e.g. vitamin B6 and magnesium), or randomized controlled methodologically sound evidence does not support its use (e.g., gluten-free, casein-free diet, u-3 fatty acids, oral human immunoglobulin).<sup>20,21</sup> Some CAM practices, such as chelation and hyperbaric oxygen therapy, have shown no evidence for its efficacy and instead seem to be associated with harmful side effects, while others like stem-cell therapy are being tested in limited clinical trials.<sup>10,21,22</sup>

### **Role of pediatricians**

Pediatricians and parents view the primary care pediatric setting as one that coordinates comprehensive care for children with ASD.<sup>23</sup> In India, families often express their

first concerns about their children to pediatricians and primary care physicians.<sup>24</sup> Pediatricians play an essential role in providing longitudinal medical care and guiding the families to effective evidence-based educational and medical interventions.<sup>25</sup>

Previous surveys in Western countries indicate that most parents want to inform their physicians and value their information and guidance for decision-making if they wanted to consider using a CAM.<sup>6,26</sup> However most families rarely asked physicians for information about CAM. Only 36% to 62% of caregivers who used CAM therapies for their children with ASD had informed the child's primary care physician.<sup>6,26</sup> Reasons for this lack of disclosure included a perception of physician's lack of knowledge about CAM therapies, lack of time for discussion, not seeing the necessity of reporting the use of other therapies, and concern regarding disapproval by the physician.<sup>6</sup> A parental survey in an LMIC setting also revealed that 56% of caregivers had not discussed about the usage of CAM with their child's pediatrician.<sup>16</sup>

Golnik studied U.S. physicians' perceptions about CAM in ASD and found that primary care providers viewed CAM as a challenge for children with ASD compared to children with other neurodevelopmental and chronic/complex conditions.<sup>27</sup> Participating physicians encouraged multi-vitamins (49%), essential fatty acids (25%), melatonin (25%), and probiotics (19%). At the same time, they discouraged withholding immunizations (76%), chelation (61%), anti-infectives (57%), and secretin (43%).<sup>27</sup>

Given the high prevalence rates of ASD in LMIC settings like India, most physicians and pediatricians are likely to care for children and adolescents with ASD in their practice.<sup>28</sup> The reality is that pediatricians are often not trained or prepared to provide the kind of guidance and discussion that parents need after receiving a diagnosis of ASD for their child.<sup>23,24,27,29,30</sup> Since the pediatricians' role in guiding families about the use of CAM is pivotal, it is crucial to examine their perceptions about the use of CAM in diverse settings.

Our study aims to look into the knowledge, attitude, and practices of pediatricians/physicians in India regarding CAM in ASD, the extent of use, their comfort, and the practice of communicating with patients about it. Additionally, we examined their perception of barriers to communication about CAM and the need for further training about CAM

### **METHODS**

A cross-sectional survey questionnaire developed by Golnik and Ireland was modified and contextually adapted with permission from the author for use in this study.<sup>27</sup>

The survey instrument had 15 items, including items directed at practices and attitudes of physicians towards various management modalities in ASD, including CAM. Additional items included physician demographics and practice characteristics, percentage of CAM use in children with and without ASD, barriers perceived in ASD management, and desire for training in ASD and CAM in ASD.

The list of CAM modalities was developed based on previous literature and clinician consensus about commonly used CAM practices in Indian settings.<sup>6,7,10,27</sup> The survey included multiple response questions and Likert scales of agreement. The survey instrument was pilot tested on a group of 10 pediatricians for face validity.

After Ethics Approval was obtained from an independent review board, the survey was emailed to physicians, including pediatricians, child neurologists, psychiatrists, and developmental pediatricians, through Survey Monkey accompanied by a cover letter describing the purpose of the survey and assuring complete anonymity. While the survey was emailed broadly, only those pediatricians and physicians with previous or current experience of caring for children with ASD in their clinical practice were invited to participate in the study. Three reminders were dispatched at monthly intervals from February to April, 2018.

Participants provided informed consent by signing a consent clause before the survey questionnaire. Complete responses were obtained from 417 physicians (11.79%). Percentages and statistical significance were calculated for each question response, and comparisons were drawn.

## RESULTS

### Demographics

Participating physicians represented both males (55%) and females (45%). 78% of the participants were pediatricians, 16% were developmental pediatricians while the remaining included neurologists, child psychiatrists, and others like public health and genetics. 96% of our respondents were from tier I and II cities. On average, pediatricians reported seeing one child with ASD every five days, while developmental pediatricians and pediatric neurologists cared for at least one child with ASD daily (Table 1).

### Perception of use of CAM in ASD by families

Majority of the pediatricians (71%) and developmental pediatricians (57%) who responded felt that less than 25% of their patients use CAM in ASD. One-third of the developmental pediatricians perceived CAM use in ASD to be between 25-50%. The opinions of neurologists on use of CAM in ASD varied almost equally from <25% (35%), 26-50% (35%), and 51-75% (26%) (Table 2).

**Table 1: Socio demographic details of the participants.**

Variable	N	%
<b>Age (n=417)</b>		
<35 years	84	20
36-45 years	130	31
46-55 years	105	25
>55 years	98	24
<b>Gender (n=415)</b>		
Male	228	55
Female	187	45
<b>Speciality (n=417)</b>		
Pediatrics	327	78
Developmental pediatrics	68	16
Pediatric neurology	28	7
Psychiatry	8	2
Other	26	6
<b>Type of practice (n=413)</b>		
Private	290	70
Government	82	20
NGO	21	5
Corporate	57	14
Other	15	4
<b>Practice location(n=414)</b>		
Tier I cities	231	56
Tier II-IV cities	168	41
Rural	15	4
<b>Years since practice post residency (n=416)</b>		
<10 years	137	33
11-20 years	107	26
21-30 years	97	23
>30 years	75	18
<b>Speciality wise average number of autism spectrum disorder patients seen/ month</b>		
Pediatrics	6	7
Developmental pediatrics	32	37
Pediatric neurology	33	38
Psychiatry	15	17

### Prescription of CAM in ASD

Total 44% of practitioners across all areas of practice endorsed that they often suggested vitamins, minerals, and other supplements like carnosine, vitamin B12, and omega 3 fatty acids. A majority (83%) of pediatricians did not offer an opinion to parents about GFCF, one of the commonest CAM modalities used by families for ASD, preferring either to stay neutral or refer to a specialist. A similar stance was adopted by 69-71% of the pediatricians about stem-cell transplant and hyperbaric oxygen and by about half of the physicians (49%) about ayurveda and homeopathic remedies. Less than two-thirds (60%) of all pediatricians in our study felt that they recommend educational and behavioral interventions for ASD, while 30% of the pediatricians preferred to refer to a specialist for decisions about interventions (Table 3).

**Common practice parameters in ASD management**

60% of pediatricians and 48% of pediatric neurologists felt that parents do not bring up the discussion about the use of CAM or bring it up only to a small extent. 40% of developmental pediatricians felt that parents bring up CAM use with them to a moderate extent.

Total 62.78% of the practitioners responded that they do not ask the families about CAM or ask only to a small extent when families do not bring it up themselves (Table 4).

**Knowledge of benefits and risks of CAM in ASD**

More than two-thirds (69%) of pediatricians have expressed interest in caring for children with autism, from a moderate to a very large extent, but more than half of the pediatricians (57%) reported that their knowledge and access to information about the benefits of CAM in autism was mostly inadequate. Most practitioners seemed to be equally unaware of both benefits as well as risks about CAM (79% and 74%), respectively. More developmental pediatricians seem to have access to information and knowledge about the benefits of CAM than paediatricians (Table 4).

**Table 2: Participants’ perception of use of CAM in ASD by families.**

Participants (Speciality wise)	Percentage of patients with ASD using CAM is <25%		Percentage of patients with ASD using CAM is 26 - 50%		Percentage of patients with ASD using CAM is 51- 75%		Percentage of patients with ASD using CAM is >75%	
	N	%	N	%	N	%	N	%
<b>Pediatricians (n=277)</b>	197	71	44	16	19	7	17	6
<b>Developmental pediatricians (n=62)</b>	35	57	20	32	5	8	2	3
<b>Pediatric neurologists (n=23)</b>	8	35	8	35	6	26	1	4
<b>Psychiatrists (n=7)</b>	5	72	1	14	1	14	0	0

CAM- Complementary and Alternative Medicine

**Table 3: Practices of participants regarding common CAM prescriptions in ASD.**

Modalities	I discourage it	I neither encourage nor discourage it	I often suggest it	I do not have enough information to comment on it	I prefer to refer to a specialist
	N (%)	N (%)	N (%)	N (%)	N (%)
<b>Gluten free/ Casein free diet (GFCF)</b>					
Pediatrics (n=314)	36 (11)	89 (29)	19 (6)	104 (33)	66 (21)
Developmental pediatrics (n=66)	21 (32)	24 (36)	5 (8)	16 (24)	0 (0)
Pediatric neurology (n=26)	3 (12)	13 (50)	5 (19)	5 (19)	0 (0)
Psychiatry (n= 8)	1 (13)	5 (61)	1 (13)	1 (13)	0 (0)
<b>Ayurvedic remedies</b>					
Pediatrics (n=314)	155 (49)	86 (28)	6 (2)	51 (16)	16 (5)
Developmental pediatrics (n=66)	27 (41)	23 (35)	1 (2)	11 (17)	4 (6)
Pediatric neurology (n=27)	12 (44)	9 (33)	1 (4)	4 (15)	1 (4)
Psychiatry (n=8)	4 (50)	2 (25)	0 (0)	2 (25)	0 (0)
<b>Homeopathy remedies</b>					
Pediatrics (n=314)	155 (49)	84 (27)	6 (2)	49 (16)	19 (6)
Developmental pediatrics (n=66)	30 (45)	22 (33)	0 (0)	10 (15)	4 (7)
Pediatric neurology (n=26)	11 (42)	10 (38)	0 (0)	5 (19)	0 (0)
Psychiatry (n=8)	3 (37)	1 (12)	2 (25)	2 (25)	0 (0)
<b>Vitamins/minerals, other supplements</b>					
Pediatrics (n=318)	26 (8)	91 (29)	152 (48)	34 (10)	15 (5)
Developmental pediatrics (n=66)	11 (17)	24 (36)	26 (39)	5 (8)	0 (0)
Pediatric neurology (n=27)	1 (4)	10 (37)	13 (48)	3 (11)	0 (0)
Psychiatry (n=8)	0 (0)	4 (50)	4 (50)	0 (0)	0 (0)
<b>Educational and behavioral techniques</b>					
Pediatrics (n=316)	1 (0.3)	2 (0.7)	190 (60)	16 (5)	107 (34)
Developmental pediatrics (n=67)	0 (0)	1 (2)	60 (88)	1 (2)	5 (8)

Continued.

Modalities	I discourage it	I neither encourage nor discourage it	I often suggest it	I do not have enough information to comment on it	I prefer to refer to a specialist
	N (%)	N (%)	N (%)	N (%)	N (%)
Pediatric neurology (n=27)	0 (0)	0 (0)	23 (85)	1 (4)	3 (11)
Psychiatry (n=8)	1 (12)	0 (0)	5 (63)	0 (0)	2 (25)
<b>Stem cell therapy</b>					
Pediatrics (n=305)	93 (30)	18 (6)	1 (1)	108 (35)	85 (28)
Developmental pediatrics ( n=66)	43 (65)	5 (8)	0 (0)	14 (21)	4 (6)
Pediatric neurology ( n=27)	18 (67)	4 (15)	0 (0)	5 (18)	0 (0)
Psychiatry ( n=7)	2 (29)	0 (0)	0 (0)	5 (71)	0 (0)
<b>Hyperbaric oxygen chamber</b>					
Pediatrics (n=310)	88 (28)	20 (6)	1(1)	121 (39)	80 (26)
Developmental pediatrics ( n=66)	38 (58)	4 (6)	0 (0)	22 (33)	2 (3)
Pediatric neurology ( n=27)	16 (59)	2 (8)	0(0)	8 (29)	1 (4)
Psychiatry (n=7)	2 (29)	0 (0)	1 (14)	4 (57)	0 (0)
<b>Chelation</b>					
Pediatrics (n=302)	93 (31)	16 (5)	4 (1)	120 (40)	69 (23)
Developmental pediatrics ( n=66)	39 (59)	4 (6)	0 (0)	22 (33)	1 (2)
Pediatric neurology (n=27)	17 (63)	2 (7)	0 (0)	7 (26)	1 (4)
Psychiatry (n=8)	4 (50)	0 (0)	1 (13)	2 (24)	1 (13)
<b>Delay vaccinations</b>					
Pediatrics (n=312)	217 (70)	26 (8)	15 (5)	32 (10)	22 (7)
Developmental pediatrics (n=66)	56 (84)	4 (6)	1 (2)	4 (6)	1 (2)
Pediatric neurology (n=27)	23 (85)	2 (7)	1 (4)	1 (4)	0 (0)
Psychiatry (n=7)	5 (70)	0 (0)	1 (15)	1 (15)	0 (0)

**Table 4: Participants' practice parameters and perceptions of knowledge about ASD management and CAM.**

Practice parameter	Not at all	To a small extent	To a moderate extent	To a large extent	To a very large extent
	N (%)	N (%)	N (%)	N (%)	N (%)
<b>I am interested in caring for patients with autism in my practice</b>					
Pediatrics (n=316)	6 (2)	92 (29)	103(33)	80 (25)	35 (11)
Developmental pediatrics (n= 67)	1 (1)	1 (1)	9 (14)	22 (33)	34 (51)
Pediatric neurology (n=27)	0 (0)	4 (16)	6 (22)	12 (44)	5 (18)
Psychiatry (n=8)	1 (12)	0 (0)	3 (38)	3 (38)	1 (12)
<b>The families with autism discuss the use of CAM with me</b>					
Pediatrics (n=311)	64 (21)	124(40)	83 (27)	29 (9)	11 (3)
Developmental pediatrics (n=66)	4 (6)	22 (34)	26 (39)	10 (15)	4 (6)
Pediatric neurology (n=27)	0 (0)	13 (48)	7 (26)	6 (22)	1 (4)
Psychiatry (n=7)	1 (16)	2 (28)	2 (28)	2 (28)	0 (0)
<b>I generally ask families with autism if they are using CAM, even when they don't bring it up themselves</b>					
Pediatrics (n=309)	102 (33)	92 (30)	60 (19)	40 (13)	15 (5)
Developmental pediatrics (n=64)	12 (19)	20 (31)	19 (30)	9 (14)	4 (6)
Pediatric neurology (n=27)	6 (22)	8 (30)	7 (26)	6 (22)	0 (0)
Psychiatry (n=8)	2 (25)	4 (50)	1 (13)	0 (0)	1 (12)
<b>I have adequate knowledge and access to information on the benefits of CAM for autism</b>					
Pediatrics (n=307)	175 (57)	90 (29)	27 (9)	10 (3)	5 (2)
Developmental pediatrics (n=66)	16 (24)	17 (26)	17 (26)	11 (17)	5 (7)
Pediatric neurology (n=27)	12 (44)	5 (19)	7 (26)	3 (11)	0 (0)
Psychiatry (n=6)	2 (33)	2 (33)	1 (17)	0 (0)	1 (17)
<b>I have adequate knowledge and access to information on the risks of CAM for autism</b>					
Pediatrics (n=311)	156 (50)	97 (31)	35 (12)	16 (5)	7 (2)
Developmental pediatrics (n=65)	13 (20)	15 (23)	17 (26)	16 (25)	4 (6)
Pediatric neurology (n=27)	9 (33)	9 (33)	5 (19)	4 (15)	0 (0)
Psychiatry (n=7)	2 (29)	3 (43)	1 (14)	0 (0)	1 (14)

Continued.

Practice parameter	Not at all	To a small extent	To a moderate extent	To a large extent	To a very large extent
	N (%)	N (%)	N (%)	N (%)	N (%)
<b>I have adequate practice guidelines to care for patients with autism</b>					
Pediatrics (n=318)	82 (26)	153(48)	61 (19)	18 (6)	4 (1)
Developmental pediatrics (n=67)	0 (0)	10 (15)	22 (33)	23 (34)	12 (18)
Pediatric neurology (n=27)	1 (4)	4 (15)	13 (48)	7 (26)	2 (7)
Psychiatry (n=8)	1 (12)	0 (0)	5 (64)	1 (12)	1 (12)
<b>I desire more training in primary care for patients with autism</b>					
Pediatrics (n=322)	7 (2)	53 (17)	123(38)	85 (26)	54 (17)
Developmental pediatrics (n=67)	4 (6)	7 (11)	16 (24)	21 (31)	19 (28)
Pediatric neurology (n=28)	0 (0)	7 (25)	7 (25)	10 (36)	4 (14)
Psychiatry (n=7)	0 (0)	1 (14)	0 (0)	3 (43)	3 (43)
<b>I desire more training in CAM for patients with autism</b>					
Pediatrics (n=309)	61 (20)	75 (24)	90 (29)	56 (18)	27 (9)
Developmental pediatrics (n=63)	10 (16)	18 (29)	12 (19)	12 (19)	11 (17)
Pediatric neurology (n=27)	3 (11)	12 (44)	6 (22)	5 (19)	1 (4)
Psychiatry (n=7)	1 (14)	1 (14)	1 (14)	1 (14)	3 (44)

**Table 5: Participants' perceptions of common barriers to ASD care.**

Barriers	Perceived by % of participants
Lack of available behavioural and educational therapy services	63
Lack of time with the patient/family	55
Lack of training about the disorder	50
Lack of training about CAM	48
Lack of care coordination/ help	46
Lack of formal diagnostic evaluation services	44
Lack of clinical practice guidelines	39
Not my primary area of expertise	33
Frequent use of providers like speciality services, therapies	22
Increased medical co-morbidities	22
Lack of trust from patients' families	17
Diverse/rapidly changing therapies	17
Frequent use of CAM	13
Not my primary area of interest	11
Other(please specify)	4
No barriers experienced	2

**Barriers to care**

Across specialties, physicians perceived lack of behavior and educational services as a significant barrier to care (64%), followed by other barriers like lack of time with patient/ family (55%) and lack of care/coordination/help (47%). Lack of training about ASD and CAM was also perceived as barriers to care by 46% of pediatricians. Lack of formal diagnostic evaluation (42%) and clinical

practice guidelines (36%) was another significant barrier perceived (Table 5).

**DISCUSSION**

Our study is one of the few in LMIC countries to examine pediatrician perceptions, attitudes, and knowledge about the use of CAM by families of children with ASD. Overall, research in ASD in LMICs is limited, with a few studies on parental perceptions regarding ASD and very little known about the perspectives of physicians who regularly access and provide care to children with ASD.<sup>29</sup>

More than two-thirds (69%) of pediatricians who participated in our study expressed interest in caring for children with autism, from a moderate to a very large extent, which is both heartening to note as well as establishes their perceptions as valid and relevant. The majority of the physicians in our study felt that less than 25% of their patients use CAM. This figure is grossly discrepant from the typical use of CAM (52-88%) in children with ASD reported in the literature.<sup>6-8</sup> This discrepancy highlighted by our study has multiple implications.

Our foremost concern about the discrepancy between perceived and reported use of CAM by families is the lack of communication between physicians and families. The majority (60%) of the practitioners in our study across all specialties responded that they did not ask the families about CAM or asked only to a small extent when families did not bring it up themselves. Concurrently, more than half (57%) of the pediatricians in our study felt that even parents did not bring up CAM use or brought it up only to a small extent. In short, physicians often do not ask about CAM, and families do not bring it up themselves. This unfortunate situation is possibly a

significant reason why physicians in India perceive the use of CAM to be much less than what it truly is. We acknowledge that these figures are comparable to previous studies globally, which have shown that only 20%-37% pediatricians explicitly inquired about or discussed CAM with their patients and that families rarely asked physicians for information about CAM or informed them about CAM use.<sup>31,32,6</sup> Hence, in many instances, the physicians providing medical care are unaware of the concurrent use of CAM by families of children with ASD, thereby missing critical information-sharing and shared decision-making opportunities.<sup>31</sup>

The gaps in pediatricians' knowledge and understanding of the evidence-base for CAM in managing ASD are other vital areas of consideration that emerged from our study. On the one hand, our respondents felt that less than 25% of their patients use CAM, while on the other, our data reveal that they recommend an array of CAM options. Nearly half (45%) of the respondents reported prescribing vitamins, minerals, and other supplements like carnosine, vitamin B12, and omega 3 fatty acids, similar to a previous western study on CAM in ASD, where vitamins were encouraged by 49% of physicians.<sup>27</sup> Our findings suggest that many physicians may not be aware that vitamins and nutritional supplements come under the purview of CAM and are not recommended as the mainstay of management in ASD.

Physicians reported a lack of access to behavioral and educational interventions as the most significant barrier to optimal care across all sections. Another possible reason for the high rate of prescription of vitamins could be that physicians feel pressured to prescribe vitamins, minerals, and supplements that are perceived to be relatively harmless in the absence of what is truly effective. The challenge inherent in such practices is that they place an extra burden on the families' resources, especially significant in a low-middle income country like ours, and generate a false sense of hope for a cure.

Lack of time emerged as a significant barrier in our study, which is not surprising given the considerable patient load that our country's health care systems handle. A systematic review of international variations in primary care physicians' consultation time revealed that the average time spent by an Indian primary care physician was 2-2.3 minutes per patient, as compared to 21 minutes in the United States and 22.5 minutes in Sweden.<sup>33</sup> A more extended amount of time spent during a patient visit has been shown to impact health promotion and patient empowerment positively.<sup>34</sup> Conversely, shorter visits have been found to be associated with the increased use of writing prescriptions and inadequate patient communication, suggesting that physician recommendations of vitamins and supplements could also be attributed to less time spent per patient during visits.<sup>35,36</sup>

Another critical challenge expressed by participants was limited knowledge about ASD in general and particularly CAM. Almost half of the pediatricians and neurologists and a quarter of the developmental pediatricians felt that their knowledge and access to information about the benefits and risks of CAM in autism were mostly inadequate, which could be a critical reason why they hesitate to bring up discussions about CAM. This lack of knowledge, especially about potential harm, could also explain our finding that pediatricians often do not explicitly express an opinion about more non-conventional modalities like modified diets (GFCF), stem cell, or hyperbaric oxygen therapy. Families who do not receive validation or answer to their questions may feel confused and unsure, and propagate the vicious cycle of not involving their pediatricians in decisions about CAM options.

We acknowledge that our study has limitations. The number of pediatricians who responded to our survey is low compared to the total number of pediatricians practicing in the country, which may raise questions about the extent to which this study's results are generalizable. The pertinent point is that our study excluded pediatricians who have not yet cared for children with ASD; therefore, the response rate may be a reasonably accurate representation of the small proportion of pediatricians and physicians in our country who provide care to children with ASD. A significant percentage of our respondents were from tier one and two cities, thereby reflecting a more urban perspective. We hypothesize that if our study respondents had been more representative of the pediatrician community across the country, lack of ASD-specific interventions and lack of knowledge about ASD and CAM would have emerged even more resoundingly as significant barriers in the management of children with ASD.

We did not explore associations between the different factors, for instance, associations between practitioner specialty and practice patterns due to a heavy skew towards the number of pediatricians versus other specialties that might have influenced the results.

## CONCLUSION

The use of Complementary and Alternative Medicine by families of children with ASD is an area that is often not considered or brought up for discussion by pediatricians and specialist physicians during their interactions with families. The absence of effective behavioral and educational interventions for ASD, lack of time, and limited knowledge about ASD and CAM in ASD, in particular, are the most commonly cited challenges. However, it is imperative to address this gap as prolific and unmonitored use of CAM modalities saps valuable family resources, builds false hope, and, most importantly, often leaves children vulnerable to potential side-effects.

There is a need to build awareness about the importance of family-centered care and shift from a "physicians as experts" model to one that values and acknowledges families as partners in care for their children with ASD. Such interactions may be more time-consuming but hold immense value in building physician-family relationships that allow space for conversations about issues like CAM, especially in today's times where trust in the medical system seems to be fast eroding. Furthermore, last but not least, it is paramount that ASD training for all medical students and in-service pediatricians specifically address conventional CAM modalities, their benefits, and risks, and include clear practice guidelines about evidence-based management for ASD and CAM.

Since the completion of this study, the world as we know it has changed considerably, with the Covid-19 pandemic causing unparalleled mortality and morbidity across the globe. As different degrees of lockdown has been implemented across various countries, children with all disabilities, including ASD, have borne the brunt of it with most of their therapy services suspended or moved online. Research is yet emerging about the number of families and children deprived of intervention services during the pandemic, but we anticipate the numbers to be non-negligible. With no access to services, there is a fair chance that parents may resort to whatever is feasible and available and may lead to an upsurge of the utilization of CAM options. In this scenario, the role of pediatricians and other physicians who have access to children with ASD is amplified, and we cannot stress enough about the need to proactively enquire about the utilization of CAM modalities and support families in the process of informed decision-making about their choices

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## REFERENCES

- American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th ed. Arlington, VA: American Psychiatric Association Publishing; 2013.
- Maenner MJ, Shaw KA, Baio J, Washington A, Patrik M, DiRienzo M, et al. Prevalence of autism spectrum disorder among children aged 8 years - autism and developmental disabilities monitoring network, 11 sites, United States, 2016. *MMWR Surveill Summ.* 2020;69(No. SS-4):1-12.
- Qiu S, Lu Y, Li Y, Shi J, Cui H, Gu Y, et al. Prevalence of autism spectrum disorder in Asia: A systematic review and meta-analysis. *Psychiatry Res.* 2020;284:112679.
- Arora NK, Nair MKC, Gulati S, Deshmukh V, Mohapatra A, Mishra D, et al. Neurodevelopmental disorders in children aged 2-9 years: population-based burden estimates across five regions in India. *PLoS Med.* 2018;15(7):e1002615.
- Myers SM, Johnson CP, Lipkin PH, Cartwright JD, Desch LW, Duby JC, et al. Management of children with autism spectrum disorders. *Pediatrics.* 2007;120(5):1162-82.
- Wong HHL, Smith RG. Patterns of complementary and alternative medical therapy use in children diagnosed with autism spectrum disorders. *J Autism Dev Disord.* 2006;36(7):901-9.
- Hanson E, Kalish LA, Bunce E, Curtis C, McDaniel S, Ware J, et al. Use of complementary and alternative medicine among children diagnosed with autism spectrum disorder. *J Autism Dev Disord.* 2007;37(4):628-36.
- Owen-Smith AA, Bent S, Lynch FL, Coleman KJ, Yau VM, Pearson KA, et al. Prevalence and predictors of complementary and alternative medicine use in a large insured sample of children with autism spectrum disorders. *Res Autism Spectr Disord.* 2015;17:40-51.
- National Center for Complementary and Integrative Health: National Institutes of Health. Complementary, Alternative, or Integrative Health: What's In a Name? 2015. Available at: <https://www.nccih.nih.gov/health/complementary-alternative-or-integrative-health-whats-in-a-name>. Accessed 1 Nov 2020.
- Levy SE, Hyman SL. Complementary and alternative medicine treatments for children with autism spectrum disorder. *Child Adolesc Psychiatry Clin NA.* 2015;24(1):117-43.
- Perrin JM, Coury DL, Hyman SL, Cole L, Reynolds AM, Clemons T. Complementary and alternative medicine use in a large pediatric autism sample. *Pedia.* 2012;130(SUPPL.2):S77-82.
- Krishnamurthy V. A clinical experience of autism in India. *J Dev Behav Pediatr.* 2008;29(4):331-3.
- Wong VC. Use of complementary and alternative medicine (CAM) in autism spectrum disorder (ASD): comparison of Chinese and Western culture (Part A). *J Autism Dev Disord.* 2009;39(3):454-63.
- Kelly MP, Tennant L, Al-hassan SM. Autism treatments used by parents in Abu Dhabi, United Arab Emirates. *Austin J Autism Relat Dis.* 2016;2(3):1024.
- Ong JJ. Parental satisfaction and perception of progress in influencing the practice of complementary health approaches in children with autism: a cross sectional survey from Negeri Sembilan, Malaysia. *BMC Complement Altern Med.* 2019;19(1):1-9.
- Narasimhan U, Rajendran R, Abraham DA, Rajendran L, Muhasaparur Ganesan R. Prevalence and pattern of complementary and alternative medicine for autism spectrum disorder in Tamil Nadu. *Indian J Pediatr.* 2020;87(5):400.
- Daley TC, Sigman MD. Diagnostic conceptualization of autism among Indian

- psychiatrists, psychologists, and pediatricians. *J Autism Dev Disord.* 2002;32(1):13–23.
18. Rehabilitation Council of India. Autism. Available at: <http://www.rehabcouncil.nic.in/writereaddata/autism.pdf>. Accessed 1 Nov 2020.
  19. Sharma V, Holmes JH, Sarkar IN. Identifying complementary and alternative medicine usage information from internet resources: a systematic review. *Methods Inf Med.* 2016;55(4):322–32.
  20. Findling RL, Maxwell K, Scotese-Wojtila L, Huang J, Yamashita T, Wiznitzer M. High-dose pyridoxine and magnesium administration in children with autistic disorder: an absence of salutary effects in a double-blind, placebo- controlled study. *J Autism Dev Disord.* 1997;27(4):467–78.
  21. Whitehouse AJO. Complementary and alternative medicine for autism spectrum disorders: rationale, safety and efficacy. *J Paediatr Child Health.* 2013;49(9).
  22. Siniscalco D, Kannan S, Semprún-Hernández N, Eshraghi AA, Brigida AL, Antonucci N. Stem cell therapy in autism: recent insights. *Stem Cells Cloning Adv Appl.* 2018;11:55–67.
  23. Golnik A, Ireland M, Borowsky IW. Medical homes for children with autism: a physician survey. *Pediatr.* 2009;123(3):966–71.
  24. Desai PP, Mohite P. An exploratory study of early intervention in Gujarat state, India: pediatricians' perspectives. *J Dev Behav Pediatr.* 2011;32(1):69-74.
  25. Myers SM. Management of autism spectrum disorders in primary care. *Pediatr Ann.* 2009;38(1):42–9.
  26. Sibinga EMS, Ottolini MC, Duggan AK, Wilson MH. Parent-pediatrician communication about complementary and alternative medicine use for children. *Clin Pediatr (Phila).* 2004;43(4):367–73.
  27. Golnik AE, Ireland M. Complementary alternative medicine for children with autism: a physician survey. *J Autism Dev Disord.* 2009;39(7):996-1005.
  28. Sengupta K, Lobo L, Krishnamurthy V. Educational and behavioral interventions in management of autism spectrum disorder. *Indian J Pediatr.* 2017;84(1):61–7.
  29. Munir KM, Lavelle TA, Helm DT, Rustamov I, Azeem W. Developing countries and autism. In: Volkmar F. (eds) *Encyclopedia of Autism Spectrum Disorders.* New York, NY: Springer; 2018.
  30. Alallawi B, Hastings RP, Gray G. A systematic scoping review of social, educational, and psychological research on individuals with autism spectrum disorder and their family members in Arab countries and cultures. *Rev J Autism Dev Disord* 2020:1-9.
  31. Kemper KJ, O'Connor KG. Pediatricians' recommendations for complementary and alternative medical (CAM) therapies. *Ambul Pediatr.* 2004;4(6):482–7.
  32. Sawni A, Thomas R. Pediatricians' attitudes, experience and referral patterns regarding complementary/alternative medicine: a national survey. *BMC Complement Altern Med.* 2007;7:1–7.
  33. Irving G, Neves AL, Dambha-Miller H, Oishi A, Tagashira H, Verho A, et al. International variations in primary care physician consultation time: a systematic review of 67 countries. *BMJ Open.* 2017;7:e017902.
  34. Chattopadhyay A. An audit of prescribing practices in CGHS dispensaries of Kolkata, India. *IOSR J Dent Med Sci.* 2013;8(1):32–7.
  35. Nizami SQ, Khan IA, Bhutta ZA. Drug prescribing practices of general practitioners and paediatricians for childhood diarrhoea in Karachi, Pakistan. *Soc Sci Med.* 1996;42(8):1133–9.
  36. Jin G, Zhao Y, Chen C, Wang W, Du J, Lu X. The length and content of general practice consultation in two urban districts of Beijing: a preliminary observation study. *PLoS One.* 2015;10(8):e0135121.

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