Published in final edited form as:

Complement Ther Med. 2017 December ; 35: 47–52. doi:10.1016/j.ctim.2017.09.003.

Parent disclosure of complementary health approaches used for children with autism spectrum disorder: Barriers and facilitators

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Abstract

Background and Objectives—Complementary health approaches (CHA) are widely used among children with autism spectrum disorder (ASD). As part of shared treatment decision-making, healthcare providers are encouraged to discuss CHA with parents of children with ASD. Yet prior research suggests that parents often do not disclose CHA used for children, and their reasons for nondisclosure are poorly understood. We, therefore, aimed to identify barriers and facilitators to parent disclosure of CHA used for children with ASD.

Design and Setting—In-depth interviews were conducted with 31 parents who reported that they were currently using CHA for their child's ASD in Denver, Colorado or Portland, Oregon.

Results—We used content analysis to identify six main themes indicating that the following factors play a role in disclosure: parents' drive to optimize their child's health, parent self-efficacy discussing CHA with healthcare providers, parent beliefs about the effectiveness of CHA, parent-provider relationship quality, provider attitudes and knowledge regarding CHA and ASD, and visit characteristics.

Conclusions—Study findings suggest that family and health system factors, together, influence parent disclosure of CHA used for children with ASD. Multifaceted intervention concurrently targeting the CHA-related knowledge, beliefs, and self-efficacy of parents whose children have been recently diagnosed with ASD, in addition to the CHA-related attitudes and knowledge of their healthcare providers may promote disclosure and shared treatment decision-making about the use of CHA.

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Keywords

autism spectrum disorder; complementary health approaches; disclosure; shared treatment decision-making

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Introduction

Autism spectrum disorder (ASD) is a complex neurodevelopmental condition characterized by impairment in social and/or behavioral functioning.¹ ASD is a relatively prevalent childhood condition: 1 in 68 US children are estimated to have ASD.² Although no curative treatment for ASD exists, treatment to manage or reduce symptoms is recommended.³ In seeking treatment, parents are likely to use complementary health approaches for their child with ASD.

Complementary health approaches (CHA) are developed outside of or parallel to mainstream medicine and may be categorized as natural products (e.g., herbal supplements), mind and body practices (e.g., yoga), or other approaches (e.g., special diets).⁴ CHA use is common among children with ASD: between 28⁵ and 95⁶ percent are estimated to use CHA. Many CHA do not pose safety risks for children with ASD; however, certain modalities such as chelation and hyperbaric oxygen therapy can have harmful effects.^{7–10} Moreover, many CHA have limited evidence of efficacy for ASD^{7,11–14} and are not covered by health insurance plans.¹⁵

The American Academy of Pediatrics and other child health organizations recommend that pediatric healthcare providers routinely communicate with families about CHA, in accordance with the existing evidence of efficacy and safety for CHA, and more broadly as part of shared treatment decision-making.^{16–21} Parent disclosure of CHA for children with ASD to conventional healthcare providers is important because it enables bidirectional information exchange about CHA between families and healthcare providers.^{16,19,22} That is, when parents disclose they are using or considering the use of CHA for their child with ASD, healthcare providers can more holistically discuss treatment options and build consensus about the child's treatment plan.

Despite growing recognition that disclosure of CHA is necessary to ensure patient safety and quality healthcare, little research has examined why disclosure of CHA does or does not occur. We identified three published studies that examined parent disclosure of CHA used or considered for children,^{23–25} and only one focused on children with ASD. Study findings, together, suggest that parent disclosure of CHA to conventional providers may not occur for multiple reasons such as parent perceptions that their child's provider lacks knowledge about CHA, the parent feeling it is unnecessary to inform their child's provider about CHA use, or the provider not asking the parent about CHA.^{23–25} Younger child age, greater condition severity, the parent not using CHA, high parent-provider relationship quality, or the use of certain CHA (e.g., mind and body practices) may additionally be associated with disclosure.^{23–25}

Still further research is needed to comprehensively determine how various factors affect parent disclosure of CHA, especially for children with ASD who are likely to use CHA. This study, therefore, aimed to identify factors perceived to be barriers or facilitators to disclosure from the perspective of parents using CHA for their child with ASD. Our study was informed by a conceptual framework (Figure 1) adapted from the Complementary and Alternative Medicine (CAM) Healthcare Model.²⁶

Methods

This qualitative study was added to a larger study conducted from March 2014 to October 2015 that investigated barriers to autism care for Latino children. Methods for the larger study have been previously described.²⁷ The Institutional Review Boards at the affiliated universities approved this study.

Sampling and Recruitment

For the larger study, probability samples of parents of Latino and non-Latino white children aged 2–10 years with a confirmed ASD diagnosis in the past five years were selected from ASD clinics in Los Angeles, California; Denver, Colorado; and Portland, Oregon. Then, eligible parents who provided informed consent completed a structured survey about barriers to accessing ASD care and their current use of CHA for ASD. To be eligible for this study, parents had to have reported (1) current use of CHA for ASD and (2) English-speaking proficiency in the structured survey. Parents who met these criteria from Portland, Oregon ($n = 47$) or Denver, Colorado ($n = 42$) were recruited using an advance mailing and follow-up by telephone. Eligible parents who were interested in participating in this study were re-screened by telephone to determine if (1) their child still had ASD and (2) they used CHA for their child in the past year. Of the 89 parents re-contacted, 31 completed interviews (18 from Portland, Oregon and 13 from Denver, Colorado).

Data Collection

From March 2016 to January 2017, three trained researchers conducted in-depth interviews in English by telephone. Verbal consent was obtained before all interviews. Most interviews were conducted with the child's mother. Interviews lasted 35 to 120 minutes and were recorded then transcribed verbatim. Each participant received a \$20 gift card.

Interview Guide

The semi-structured interview guide included predominately open-ended questions and probes about parents' experiences using and disclosing CHA, which were informed by past research and the conceptual framework. An initial version of the interview guide was pilot tested with two parents who had each used CHA for their child with ASD in Portland, Oregon. All participants were asked the same questions (Table 1).

Analysis

A directed content analysis approach was used to analyze interview data.²⁸ An initial coding scheme was developed after the first and third authors reviewed transcripts from four interviews. Elemental coding methods were primarily used including descriptive, in vivo,

and structural coding.²⁹ After the two authors independently coded the same four interview transcripts, the initial coding scheme was revised. The coding continued in an iterative process with each of the two authors independently coding all other interview transcripts, routinely meeting to discuss and resolve coding discrepancies with another author, and revising the coding scheme accordingly. Research team members and a parent advocate who had used CHA for her child with ASD, then reviewed coded data and met several times to discuss and extrapolate broader themes regarding barriers and facilitators to disclosure. QSR NVivo 11.3.2³⁰ was used for data analysis.

Results

Participant Characteristics

As shown in Table 2, all parents had 12 or more years of education, many were married or living with a partner, and on average had two children. Children with ASD ranged in age from 6 to 12 years and were mostly male. The median age of initial ASD diagnosis was three years, nearly half were publicly insured, a majority were non-Latino, and more than half were reported to have moderate or severe ASD. All participants reported their child with ASD currently had a regular healthcare provider and had used at least one conventional health service in the past year.

Barriers and Facilitators to Disclosure

All participants described one or more experience(s) disclosing CHA used for their child with ASD to a conventional healthcare provider; however, the extent of disclosure described varied among them. While some parents explained how disclosure had led to ongoing and in-depth conversations about CHA with their child's provider, other parents recounted how no follow-up or additional communication about CHA had occurred after they reported it. Six main themes were identified in relationship to parents' perspectives of factors influencing disclosure.

Disclosure is important to help optimize the child's health—Among the 17 parents who expressed the importance of disclosure to help optimize the health of their child with ASD, nine further described how they believed that maintaining transparency with their child's healthcare provider(s) about CHA was essential to avoiding health risks and/or holistically promoting their child's health. As the grandmother caring for a seven-year-old boy in Oregon explained:

[Child's doctor] knows I had done the qigong and knows that he takes a multivitamin and melatonin. Yeah, I'm open about everything with everyone... because it's all for him. And if I shouldn't be doing it, let me know and tell me why. No secrets here.

Seven parents focused most on optimizing the child's health via disclosure to avoid health risks such as adverse drug interactions with CHA. Parents were generally the most concerned about minimizing health risks from natural products (e.g., herbal supplements) rather than mind and body practices (e.g., qigong).

Self-efficacy to discuss CHA with the child's provider(s) facilitates disclosure

—Fourteen parents discussed feeling capable of discussing CHA with their child's healthcare provider(s) as promoting disclosure. Specifically, parents described their self-efficacy in terms of knowing enough about CHA to ask about it and/or feeling empowered to ask their child's healthcare provider about CHA. Many parents described how they initially found information about CHA online or from other sources (e.g., parent classes, support groups) and then had brought it or mentioned it to their child's healthcare provider during visits. As a mother of a seven-year-old boy from Colorado recounted:

Originally, I would come to [child's doctor] with the information and the things that I was using. Then when she found out that we were interested in that a little more, she would tell us some of the different [CHA], mostly it's just been the fish oil and the vitamin D that she has recommended.

Other parents attributed their self-efficacy to their professional experience in the healthcare field, older age, or being an experienced parent. Two parents also explained how they had given their child's healthcare providers informational materials about certain CHA they used for their child because they believed it could help other children with ASD.

Beliefs about the effectiveness of CHA can help or hinder disclosure—Thirteen parents described how their beliefs about the effectiveness of CHA for their child with ASD could help or hinder disclosure. Most explained how the effectiveness of CHA, in terms of its safety and/or efficacy, for their child with ASD made discussions with their child's healthcare provider easier. Alternatively, two parents described how they did not disclose use of CHA for their child with ASD because they believed the CHA were effective and, therefore, did not think it would be worthwhile to discuss it with the child's provider.

Parent-provider relationship quality can facilitate or discourage disclosure

All parents described how the quality of their relationship with their child's healthcare provider(s) had been a barrier or facilitator to disclosure. High relationship quality between a child's family and healthcare provider was described as a facilitator to disclosure by 25 parents. Parents most commonly characterized high relationship quality in terms of open communication, nonjudgmental interaction, and collaborative decision-making. As the mother of a seven-year-old girl in Oregon described:

[My child's doctor] just makes me feel comfortable. I don't feel judged. We had one pediatrician before, and the moment he walked into the door, I felt like he was judging me, he was judging my child. I don't know. I just didn't like his attitude. And you know, I switched. That's when I met [child's doctor], and just his whole attitude about it, it felt like he was a friend. I felt comfortable just talking about [child].

Several parents additionally spoke of how positive interactions between their child with ASD and his or her healthcare provider was an important aspect of their relationship quality.

Sixteen parents described relationship quality between the child's family and provider(s) as a barrier to disclosure. In some of these cases, parents recounted how poor relationship quality had been a disclosure barrier with their child's previous provider but was not with

their child's current provider. Others described how they felt poor relationship quality was a barrier to disclosure more generally for parents of children with ASD. Medical mistrust and lack of communication were most frequently ascribed to poor relationship quality hindering disclosure. Medical mistrust was often related to the recommended use or perceived overuse of medication or vaccines by the child's healthcare provider. In some cases, parents expressed how they felt they would be dismissed or redirected to medication if they disclosed CHA use to their child's healthcare provider. As the mother of a seven-year-old boy in Oregon conveyed:

Interviewer: Do you think that some parents are hesitant to talk about complementary and alternative medicine with their doctors and nurses?

Parent: Yes.

Interviewer: And why do you think that is?

Parent: Because I think doctors just tend to go more...I [have] been in the medical field for a while now, and I just see this push for meds, you know, a lot of medication. It seems like an easy scapegoat to be honest with you. That's my personal feeling. They're having this problem, "oh, let's just put them on this med," you know?

In describing a lack of communication with their child's healthcare provider as being a barrier to disclosure, some parents explained how they had noted using CHA on their child's intake form or had mentioned it to the provider; yet, the provider did not initiate or pursue a dialogue about CHA with the parent.

Provider attitudes and knowledge related to CHA and ASD can affect

disclosure—Twenty-nine parents described how certain provider characteristics, primarily attitudes toward CHA and/or knowledge of CHA and ASD, were attributes that facilitated disclosure or were deficits that impeded disclosure. Parents focused most on provider deficits. Attitudes about CHA were the most common characteristic described by parents as helping or hindering disclosure. Often parents described positive provider attitudes about CHA in terms of the provider's general receptivity to non-conventional health approaches. Conversely, parents frequently typified negative provider attitudes toward CHA as being "closed-minded" or fixed. Some parents related negative provider attitudes to their relationship, expressing they might feel judged or dismissed by their child's provider for disclosing. As the mother of a nine-year-old boy in Colorado related:

[Child's doctor's] demeanor changes right away when I talk about [CHA]. I even had [a doctor]...the doctor was horrible...I told him that [child] was allergic to milk and then I told him that we were gluten free, and he just labeled me right away that I was a quack. He even wrote in his report that he didn't think that [child] was allergic to milk and all this stuff. I just I couldn't believe the way he treated me. I'd never experienced that from any of [child's] doctors before. Yeah, it was a very frustrating experience.

Provider knowledge of CHA was similarly described as either facilitating disclosure, when the provider was knowledgeable about CHA, or impeding disclosure, when the provider had

limited CHA knowledge. Some parents described provider knowledge about CHA as related to disclosure, in terms of the provider's willingness to learn about CHA.

Interviewer: Is there anything else that's made it easy to discuss with her?

Parent: ...[I]t's an area that she's very interested in, and she learns about it outside of work. She's discussed massage with us and different things we can do that are homeopathic, like using green tea and sea salt and thing like that. She's interesting and helpful. (mother, 6 yr. old boy, Oregon)

Beyond provider CHA attitudes and knowledge, parents also raised knowledge of ASD as a provider characteristic influencing disclosure. Thirteen parents mentioned how a provider's limited knowledge of ASD had been a deterrent to disclosure insofar as they had felt their child's provider would not know much about ASD treatment options including CHA. Conversely, five parents described how their child's provider had greater knowledge of ASD than did other doctors and that had facilitated disclosure, as well as higher relationship quality more generally.

Length of provider visit and other visit characteristics impact disclosure—

Seventeen parents described some aspect of visits to their child's healthcare provider as a disclosure barrier and/or facilitator. Time allotted was the most frequently mentioned visit characteristic, with parents indicating that having enough time or a relatively long amount of time facilitated disclosure whereas having not enough time or a short amount of time was as a barrier to disclosure. Some parents also related the amount of time spent by providers during visits to the quality of their relationship with the child's provider.

I just feel like, the information sometimes that I want to say or how I want to say things, it doesn't come out in the way that it should be. But, for instance, when I see [child's naturopath] once a month, which is his alternative doctor, per se. And, that one hour that I have with her, once a month, literally that is all we do. We talk about his diet, and what's been working for him. How's he doing in school, and so there's a whole different approach of dietary, and behavior, physically, and just overall. And, the doctor's visit, it's basically, like I go in there, but I go in there for a specific reason, and I feel like I can't talk about anything else because I have to schedule something else, another appointment just to touch on that one thing. (mother, 8 yr. old boy, Oregon)

In describing visit characteristics, 10 parents additionally explained how being asked to report or list the treatments, including CHA, used by their child had facilitated disclosure. Some parents elaborated that they kept a detailed list medications and supplements (e.g., vitamins) their child took, so they could give this to providers at visits. The mother of a six-year-old boy in Oregon detailed:

Interviewer: Have you ever discussed his use of complementary and alternative medicine with his regular doctor or healthcare providers?

Parent: Yes, they're aware of all the supplements he takes.

Interviewer: How does it usually come up?

Parent: They ask us for our med list, and we give them two sheets of paper.

Discussion

Our study provides new insights into the barriers and facilitators of parent disclosure about CHA used for children with ASD. Parents' drive to optimize their child's health and self-efficacy to discuss CHA with their child's provider(s) were each viewed as facilitating disclosure. Parent beliefs about CHA effectiveness could, however, be a barrier or facilitator to disclosure. Parent-provider relationship quality, provider characteristics, and visit characteristics were also key factors identified as impacting disclosure.

Findings from our study suggest that several factors at the family level, such as parent beliefs about CHA effectiveness, affect disclosure. However, little past research serves as a point of comparison with our study's findings. One study found that parents who do not use CHA themselves are more likely to disclose the use of CHA for their child,²³ but this was not a factor identified in our study. Another study found that parents, on average, perceived some efficacy of the CAM for their child with ASD, yet the relationship of perceived CAM efficacy with disclosure was not determined.³¹ Future research is, therefore, needed to better understand associations of the family factors with disclosure. Still, our study's initial findings could be used to inform intervention promoting disclosure. For example, our study's finding that self-efficacy facilitates disclosure could be used as a basis for an educational intervention to increase parents' self-efficacy to discuss CHA and other treatments with pediatric healthcare providers

In alignment with past research,^{23,24} we found that parent-provider relationship quality and provider characteristics—namely attitudes toward CHA and knowledge of CHA/ASD—were key factors helping or hindering disclosure. We further found that provider attitudes (vs. knowledge) about CHA were the most salient provider characteristics influencing disclosure for parents. Within the broader context of shared treatment decision-making, research on the perspectives of both parents and providers of children with ASD regarding CHA use reinforces that CHA can be a divisive for families and providers.³² In addition, research on provider perspectives of CHA suggests that a majority of providers encourage the use of some CHA for ASD but may want additional training on CHA.³³ Increased provider training regarding CHA and ASD may, consequently, help promote disclosure. Future research is also needed to determine how providers can best engage parents in discussion about CHA for ASD to preserve shared treatment decision-making and their therapeutic relationship with families over time. One starting point for this may be the adaptation of brief provider training interventions shown to have promise for promoting parent-provider communication about various health risks.³⁴

This study has several limitations. Given its design and exploratory nature, the findings are not generalizable to the broader population of parents of children with ASD. All parents were recruited from Denver, Colorado or Portland, Oregon; locations that may be more conducive to using CHA than other geographic areas in the United States. We also did not sample parents of children with ASD who might have considered CHA but had never used CHA for their child; therefore, parent perspectives on hypothetical use and disclosure of

CHA are not represented. Though we primarily asked parents about their experiences during the past year, the potential for recall bias still exists.

Nevertheless, our study's findings have utility. Perhaps one of the most important messages for conventional healthcare providers is that disclosure is often influenced by parents' perceptions of provider knowledge, attitudes, and communication about CHA and ASD. Increased provider training about ASD, CHA, and best practices for shared treatment decision-making could, therefore, be beneficial in terms of increasing disclosure.

Conclusion

Family and health system factors influence parent disclosure of CHA used for children with ASD. These factors could be intervened upon using educational and organizational strategies targeting families of children with ASD and their healthcare providers. As part of effective shared treatment decision-making, encouraging parent disclosure of CHA may help to advance health for children, including those with ASD, and their families.

Acknowledgments

This research was supported in part by the Ruth Warnke Graduate Fellowship from Oregon State University and grant # K23MH095828 from the National Institute of Mental Health. We thank Lorraine Ball, Dr. Adam Branscum, Dr. Joseph Catania, Dr. Kari-Lyn Sakuma, and Dr. Emily Ho for their feedback on the research reported. We also thank Dr. Ann Reynolds and Dr. Kathryn Smith for their assistance with the submission of research protocol materials to their respective Institutional Review Boards.

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Figure 1.

Conceptual framework for exploring factors promoting and impeding the disclosure of complementary health approaches among children with autism spectrum disorder (adapted from Fouladbakhsh & Stommel, 2007)

Table 1

Interview Questions and Probes about Parent Disclosure of CHA used

Order	Question
1	Have you discussed [child's name]'s complementary and alternative medicine use with [his/her] doctor or other healthcare providers? Please describe how this discussion occurred.
2	What, if anything, has made it easier for you to talk with [child's name]'s doctor or other healthcare providers about using complementary and alternative medicine for [him/her]?
3	What, if anything, has made it difficult to talk [child's name]'s doctor or other healthcare providers about using complementary and alternative medicine for [him/her]?
4	Have you ever intentionally not brought up using complementary and alternative medicine for [child's name] with [his/her] doctor or other healthcare providers? Why?
5	Thinking about other families of children with autism, what might make it difficult for them to talk with doctors or other healthcare providers about using complementary and alternative medicine for their child?
6	How could doctors or other healthcare providers make it easier for families to talk with them about using complementary and alternative medicine for children with autism?
7	Now, thinking more specifically about how visits with your child's doctor typically go. During the visit, how could the doctor or other healthcare providers make it easier to discuss using complementary and alternative medicine for children with autism?

Table 2 Characteristics of Interview Participants (*N* = 31)

	<i>n</i>	%
<u>Parent</u>		
Relationship to child with ASD ^a		
Mother	29	94%
Father	1	3%
Grandmother	1	3%
Age, years		
Mean (<i>SD</i>)	35.8 (6.6)	
Years of education		
12–16 years	24	81%
17–20 years	6	19%
Married or living with a partner	23	74%
Number of children		
Median (Range)	2 (1–6)	
<u>Child with ASD</u>		
Age ^a		
6–9 years	25	81%
10–12 years	6	19%
Ethnicity		
Non-Latino	19	61%
Latino	12	39%
Gender ^a		
Male	25	81%
Female	6	19%
Health insurance type		
Public only	15	48%
Any private	16	52%
Initial age of ASD diagnosis, years		
Mean (<i>SD</i>)	3.4 (1.6)	
ASD severity		
Mild	12	39%
Moderate or severe	19	61%
<u>Type of CHA ever used^a</u>		
Natural products	29	94%
Mind and body practices	25	81%
Other approaches	25	81%
<u>Conventional services used^{a,b}</u>		
Preventive or well-child care	26	84%
School-based services	26	84%

	<u><i>n</i></u>	<u><i>%</i></u>
Outpatient therapy	25	81%
Medication	16	52%
Specialty care	12	39%
Early intervention	9	29%

^aData were gathered through the interviews. One participant did not report years of education.

^bThe most frequently reported conventional health services are shown (i.e., services for which < 2 children used are excluded).

School-based services included special education, as well as school-based therapy such as speech and language therapy or social skills training. Medication includes prescription and over-the-counter medication.