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Parents' assessments of their child's autism-related interventions

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ABSTRACT

Background: Interventions for autism spectrum disorders (ASD) are typically evaluated on the basis of symptom-focused outcome measures. These measures tend to be clinician rated and derived in clinical studies, whilst broader parental experiences are often neglected.

Method: Here we report a study of 585 parents of children diagnosed with ASD, focusing on their assessments of their child's ASD Interventions, and how they are perceived to impact parental stress.

Results: Overall, high proportions of parents reported disengagement with treatment. The highest completion rates were evident with speech-language therapy, and the lowest with intensive applied behaviour analysis (iABA). However, parents reported the highest expectations, satisfaction and stress reduction with iABA. These paradoxical findings are perhaps due to the relative cost and lack of funding directed towards iABA.

Conclusions: Our research suggests that parental expectations and the factors influencing them are worthy of further investigation. More pertinently, parental ratings of intervention effectiveness along with current intervention engagement are a vital and often overlooked component of understanding the effects of interventions on children with ASD and their families.

1. Introduction

Determining an accurate symptom profile of a child with autism spectrum disorder (ASD) is important not only for diagnostic purposes, but also for ASD-related intervention choices and the evaluation of such interventions. Assessing a child's ASD core symptoms can be undertaken through formal clinical assessments or by parental reports, the former being considered 'objective' and the latter 'subjective'. From a psychometric standpoint, practitioners and researchers champion 'gold standard' objective measures that are considered bias-free and more accurate. From a service delivery perspective, the use of objective standardised tests by a trained administrator allows the impression of equitable testing across children, important when diagnostic decisions have funding consequences. However, a reluctance of practitioners to utilise parental assessments of their child's ASD symptoms may come at the cost of incremental validity, whereby parental ratings may potentially inform clinical decision making and lead to more accurate diagnoses and better intervention evaluations.

There is little guidance in the literature as to which of the objective or subjective approach best captures the characteristics of the child being assessed (Miller, Perkins, Dai, & Fein, 2017). Parental assessments could be conflated by a multitude of factors, including care-related self-esteem, parenting stress levels, and the existence of mental health issues (Karst & Van Hecke, 2013; Miller et al., 2017). Additionally, parents may underplay the severity of their child's symptoms due to denial (Ozonoff et al., 2011), or overplay them by focusing on their child's more problematic behaviours (Zapolski & Smith, 2013). The case of secretin use in the late 1990's is

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a disquieting example of how parents can exhibit bias when judging treatment effectiveness (Sandler, 2005). However, far from providing an accurate assessment of a child's core symptoms, objective testing undertaken in the clinical environment is also vulnerable to compromised validity. Here, child behaviour may change due to an unfamiliar environment, for example, reduced verbal behaviour during a language test. Furthermore, ASD-related problem behaviours such as defiance or indifference may likewise limit the validity of standardised tests that were originally designed for neurotypical children (Nordahl-Hansen, Kaale, & Ulvund, 2014).

A plethora of studies have found links between parenting stress and both ASD core symptoms (Lecavalier, Leone, & Wiltz, 2006) and ASD-related problem behaviours (Huang et al., 2014). The negative impacts that ASD has on functioning can be lessened through the provision of evidence-based Interventions, most effectively when applied at the onset of the disorder (Caron, Bérubé, & Paquet, 2017; Salomone et al., 2016). However, what constitutes 'evidence-based' interventions' in the ASD literature is disputed (Rogers & Vismara, 2008), and some have appealed for improved approaches to the evaluation of outcomes measures across ASD interventions (Odom, Boyd, Hall, & Hume, 2010; Bulkeley, Bundy, Roberts, & Einfeld, 2013). As a general rule, ASD interventions are evaluated in terms of symptom-focused outcome measures, while the parental and family factors that may determine the long-term success of the intervention are typically side-lined (Karst & Van Hecke, 2013). Murray, Ruble, Willis, & Molloy (2009) maintain that the contextual nature of ASD problem behaviours requires the involvement of multiple assessors, including parents, when assessing a child's function across different settings. It can be argued that the same should hold for intervention evaluation, particularly if the generalisability of outcomes are being appraised.

The best-practice evaluation of an intervention consists of randomised control designs involving comparisons of outcome measures between an intervention and matched control groups obtained under 'ideal' conditions (Gartlehner et al., 2006). Therapeutic outcome measures usually focus on child symptoms as rated by clinicians, and the judged efficacy of an intervention is said to be 'evidence-based'. An alternative approach is to measure the effectiveness of an intervention, which focuses on the "degree of beneficial effect under 'real world' clinical settings" (Gartlehner et al., 2006: p. 3). For the ASD context, this "real world" setting invariably involves home-based interventions and substantial parental involvement (Schertz, Baker, Hurwitz, & Benner, 2011). Arguably then, as the child-parent relationship is bi-directional, parents should not be excluded from assessing intervention outcomes, especially as parental assessments may have greater ecological validity. The efficacy vs. effectiveness distinction mirrors the well-known 'statistical significance vs. clinical significance' divide in medical outcomes research. While the efficacy approach maximises internal validity, the effectiveness approach maximises generalizability (i.e., external validity).

To date behavioural approaches characterised by intensive interventions delivered for up to 40 h per week for a minimum of two years, have the strongest empirical support from clinical studies (e.g., Klintwall, Eldevik, & Eikeseth, 2015). For example, intensive applied behavioural analysis (iABA) approaches utilising discrete trials methods have been found to be efficacious with adaptive and challenging behaviours, and intellectual and language skills (Caron et al., 2017). Less intensive behavioural therapies also centring on behavioural modification techniques have been shown to reduce tantrums and self-injurious or disruptive behaviours (Schell & Adams, 1971). Intervention studies involving speech therapies have been mixed, for example, while Picture Exchange Communication Systems and video-modelling are linked to improvements in communication, social interaction, and cooperative play (Lerna, Esposito, Conson, & Massagli, 2014; Wang, Cui, & Parrila, 2011), other methods such as social stories have been less well supported (Samuels, 2011; Reynhout & Carter, 2010). Likewise, occupational therapies, which predominantly target social or work skills, motor or sensory difficulties, and play (Welch & Polatajko, 2016) have support from some studies (e.g., Dunn, Cox, Foster, Mische-Lawson, & Tanquary, 2012; Kientz & Dunn, 2012) but not others (Tanner, Hand, O'Toole, & Lane, 2015). Finally, the impact of complementary and alternative interventions such as gluten- and/or casein- free diets, and dietary supplementation, have proven difficult to evaluate due to a lack of quality research (Millward, Ferriter, Calver, & Connell-Jones, 2014; Mari-Bauset, Zazpe, Mari-Sanchis, Llopis-Gonzales, & Morales-Suarez-Varela, 2014).

Few studies have focused on parent experiences of the interventions their child engages (e.g., Hume, Bellini, & Pratt, 2005; Boyd & Corley, 2001). One study involving iABA interventions found that the majority of parents reported general satisfaction or high satisfaction with the improvements in their child's behaviour (Boyd & Corley, 2001). Other studies also support the notion that iABA is perceived as effective by parents (Bowker, D'Angelo, Hicks, & Wells, 2011; Runco & Schreibman, 1983). Using an internet-based survey, Goin-Kochel and colleagues (2009) examined parent's ($n = 479$) "efficacy" ratings of their child's ASD-related Interventions, including speech language therapy, occupational therapy, iABA, and dietary interventions. They reported mixed results both across and within intervention types, and noted that there were substantial numbers of parents indicating that these interventions dramatically or somewhat improved their child's core symptoms. Interestingly, these improvements were reported even for interventions lacking an evidence-base, for example, dietary interventions were reported by parents to be particularly effective in improving social behaviours. However, parental assessments of child intervention outcomes may be influenced by their expectations, and subsequently how they report that their expectations have, or have not, been met. While parental expectations of intervention outcomes ('outcome expectancy') and their ability to effectively contribute to the intervention ('efficacy expectations') have been associated with actual intervention outcome (Ivy, 2004), little research dedicated to parental expectations has been published.

A number of studies have reported discrepancies between parental assessments and statistically significant improvements reported from clinical intervention studies. Using a dietary example, Pennesi and Cousino Klein (2012) reported no statistically significant improvements in communication deficits and behavioural problems, even though the children's parents did. Similarly, exploring the effect of a classroom-based language invention, Adams et al. (2012) reported no significant advances in speech or narrative ability, yet both parent and teacher measures indicated significant improvements. Likewise, Elder et al. (2006) reported non-significant effects on problem behaviours with a dietary intervention, nevertheless parents reported improvement in their child's language and a reduction in hyperactivity and tantrums. Hutchins & Prelock (2013, 2016); reported conflicting findings between objective clinical measures and subjective parental assessments when evaluating the impact of social stories on children. What these

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