



Contents lists available at ScienceDirect

Research in Autism Spectrum Disorders

journal homepage: www.elsevier.com/locate/rasd

A systematic review of factors related to parents' treatment decisions for their children with autism spectrum disorders

Meghan Wilson*, David Hamilton, Thomas Whelan, Pamela Pilkington

School of Psychology, Faculty of Health Sciences, Australian Catholic University, 115 Victoria Parade, Fitzroy VIC 3065, Australia

ARTICLE INFO

Number of reviews completed is 2

Keywords:

Autism spectrum disorder
ASD
Treatment decisions
Parents
Systematic review

ABSTRACT

Background: There are many treatment options for children with Autism Spectrum Disorder (ASD). Misinformation and easy access to ineffective treatments complicates the decision-making process for parents. Research on implicit factors (e.g., parent or child characteristics) and declared factors (e.g., parent-reported reasons) contributes to an understanding of what influences these decisions.

Method: The aim of this systematic review was to examine the significance of factors associated with treatment selection. The review was conducted in accordance with the PRISMA protocol. **Results:** The search revealed 51 studies which contained data on implicit and/or declared factors associated with treatment selection. The data were tabulated by factor and synthesised. The severity of a child's behavioural problems, parental stress, and parent beliefs about ASD were consistently identified as implicit factors associated with the use of particular treatments. A wide range of reasons for treatment choices were declared by parent respondents, including; the individual needs of their child, recommendations from others, practical reasons (e.g., cost), child age, hope for recovery, hope for improvement, and concerns about side-effects.

Conclusion: A better understanding of these factors will inform targeted educational approaches which encourage evidence-based practice and a more informed view of treatments not yet supported by research.

1. Introduction

Following a diagnosis of Autism Spectrum Disorder (ASD), parents are encouraged to access an intervention for their child. This can be challenging given that there are many options. Green et al. (2006) identified 111 different treatments for ASD. The list included a wide range of options such as dietary interventions (e.g., restricted diets or vitamin supplements), other alternative therapies (e.g., detoxification treatments), educational or clinical approaches (e.g., Applied Behaviour Analysis programs or speech therapy), and combined programs (e.g., Floor Time). The commitment of resources (e.g., time or cost) and ease of implementation can vary greatly between approaches (Green, 2007). The selection of interventions is further complicated in that it is common for professionals to recommend treatments that are not evidence-based (Miller, Schreck, Mulick, & Butter, 2012) and the internet provides a forum for misinformation (Matson, Adams, Williams, & Rieseke, 2013). Not surprisingly, choosing treatments can be overwhelming for parents. Exploring the reasons treatments are chosen is a worthwhile step in understanding the scope of this problem and developing meaningful strategies to assist with choice making. Therefore, the present review aimed to identify and understand the significance of factors associated with the selection of ASD treatments.

* Corresponding author.

E-mail address: meghan.wilson@myacu.edu.au (M. Wilson).

<https://doi.org/10.1016/j.rasd.2018.01.004>

Received 28 July 2017; Received in revised form 18 December 2017; Accepted 9 January 2018

Available online 03 February 2018

1750-9467/ © 2018 Elsevier Ltd. All rights reserved.

Intervention research has largely focussed on programs based on behavioural principles (e.g., ABA programs) or educational approaches (e.g., Treatment and Education of Autistic and Related Communication Handicapped Children) (Myers & Johnson, 2007). Such programs are implemented to teach new skills and address maladaptive behaviours. Behavioural interventions are supported by the best available evidence (Anagnostou et al., 2014; Myers & Johnson, 2007). Along with traditional intensive behavioural interventions, there is emerging evidence for variations to these approaches, for example, developmental, play-based, or social skills interventions (Weitlauf et al., 2014). Yet, evidence-based treatments do not result in equal gains for every child, progress can be slow, and there is no expectation of a cure (Myers & Johnson, 2007).

The high prevalence of comorbidity in children with ASD (e.g., ADHD or intellectual disability) adds to the difficulty of choosing an appropriate intervention (Matson & Williams, 2015). Some common approaches used for children with ASD (e.g., restricted diets or drug treatments), may be warranted for comorbid problems, but are not currently recommended to treat the core features of ASD (National Institute for Health and Care Excellence, 2013).

Treatments outside of the realm of conventional practice (known as complementary and alternative medicine, CAM) continue to be used (Matson et al., 2013; Whitehouse, 2013). In addition, parents often access multiple treatments simultaneously. For example, Smith and Antolovich (2000) found that, of 121 children engaged in ABA therapy, parents reported accessing an average of seven additional treatments. Commonly used CAM treatments in the paediatric ASD population are the use of vitamins (e.g., vitamin B6/Magnesium) and restrictive diets (e.g., a gluten-free/casein-free diet) (Levy & Hyman, 2008; Whitehouse, 2013). Other examples are detoxification treatments, mind-body practices, hyperbaric oxygen therapy and sensory integration therapies (Levy & Hyman, 2008; Whitehouse, 2013). CAM practices may be ineffective or pose unnecessary risks (e.g., nutritional imbalances) (Levy & Hyman, 2008; Whitehouse, 2013). Other concerns about using CAM include high financial costs and missing out on treatments supported by research (Matson et al., 2013).

It appears that the research evidence guiding professional practice is often not the driving force behind parent decisions (Matson & Williams, 2015). Indeed, many factors have been hypothesised to influence parents' decisions about treatments. *Implicit factors* are those characteristics associated with the use of treatments, but not necessarily cited by parents as a reason for choosing a treatment. Parent demographics (e.g., education or age), child characteristics (e.g., age, gender or ASD severity), and family demographics (e.g., income or ethnicity) are examples of implicit factors that have been explored (Matson & Williams, 2015). *Declared factors* are reasons or influences that parents cite regarding their intervention choices. A systematic review of 16 studies (Carlon, Carter, & Stephenson, 2013) examined factors parents declared to have influenced treatment choices for their child with ASD. Recommendations (by health professionals or others) was the most cited reason for choosing a treatment. Other frequently declared factors included practical reasons (e.g., availability, accessibility, cost, time constraints, funding, and availability of other interventions), perception of progress, use and perceived effectiveness of other interventions, needs of the child, research evidence, child's resistance, side effects, and compatibility with other interventions (Carlon et al., 2013).

In a recent discussion paper, Matson and Williams (2015) identified concerns about the process of ASD treatment selection and highlighted the importance of researching parent decision-making. Both implicit and declared factors contribute to a complete understanding of why treatments are selected (Carlon et al., 2013). To date, there has been no systematic review incorporating both implicit and declared findings.

Knowledge of the relationship between implicit factors and treatment use may be useful in understanding the context in which parents choose treatments. If groups with specific characteristics are likely to choose particular treatments, this information could inform the development of targeted educational strategies. In some instances, factors that influence decision-making (e.g., beliefs about ASD) may be modifiable. Equally, the explanations provided by parents are key to understanding what is important or not important to their decision-making. The present systematic review of the literature was not limited to specific study designs. It aimed to synthesise (a) the implicit factors (e.g., child or family characteristics) significantly associated with the use of any treatment reported by parents for their children with ASD and (b) the reasons reported by parents of children with ASD to influence or explain their decision to use any treatment.

2. Method

A systematic search of the literature was conducted in accordance with the PRISMA guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009). The review protocol was registered on the PROSPERO *International prospective register of systematic reviews* (Registration number: CRD42016033955).

2.1. Inclusion and exclusion criteria

Included studies reported on factors associated with the use of treatments or declared reasons for selecting treatments for children with ASD. Included studies met the following criteria.

- (a) Studies were published after 1993. This timeframe was selected to target studies where children were more likely to have been diagnosed under recent criteria and a similar range of treatments would have been available.
- (b) Respondents were mothers, fathers, or the child's primary caregivers.
- (c) Children reported on in the studies had a primary diagnosis of ASD (as indicated by the mother, father, or primary caregivers or independently confirmed). A study was excluded if it was specified that criteria prior to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)* were used (i.e., DSM-III) or if it was not clear that a sample or sub-sample of the children

Download English Version:

<https://daneshyari.com/en/article/6847981>

Download Persian Version:

<https://daneshyari.com/article/6847981>

[Daneshyari.com](https://daneshyari.com)