DISCUSSION AND REVIEW PAPER





Factors Affecting Parent Treatment Decisions for Children with Autism Spectrum Disorders: A Brief Review

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Abstract

Parents and caregivers of individuals with autism spectrum disorders (ASD) are faced with a vast array of treatment options, which vary greatly in evidence-based merits, and it is unclear what factors affect their final selections. Understanding the factors that influence family decisions can shed light on avenues for more effectively communicating the importance of selecting empirically supported treatments. In this article, we conducted a systematic literature review on how parents select evidence-based treatments for their children with ASD. We categorized treatment types using a combination of established resources, such as the National Standards Project (NSP), to determine the validity of research evidence for different ASD treatments. We reported the various treatment types, decision-making factors, and sources of recommendations across the literature, and compared those with earlier systematic literature reviews. The results of the present review indicate that parents' decisions are influenced by the accessibility of treatment, trust of practitioners, and alignment on factors such as parental values and the child's specific needs. We conclude with suggestions for practitioners and researchers on future research and wider adoption of evidence-based treatments (EBTs).

 $\textbf{Keywords} \ \ \text{Evidence-based treatment} \cdot \text{Autism spectrum disorder} \cdot \text{Caregiver treatment selection} \cdot \text{Treatment decision} \\ \text{making} \cdot \text{Systematic review}$

In the United States, the prevalence of autism spectrum disorder (ASD) has nearly tripled from 1 in 150 in the year 2000 to 1 in 54 children in 2016 (Centers for Disease Control & Prevention [CDC], 2020). Increases in children diagnosed with ASD mean that more parents are faced with difficult decisions about selecting their child's intervention(s) (Edwards et al., 2018). Making treatment decisions can be difficult with so many options available. There is an abundance of intervention options targeted at treating the symptoms correlated with ASD (CDC, 2016). Green et al. (2004) identified 108 unique ASD treatments that parents selected for their children; many of which do not meet the criteria to be considered evidence-based (National Autism Center, 2015). There is substantial evidence that early intensive behavioral intervention (EIBI) is the best available treatment targeting the core symptoms commonly observed in children with ASD (Eldevik et al., 2009), but parents do not always

select it (McDonald & DiGennaro Reed, 2018). There are several variables other than research evidence that influence treatment selection (Carlon et al., 2013; Wilson et al., 2018).

With many treatment options to choose from, parents may have difficulty discriminating between empirically supported and unsupported treatments. Health-care professionals tend to make recommendations for which ASD behavioral treatment outcomes are mixed (Miller et al., 2012; e.g., sensory integration, gluten-free casein-free diet, speech therapy), making the decision even more difficult. McCormack et al. (2020) conducted a systematic review and found that most primary care physicians made referrals based on personal experiences with autism rather than robust, scientific evidence. The selection of nonevidence-based treatments can cost families time, money, and delay the treatment process altogether (Heward, 2003). Individuals with ASD make the most progress when they receive treatment during their peak years of neuroplasticity (e.g., under the age of 5 years old; Gormley et al., 2020). Early intervention is imperative given the positive correlation between neuroplasticity and successful treatment outcomes (Espinosa, 2018). Little research has been conducted to identify the trends that correlate with

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parents' ASD treatment decisions (Carlon et al., 2013; Wilson et al., 2018). Carlon et al. (2013) reviewed 16 studies and Wilson et al. (2018) reviewed 11 studies to identify the factors parents self-reported influenced their treatment decisions for their children with ASD. Carlon et al. (2013) and Wilson et al. (2018) both identified that the most declared treatment decision-making factors were recommendations (i.e., a third party encouraging the pursuit of a particular treatment) and availability/accessibility (i.e., opportunities to uptake a particular treatment). However, neither Carlon et al. (2013) nor Wilson et al. (2018) utilized standardized criteria to discriminate evidence-based treatments from nonevidence-based treatments, which makes it difficult to compare their variables to other published literature because there are inconsistencies in the categorization of treatments. Addressing this gap in the literature is an important first step to fixing a much larger issue: a complex health-care system that neglects the most crucial elements of treatment decision making. The purpose of this discussion and review article is to identify factors that influence parents' treatment decisions for their children with ASD and recommend a standardized procedure of categorizing treatment types for future research in this area.

Method

Selection Criteria

We included any peer-reviewed articles in which data were collected from parents of children with ASD on decision-making factors regarding treatment for their child. We excluded articles that cited Carlon et al. (2013) if they were also cited by Wilson et al. (2018); articles with data that were obtained from anyone other than parents; chapters from books; conceptual papers; literature reviews; duplicates; and articles in any language other than English.

Search Protocol

We consulted subject expert librarians from California State University, Northridge, to come up with the method of conducting the search. In particular, we searched articles that cited Carlon et al. (2013; n = 38) and Wilson et al. (2018; n = 3) on the Google Scholar search engine to expand upon these previously published literature reviews.

Data Extraction and Coding

The following variables were extracted and coded into the following: (1) Treatment Types (i.e., evidence-based treatment (EBT), complementary and alternative medicine (CAM), EBT/CAM, dietary interventions and/or supplements only, and medication; (2) decision-making factors (e.g., parent values

and preferences, availability and/or accessibility, specific needs of the child, recommendation(s), cost/affordability, research evidence, time constraints, treatment side effects/adverse, child's age, language barriers, and other); (3) sources of recommendations (e.g., professionals, physicians, parents, internet, books/authors on autism, family members, health food store, and other). All variables were adopted and synthesized from Carlon et al. (2013) and Wilson et al. (2018). We used Slocum et al.'s (2014) definition of evidence-based practice (i.e., "... decision making in which practitioners integrate the best available evidence with client values/context and clinical expertise") and the National Standards Project (NSP; National Autism Center, 2015) to categorize treatment types.

Treatment Types

Evidence Based Treatment (EBT)

We used the criteria outlined by the NSP (National Autism Center, 2015) and Slocum et al.'s (2014) definition of evidence-based practice to determine which treatments to classify as EBTs. The NSP considered studies with strong experimental design that had been replicated and included interventions with individuals with ASD as evidence-based. The aforementioned criteria were vetted by a panel of 27 ASD professionals ranging from BCBA-Ds and individuals with Master's degrees to PsyDs and current graduate students, who identified articles through various search engines and scored them using a scientific merit rating scale (for a comprehensive breakdown of the scale, see pp. 25-35 of the NSP.) According to NSP, the following have been identified as having an established level of evidence: behavioral interventions, cognitive behavioral intervention package, comprehensive behavioral treatment for young children, language training (production), modeling, natural teaching strategies, parent training, peer training package, pivotal response training, schedules, scripting, self-management, social skills package, and story-based intervention (National Autism Center, 2015).

In our review, we included all the treatments listed above as EBTs apart from "story-based intervention." We categorized this treatment as combination EBT/complementary alternative medical treatments (CAM) for numerous reasons. First, the example given in the NSP (National Autism Center, 2015, p. 70) did not use the Social Story TM in isolation from the other treatments. This lack of experimental control is also reflected in a single-case meta-analysis conducted by McGill et al. (2015) who also found that "small to negligible effect on behavioural functioning . . . was observed across settings on several of the indicators, [so] there is insufficient evidence for justifying the use of Social Story treatments as a primary intervention for decreasing problem behaviours for children with autism" (p. 37). Finally, the author of the recommended reading herself stated "[the] most common misconception is

that the goal of the Social StoryTM is to change [audience] behavior. This has never been the case. The goal of a Social StoryTM is to share accurate information meaningfully and successfully" (Gray, 2010, p. xxxi). For these reasons, we decided to categorize this treatment as EBT/CAM.

Nonevidence-Based Complementary and Alternative Medicines (CAMs)

We categorized treatments as CAMs when the published research evidence for the treatments did not meet the criteria for established interventions. These treatments are defined as a "broad set of health care practices that are not part of that country's own tradition and are not integrated into the dominant health care system" (World Health Organization, 2000) and include such practices as music therapy, aromatherapy, shock therapy, and chelation therapy.

Combination (EBTs/CAMs)

We categorized treatments as combination EBTs/CAMs when the treatments consisted of packages in which at least one treatment met EBT criteria and at least one treatment met CAM criteria. Some examples would include treating symptoms of ASD with animal-assisted therapy and priming, a Social StoryTM with modeling and rehearsal, etc.

Dietary Interventions and/or Supplements Only

We used this category for treatments exclusively comprised of diets or supplements that claim to help with symptoms of ASD. According to the NSP, health care professionals are commonly expected "to implement curative diets with a high degree of fidelity" (National Autism Center, 2015, p. 19). We created the dietary interventions and/or supplements only category of treatments to have the treatment categories similarly reflect procedures that health care professionals are often required to implement. We counted each example in which the caretaker was treating ASD symptoms with diet-based interventions alone (e.g., gluten-free diets, casein-free diets, increasing vitamin B12).

Dietary interventions were categorized as "unestablished" by the NSP. However, we categorized "dietary and/or supplements only" separately from CAMs for two reasons. We categorized in this way in order to maintain consistency with Carlon et al. (2013) and Wilson et al. (2018) and to help differentiate the prevalence of specific unestablished interventions.

Medications

We categorized treatments as "medications" when caregivers reported use of prescribed pharmaceutical interventions to address symptoms of ASD. Although the NSP largely

excluded biomedical interventions (see p. 19 of the NSP), we included this subcategory because caregivers reported prescribed medications as treatment for ASD in the literature reviewed by Carlon et al. (2013) and Wilson et al. (2018).

Although there are certain medications approved by the National Institutes of Health (NIH) for treating symptoms of ASD (e.g., tricyclics, stimulants, anticonvulsants; NIH, n.d.), the literature does not always differentiate the exact medication prescribed (Carlon et al., 2019; Chaidez et al., 2018; Frame & Casey, 2019). In addition, some of the demographics came from countries other than the United States (Carlon et al., 2019; Edwards et al., 2018; Shepherd et al., 2017; Shepherd et al., 2018), which eliminates the applicability of NIH- and Food and Drug Administration (FDA)-approval for medications. For this reason, we have isolated "medications" as their own category.

Decision-Making Factors

We selected and identified variables parents reported to influence their choice of treatment as "decision-making factors." We discovered each of the following decision-making factors in the results section or the tables and/or figures in each research article and coded them as follows. We coded a decision-making factor as "parent values and preferences" when parents reported their culture, personal or religious beliefs, and personal or religious values influenced their treatment decision. We coded "availability and/or accessibility" any time parents reported the geographical location of or waitlists for certain treatments as factors in their treatment decision. We chose to consolidate geographical location and waitlists to maintain consistency with Carlon et al.'s (2013) categorization of "availability and/or accessibility." We coded "specific needs of the child" any time parents reported specialization of the treatment to work on their child's specific symptoms or idiosyncratic treatment targets as a decision-making factor (e.g., treatments that specifically target language development). Any time parents reported suggestions from others to pursue a particular treatment (e.g., a physician suggested pursuing a treatment, another parent recommended the treatment that worked for them), we coded "recommendation(s)." We coded "cost/affordability" as any time parents reported the financial considerations and/or availability of funding assistance as a factor for their treatment decision. We coded "research evidence" any time parents reported empirically established scientific literature as a factor in making a treatment decision (e.g., studies from academic journals). We coded "time constraints" when parents reported time commitment or scheduling conflicts as a treatment-decision factor (e.g., a parent cannot commit the 40-hr recommended for EIBI due to their work schedule). We coded "treatment side effects/adverse" any time parents reported scientifically established or anecdotally reported side effects of the treatment (e.g., a certain medication can cause sleep disturbances, a diet is reported to potentially cause weight gain) as a factor for their treatment decision. We coded "child's age" any time parents specified that their child's chronological age influenced their treatment decision (e.g., the parent's child was too old for EIBI). We coded "language barriers" any time parents reported language accessibility for treatments influenced their treatment decision (e.g., parents only speak Spanish but there is no Spanish or translation services for a particular treatment). We coded any decision-making factor outside of those listed above as "other."

Sources of Recommendation(s)

We investigated and coded parent-reported recommenders for treatments as "sources of recommendation(s)." We found each of the following sources of recommendation(s) in the results section or the tables and/or figures in each research article and coded them as follows. A source of recommendation was categorized as a "professional" when parents reported that behavior analysts, speech and language pathologists, psychologists, teachers, social workers, occupational therapists, or any other nonphysician professional working with their child recommended a treatment. We coded any treatment recommendation from a medical doctor as "physicians." Any treatment recommendation from other parents not related to the family that made the treatment decision was classified as "parents" (i.e., a parent of a child with autism in a support group made a treatment recommendation). We coded treatment recommendations from anyone related to the parents as "family members" (e.g., a cousin, aunt, brother). We categorized any treatment recommendations from web-based searches (i.e., parents searched internet browsers for treatment recommendations) as "internet." We coded treatment recommendations parents reported from published books specifically about ASD as "books/authors on autism." We classified treatment recommendations from stores that sell organic produce and/ or supplements as "health food store." We coded any recommendation outside of those listed above as Other.

Data Analysis and Interobserver Agreement

Interobserver Agreement for the Inclusion of Articles

The first and second authors independently read through the abstracts and bodies of all relevant articles and used a 46-item checklist to rate which articles to include and exclude. The first two columns of the checklist delineated the inclusion criteria ((i.e., Articles that cite Carlon et al. (2013), Articles that cite Wilson et al. (2018), quantitative or qualitative data obtained from parents of children with ASD, research on factors influencing parents' treatment decisions for their children with ASD, peer-reviewed, and English only)) and exclusion criteria ((Articles that cite Carlon et al. (2013) if they have been cited

by Wilson et al. (2018), data obtained from anyone other than parents (e.g., staff, teachers), chapters, conceptual papers, and reviews)). Each criterion corresponded to a code that was used to label articles incase discussions were required to resolve conflicts in agreement. The third column contained a list of 46 articles in alphabetical order. In the fourth and fifth columns, we independently rated which articles should be included from Carlon et al. (2013) and Wilson et al. (2018). Likewise, in the sixth and seventh columns, we independently rated which articles should be excluded from Carlon et al. (2013) and Wilson et al. (2018). We compared ratings and determined the final number of articles from which to gather data (n = 8). Interobserver agreement (IOA) of articles that met inclusion criteria was 100%.

IOA for Coding Variables

The first and second authors used a matrix to independently extract data from the articles and categorize data to determine whether specific components relating to treatment selection were present within the literature. We adopted a total of 48 variables across three categories (e.g., decision-making factors, sources of recommendation, treatment types) synthesized from Carlon et al. (2013) and Wilson et al. (2018). We defined the presence of a treatment selection component as any overt tact of 1 of the 48 variables of interest within the paper (e.g., written in figures, found in narratives).

The first and second authors calculated exact agreement IOA for all variables across all 8 articles. If we determined that an article met one of the variables, we counted that as an agreement. Contingent on an instance in which one author scored an article as meeting one of the variables and the other author reported that the same article did not meet the same variable, we counted that as a disagreement. We then added all agreements for each variable and divided the sum by the total number of articles in which at least one author scored an article as meeting a variable. The primary database was developed following a postscoring discussion between the first and second authors and coming to an agreement regarding each variable. The first and second authors compared data to determine the occurrence of variables across the eight articles and calculated exact agreement IOA to be 92%.

IOA for Treatment Types

Exact agreement IOA between the first and second authors for the category evidence-based treatment was 88%. Exact agreement IOA for CAMs was 80%. Exact agreement IOA between the first and second authors was 40% for EBT/CAMs. Upon discussion, we agreed this category had low IOA due to the lack of clarity of whether parents selected a combination of treatments or a single treatment. If combination treatments were established, there was no indication of whether treatments were implemented simultaneously

or sequentially. As a result, any category that included both EBTs and CAMs, we categorized as EBT/CAMs. IOA for EBTs/CAMs was 100% after discussion of the criteria to meet the EBT/CAMs. Exact agreement IOA between the first and second authors for dietary interventions and/or supplements only was 80%. Exact agreement between the first two authors IOA was 100% for medications.

Results

Treatment Types

All the studies in the present review (n = 8) concern caregivers' selection of EBTs for their children with ASD. We found that in 63% (n = 5) of studies parents selected CAM interventions, a combination of EBTs and CAMs, or dietary interventions and/or supplements only. We found 38% (n = 3) of studies overtly tact medications as parents' intervention of choice for ASD (See Appendix Table 1).

Decision-Making Factors for Treatment Choices

We identified parent values and preferences as a decision-making factor present across all studies (n=8). We found availability and/or accessibility of treatment and the specific needs of the child as factors as the next most cited decision-making factors at 88% of studies (n=7) each. We found 75% of studies (n=6) highlighted recommendations and cost/affordability as factors influencing caregivers' choice of treatment. Regarding research evidence (e.g., parents consulting scientific literature to inform treatment), we found 50% of studies (n=4) included it as an influential factor. We found that time constraints, treatment side effects/adverse, and other decision-making factors (e.g., internet, past experiences) influence parents in 38% of studies (n=3). We found 13% of studies (n=1) listed child's age as a factor influencing parents' treatment choice (See Appendix Table 2).

Sources of Recommendations for Specific Treatments

We identified 88% (n=7) of studies listed nonphysician professionals as the recommenders for specific ASD treatments. We found that the next-most cited recommenders are physicians and other parents, both at 75% (n=6) of studies. Internet and other factors are listed as a source of recommendation for treatment in 50% (n=4) of studies. Books/authors on autism were reported to influence parents' treatment decisions in 38% (n=3) of studies and parents' family members were listed in 25% (n=2) of studies (See Appendix Table 3).

Discussion

We conducted a systematic review to extend the literature on factors influencing parents' treatment decisions for their children with ASD. Overall, the present review's findings are consistent with those of Carlon et al. (2013) and Wilson et al. (2018), with a few new insights. Like the aforementioned reviews, we found that parents' selection of interventions is influenced by their personal values, child's needs, and accessibility to treatment. In addition, our results show a significantly greater emphasis on parents' values and preferences than previously reported. Also, in line with Carlon et al. (2013) and Wilson et al. (2018), we identified that nonphysician professionals (e.g., behavior analysts, speech and language pathologists, psychologists, teachers) were reported to influence parents selecting treatment for the behavioral symptoms of their child with ASD, even though their recommendations varied widely. In addition, in line with Carlon et al. (2013) and Wilson et al. (2018), waitlists and geographical locations were found to influence parents' selection of treatment, which is consistent with findings by Murphy and Ruble (2012).

Not only does this review extend the literature on factors influencing parents' treatment decisions, but it also serves as both a framework for practitioners with parents and a recommendation for researchers conducting future work in this area. In the next two sections of the present review, we share recommendations for wider adoption of EBTs and future research.

Recommendations for Practitioners

Although practitioners are ethically and professionally obligated to make treatment decisions that are empirically supported, they are also ethically obligated to disseminate information about behavior analysis and treatment-related procedures in consumable terms (Bailey & Burch, 2016). In this way, the practitioner takes the role of a liaison between researchers and parents. As shown in our review, comprehensibility of available research may play a critical role in the lack of influence that research evidence has on parents' treatment decisions. Practitioners can actively take steps to disseminate EBTs to parents by translating research in a way that is consumable and socially valid such that it relates back to parent values and preferences. By taking these steps, practitioners remove barriers that parents face in accessing EBTs.

Another difficulty for practitioners disseminating EBTs is that, as shown in our review, parents are most heavily influenced by their values and experiences of those in their communities. Researchers in other fields have thoroughly investigated approaches with appropriate interpersonal skills as a cornerstone for service professions (Sulzer et al., 2016). The field of behavior analysis has identified the necessity for

research on interpersonal skills (Callahan et al., 2019; LeB-lanc et al., 2019; Taylor et al., 2018). Although a growing research topic, there are already a few significant implications form these works. Taylor et al. (2018) suggested that it is crucial for practitioners to use any interaction with parents as an opportunity for dissemination. Further, practitioners should try to improve their relationship building skills by listening to parents' views and learning about their experiences. For practitioners to become effective agents in advocating for evidence-based treatment, they should incorporate parents' values and preferences within their treatment recommendations, thus establishing trusting partnerships with families and increasing EBT adoption among parents.

Recommendations for Researchers

The lack of standardization across independent variable categories throughout the literature was an issue that made aggregation and comparison of data between studies an immense challenge. Although many authors used similar categorizations of treatments and decision-making factors, not all used the same coding criteria. We recategorized the results from these works into a standardized coding criteria using the NSP and Slocum's definition of evidence-based practice (National Autism Center, 2015; Slocum et al., 2014). We recommend that researchers adopt this standardized criteria to code their variables in future studies. This standardization will not only help with data aggregation and comparison but will also improve the objectivity and ensure the validity of individual works. Further, these standardized criteria may aid in the replication of studies. This review provides an example of standardization in EBT literature that other researchers in the area can use as a framework for future work.

The goal of behavior analyst researchers should always be to provide practitioners with scientifically supported treatments that they can offer clients (Bailey & Burch, 2016). Far too often, a researcher's merit is evaluated through other metrics such as h-index (i.e., number [n] of publications that has [n] or more citations). These metrics are frequently considered during interviews for tenured faculty positions, whereas the ethical guidelines to disseminate science do not provide the same reinforcers (Björk & Solomon, 2012). Research publication and dissemination are therefore not operating under the same contingencies. This review looks to highlight future research avenues that provide the most impact to clients. In particular, effective dissemination strategies are currently underresearched in behavior analysis (Taylor et al., 2018). Approaches from other health-care professionals (e.g., physical therapy, diabetes management) could provide a model for promoting adoption of treatments in behavior analysis. We hope this review will spark further interest into this area enabling the adoption of more EBTs for children with autism.

Appendix

 Table 1
 Treatment Types across the Number of Articles.

	Article								No. of	% total sample
	Carlon et al. (2019)	Carlon et al. Chaidez et al. (2019)	Dinora and Bogen- Dinora et al. Edwards et al. Frame and Shepherd et al. Shepherd et al. schutz (2018) (2017) (2018) (2018) (2017) (2018)	Dinora et al. (2017)	Edwards et al. (2018)	Frame and Casey (2019)	Shepherd et al. (2017)	Shepherd et al. (2018)	articles	
Treatment types										
EBT^{a}	>	>	>	>	>	>	>	>	8	100
EBT ^a /CAM ^b	>	>	>			>	>		5	63
CAM b	>	>	>		>	>			5	63
Dietary interventions and/ or Supplements only	>				>	>	>	>	5	63
Medication	>	>				>			3	38

The percentage reflects the number of articles mentioning specific treatment types. a EBT = Evidence-based treatment. b CAM = complementary and alternative medicine.

Table 2 Decision-Making Factors for Treatment Choices across the Number of Articles.

	Article									% total sample
	Carlon et al. Chaidez (2019) et al. (20	Chaidez et al. (2018)	Dinora and Bogenschutz (2018)	Dinora et al. Edwards (2017) et al. (201	Edwards et al. (2018)	Edwards Frame and Shepherd Shepherd et al. (2018) Casey (2019) et al. (2017) et al. (2018)	Shepherd et al. (2017)	Shepherd et al. (2018)	articles	
Decision-Making factors										
Parent Values and Preferences	>	>	>	>	>	>	>	>	∞	100
Availability and/or Accessibility		>	>	>	>	>	>		7	88
Specific Needs of the Child	>	>		>	>	>	>	>	7	88
Recommendation(s)	>	>	>	>	>	>			9	75
Cost/affordability	>		>	>	>	>	>		9	75
Research Evidence	>		>	>		>			4	50
Time Constraints	>		>				>		3	38
Treatment Side Effects/Adverse	>					>	>		3	38
Child's Age	>								1	13
Language Barriers									0	0
Other	>			>		>	>		4	50

The percentage reflects the number of articles mentioning specific decision-making factors.

Table 3 Source of Recommendation(s) for Specific Treatments across the Number of Articles.

	Article								No. of	No. of % total sample
	Carlon et al. (2019)	Chaidez et al. (2018)	Carlon et al. Chaidez et al. Dinora and Bogen- Dinora et al. Edwards et al. Frame and (2019) schutz (2018) charz (2018) (2017) (2018) Casey (2019)	- Dinora et al. (2017)	Edwards et al. (2018)	L. Frame and Shepherd Shepherd Casey (2019) et al. (2017) et al. (2018)	Shepherd et al. (2017)	Shepherd et al. (2018)	articles	
Source of recommendation(s)										
Professionals	>	>	>	>	>	>	>		7	88
Physicians		>	>	>	>	>	>		9	75
Parents	>		>	>	>	>	>		9	75
Internet			>	>		>	>		4	50
Books/Authors on Autism				>		>	>		3	38
Family Members			>	>					2	25
Health Food Store									0	0
Other	>			>		>	>		4	50

The percentage reflects the number of articles mentioning specific sources of recommendation.

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Declarations

Conflict of Interest The authors have no relevant financial or nonfinancial interests to disclose.

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