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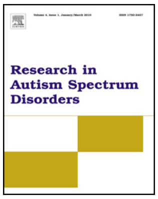

# Factors influencing treatment decisions by parents for their children with autism spectrum disorder

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ABSTRACT

Studies examining the treatment choices of parents of children with autism spectrum disorder (ASD) have mostly addressed questions about the prevalence of certain treatments. Fewer studies have examined the factors that influence their treatment decisions. In this study, 18 parents of children with ASD rated treatments according to their knowledge about them and how effective they believed them to be. They then distributed tokens representing resources (i.e., money, time, and energy) amongst the treatments they were currently using, or would use were there fewer constraints. Finally, they distributed tokens amongst hypothetical treatments about which they were only given information regarding empirical support and immediacy of outcome. Without the constraints of cost and availability participants distributed resources broadly. However, participants showed a preference for empirical support over immediacy of treatment outcome.

Even a relatively superficial review of the research literature or popular media reveals that there are a great many treatments that purport to be effective for individuals with autism spectrum disorder (ASD; Reichow, Barton, Boyd, & Hume, 2012). This profusion of treatment alternatives presents a challenge for the parents of individuals with ASD when it comes to making decisions about which to employ. With so many treatments and so little clear guidance it is not surprising that a wide range of treatments are utilized by parents with their children with ASD. Several studies have attempted to evaluate parents' use of specific categories of treatments for ASD, such as medications (e.g., Martin, Scahill, Klin, & Volkmar, 1999), special diets (e.g., Goin-Kochel, Myers, & Mackintosh, 2007) or complementary and alternative medicine (e.g., Hall & Riccio, 2012; Levy & Hyman, 2008). Others have attempted to be as comprehensive as possible in ascertaining which treatments are being used with individuals with ASD (e.g., Bowker, D'Angelo, Hicks, & Wells, 2010; Goin-Kochel et al., 2007; Green et al., 2006). Recurring themes that emerge from these studies are that (1) most parents utilize many treatments simultaneously (Goin-Kochel et al., 2007; Green et al., 2006; Kohler, 1999; Smith & Antolovich, 2000), (2) most parents are implementing an eclectic combination of treatments, representing diverse (and sometimes contradictory) approaches to treating ASD (Bowker et al., 2010; Goin-Kochel et al., 2007; Green et al., 2006), and (3) although the majority of treatments have advocates who assert their benefits, many are ineffective or lack empirical support (Bowker et al., 2010; Green et al., 2006; Heflin & Simpson, 1998).

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Parents of individuals with ASD have also shown a willingness to persist with this strategy of using diverse treatments that include those without empirical support, or even those that are harmful, despite evidence of ineffectiveness (Offit & Jew, 2003). For example, in a placebo-controlled trial of secretin, 69% of the parents assigned to the secretin group remained interested in using it as a treatment even after they were told that the results of the study showed it had no effects beyond placebo (Sandler et al., 1999). Although a tendency to utilize a treatment approach that emphasizes eclecticism in an environment of competing claims and a lack of clear guidance may be logical, there can be negative consequences. In many instances, parents use treatments that work at cross-purposes to each other. Using many treatments simultaneously also spreads available resources amongst more treatments rather than maximizing the ones that are most likely to improve outcomes. Finally, simultaneous use of multiple treatments makes it difficult to evaluate the effectiveness of any single treatment or specific combination of treatments for a given individual (Green et al., 2006). Thus, the way most parents are selecting treatments is at best probably preventing optimal outcomes for their children with ASD, and at worst may be doing actual harm.

More recently, researchers have gone beyond identifying which treatments are being used and begun examining the factors that seem to influence treatment selection by parents. In one such study, Goin-Kochel et al. (2007) found that the number and types of treatments employed by parents differs depending on the age and symptom presentation of their child with ASD. Other studies have attempted to ascertain parents' reasons for treatment decisions. For example, Bowker et al. (2010) found that parents reported that their reasons for discontinuing treatments differed depending on the type of intervention: they were most likely to stop using treatments based on applied behavior analysis due to cost or lack of availability, whereas they discontinued most other treatments due to ineffectiveness. Similarly, the source from which parents receive information about a treatment has also been found to affect the likelihood of their using it (Smith & Antolovich, 2000). Such studies on the variables that influence parent treatment choices (e.g., Mackintosh, Myers, & Goin-Kochel, 2005) are important because they have the potential to yield insights into how to influence parents' decisions about whether or not to adopt effective treatment strategies.

Although research into the variables that influence parent treatment choices is increasing, many factors that may affect those choices remain unexplored. For example, parents' perceptions of how knowledgeable they are about a treatment and their perceptions of the immediacy of a treatment's outcomes once implemented are both likely to influence the treatments parents select, but have not yet been thoroughly examined. Similarly, results of the study by Bowker et al. show that unavailability and cost may cause parents to discontinue some treatments, but there is little evidence on the way these constraints affect whether they initially select certain treatments to begin with. Perhaps the greatest gap in this emerging literature is that the manner in which these types of factors interact to affect treatment choices has not been examined thoroughly.

The methods used to study parents' treatment choices employed to date, which have generally consisted of brief surveys of large numbers of parents, may not be amenable to answering these types of questions. Rather, it may be necessary to collect more in-depth data on parents' decision making, even if doing so means gathering more detailed information from smaller samples. The aim of this pilot investigation was to develop and report preliminary findings from such a novel method of examining parents' treatment choices for their children with ASD. Participating parents rated individual treatments on factors such as how effective they perceived them to be and how much they knew about them. In three subsequent conditions the same participants allocated hypothetical resources toward treatments to ascertain (1) how parents were deploying their own resources toward treatments; (2) how they would use treatments when there were no constraints in the form of cost and availability; and (3) the respective influence of two treatment factors (i.e., empirical support and immediacy) on their decision making. Each of these conditions differed in the type of information on parent decision-making gathered, ranging from concrete decisions they were actually making about treatments at that time, to more abstract information about how certain factors were prioritized. Our goal was to demonstrate the feasibility of this methodology for gathering more in depth information on how various factors affect parent treatment decisions, including ascertaining how some of these factors may interact.

## 1. Methods

### 1.1. Conditions

This study included three different conditions, each of which represented a different methodology for examining variables that affect parents' decisions about treatments for ASD. Participants began by completing a questionnaire that gathered information on their perceptions of how knowledgeable they were about each treatment for ASD and its effectiveness. In all three of the subsequent experimental conditions they allocated hypothetical resources toward treatments related to their child's ASD diagnosis. In the *current treatment utilization* (CTU) condition, participants distributed those resources amongst actual treatments appearing in the research literature in proportion to how they were currently allocating their own time, money, and energy toward treatments. The *unconstrained treatment utilization* (UTU) condition replicated the CTU condition with the exception that parents distributed a larger pool of resources amongst treatments in proportion to how they would use treatments for their child if there were diminished constraints in the form of cost and availability. The *opposing treatment factors* (OTF) condition presented participants with choices between hypothetical