



## 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.

### 1. Introduction

Autism spectrum disorder (ASD) is a complex neurodevelopmental condition characterized by impairment in social and/or behavioral functioning.<sup>1</sup> ASD is a relatively prevalent childhood condition: 1 in 68 US children are estimated to have ASD.<sup>2</sup> Although no curative treatment for ASD exists, treatment to manage or reduce symptoms is recommended.<sup>3</sup> 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).<sup>4</sup> CHA use is common among children with ASD: between 28<sup>5</sup> and 95%<sup>6</sup> 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.<sup>7–10</sup> Moreover, many CHA have limited evidence of efficacy for ASD<sup>7,11–14</sup> and are not covered by health insurance plans.<sup>15</sup>

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.<sup>16–21</sup> 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.<sup>16,19,22</sup> 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

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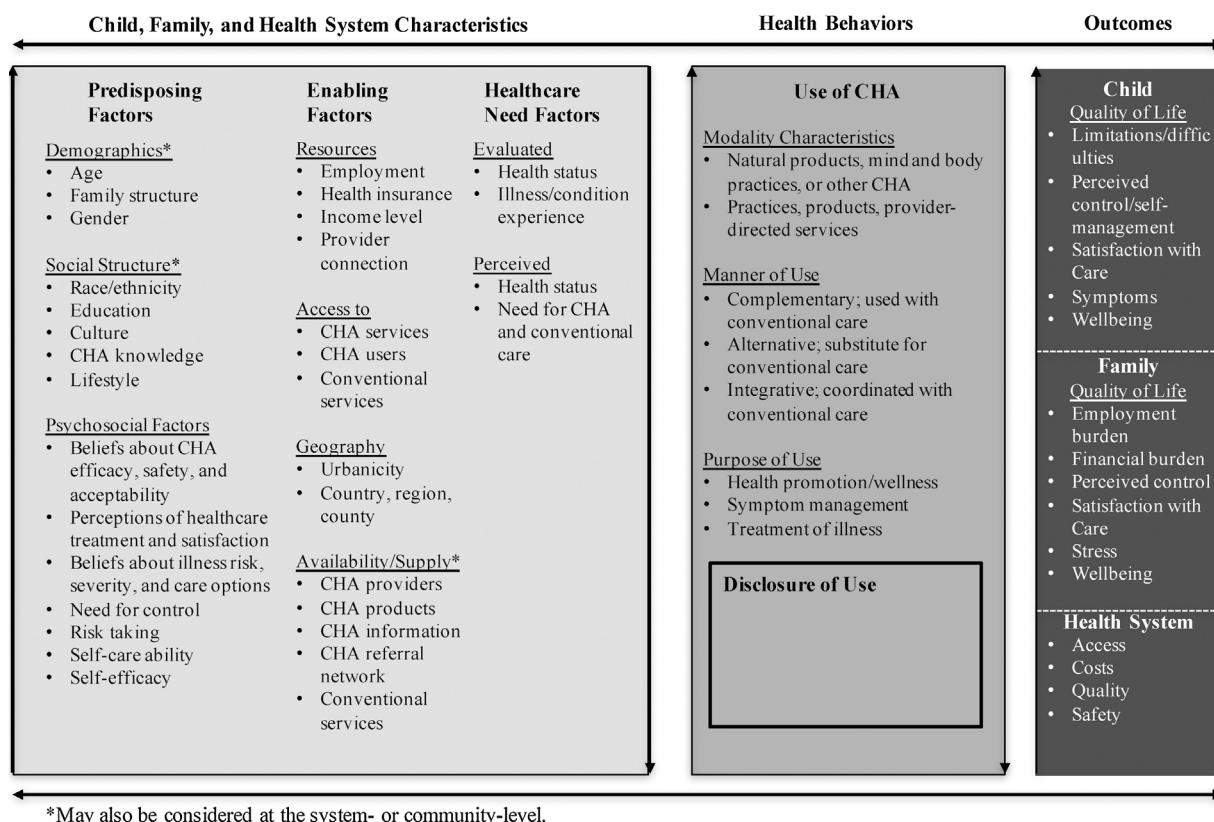


Fig. 1. Conceptual framework for exploring factors promoting and impeding the disclosure of complementary health approaches among children with autism spectrum disorder. Adapted from Ref. Fouladbakhsh and Stommel.<sup>26</sup>

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,<sup>23–25</sup> 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.<sup>23–25</sup> 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.<sup>23–25</sup>

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 (Fig. 1) adapted from the Complementary and Alternative Medicine (CAM) Healthcare Model.<sup>26</sup>

## 2. 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.<sup>27</sup> The Institutional Review Boards at the affiliated universities approved this study.

### 2.1. 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).

### 2.2. 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 35–120 min and were recorded then transcribed verbatim. Each participant received a \$20 gift card.

### 2.3. 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).

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