



Promoting Shared Decision Making to strengthen outcome of young children with Autism Spectrum Disorders: The role of staff competence



Kristin Strauss^a, Arianna Benvenuto^b, Barbara Battan^b, Martina Siracusano^b,
Monica Terribili^b, Paolo Curatolo^b, Leonardo Fava^{a,*}

^a Association for Treatment and Research in Autism and Related Conditions "Umbrella", Rome, Italy

^b Department of Neuroscience, Pediatric Neurology Unit, Tor Vergata University of Rome, Rome, Italy

ARTICLE INFO

Article history:

Received 25 September 2014

Received in revised form 21 November 2014

Accepted 25 November 2014

Available online 26 December 2014

Keywords:

Autism Spectrum Disorders
Shared Decision Making
Early intervention
Treatment outcome
Staff training

ABSTRACT

Little is known on how the conceptual description of Shared Decision Making (SDM) accomplishes clinical practice in the context of lifetime disabilities as in particular Autism Spectrum Disorders (ASD), when intervention is long-lasting and requires constant family involvement. This study aimed mainly to investigate to what extent the staff's competence in SDM contributes to positive child and parent improvement when involving parents in Early Intensive Behavior Interventions (EIBI). It was also geared to verify whether SDM staff competence contributes to a child's treatment responsiveness. A total of 25 young children with ASD (23 male, 3 female, age range 34–92 months, mean age 51.4 ± 13.6) were included in the study. Of these, nine children were allocated to a Parent Involvement condition accompanied by SDM Staff Training (PI-SDM), and eight children to a Parent Inclusion in Treatment Delivery Only condition without SDM Staff Training (PI-DO). Nine months treatment outcomes of severity, developmental and adaptive measures were compared to Treatment As Usual ($n = 8$). PI-SDM was associated with improvement of autistic symptoms ($p \leq .05$), adaptive functioning ($p \leq .01$) and developmental outcome ($p \leq .01$), as well as parent ($p \leq .05$) and staff competence ($p \leq .001$). The magnitude of outcome was inferior in the PI-PO and TAU group. A Reliable Change was identified in more than 40% of children included in PI-SDM, while PI-PO (>20%) and TAU (>12%) led to little Reliable Change and partially skill deterioration. Staff's SDM skill competence predicts reduced parental stress ($\beta = -.500, p \leq .05$) and contributes significantly to a positive treatment responder trajectory ($p \leq .01$), besides lower severity ($p \leq .05$), higher adaptive ($p \leq .01$) and communication skills ($p \leq .05$). The study indicates that parent inclusion should be conceptualized as a collaborative partnership model rather than as adherence in treatment provision, based on a target SDM staff training that may constitute an external contributor to treatment responsiveness and positive child as well as parent outcome.

© 2014 Elsevier Ltd. All rights reserved.

* Corresponding author at: Umbrella Association for Treatment and Research in Autism and Related Conditions, Via della Scrofa, 57, 00146 Rome, Italy. Tel.: +39 3464752709.

E-mail addresses: supersghy@yahoo.it, l.fava@associazioneumbrella.com (L. Fava).

1. Introduction

Autism Spectrum Disorders (ASDs) are a group of lifelong neurodevelopmental conditions characterized by core deficits in social interaction, communication and repetitive or stereotypic behaviors (American Psychiatric Association, 2013). It has been suggested that these conditions are among of the most frequent childhood neurodevelopmental disorders (Fombonne, 2003a, 2003b; Fombonne, 2009), with high heritability (Rutter, 2000) and are therefore a major public health concern (Isaksen, Diseth, Schjolberg, & Skjeldal, 2013). Although in about 20% of the patients, the use of modern neuroimaging and neurogenetic techniques have permitted to identify specific medical and/or genetic syndromes associated to autism, the causes of idiopathic ASD remains unknown in 80% of cases (Benvenuto, Moavero, Alessandrelli, Manzi, & Curatolo, 2009). Currently, there is a clear evidence of interplay of genetic origins and environmental exposure leading to alterations in brain networks (Eapen, 2011; Herbert et al., 2006; Newschaffer et al., 2006). The significant heterogeneity of ASD is expressed in the underlying etiological pathways and phenotypic presentation, co-occurring forms of psychopathologies and developmental trajectories of affected children and can consequently influence both symptom expressions and the prospective outcomes of this population (Charman et al., 2011; Gadow, DeVincenzi, Pomeroy, & Azizian, 2004; Lecavalier, 2006; Leyfer et al., 2006; Simonoff et al., 2008; Witwer & Lecavalier, 2008; Zachor & Curatolo, 2014).

The current systematic literature concludes that Early Intensive Behavioral Interventions (EIBIs) based on behavioral and developmental principles appear to be the most effective treatment for ASDs in improving autistic symptoms and global developmental outcome with regard to cognitive functioning, language skills, as well as adaptive and aberrant behaviors (Eikeseth, 2009; Eldevik et al., 2009; Makrygianni & Reed, 2010; Matson & Smith, 2008; Reichow & Wolery, 2009; Rogers & Vismara, 2008; Reichow, 2012; Spreckley & Boyd, 2009; Viruès-Ortega, 2010; Warren et al., 2011). Although there are different program protocols and curricula existing within the EIBI framework (Love, Carr, Almason, & Petursdottir, 2009), generally more intensive and longer intervention (Makrygianni & Reed, 2010; Strauss, Mancini, & Fava, 2013; Viruès-Ortega, 2010), associated with continuous staff (Reichow & Wolery, 2009) and parent training and supervision (Strauss et al., 2013) seem to result in positive child outcome. Nevertheless, considerable rates of non- (or low) response to proposed interventions have been reported (Howlin, Magiati, & Charman, 2009; Stahmer, Schreibman, & Cunningham, 2011). Moreover, there is marked difference in the magnitude of positive outcomes achieved following the same intervention approach (Viruès-Ortega, 2010; Strauss et al., 2013). As research points clearly towards the inadequacy of a “one-size-fits-all” approach favoring a single treatment approach (Kasari, 2002; Stahmer et al., 2011), there is an increasing call for treatment individualization addressing the critical issue of “what work for whom” (Benvenuto, Battan, Benassi, Emberti Gialloreti, & Curatolo, 2014; Fava & Strauss, 2014; Kasari, 2002). Broad predictors such as child pre-treatment chronological age, cognitive, adaptive, communicative abilities (Eldevik et al., 2010; Makrygianni & Reed, 2010; Reichow, 2012) and parental stress (Osborne et al., 2008; Strauss et al., 2012) could be useful for a better individualization of ASD treatment, as well as predictors specific to an intervention procedure such as child play, joint attention, imitation skills, social avoidance, rate of learning (Ingersoll, Schreibman, & Stahmer, 2001; Kasari, Paparella, Freeman, & Jahromi, 2008; Kasari, Gulsrud, Freeman, Paparella, & Hellemann, 2012; Sallows & Graupner, 2005; Sherer & Schreibman, 2005; Weiss, 1999), and parent rate of treatment implementation or fidelity (Strauss et al., 2012). In addition, the notion of the utility of parents as active participant in treatment delivery has spanned over four decades and its importance to the issue of generalization has been demonstrated in several studies (McConachie and Diggle, 2006; Strauss et al., 2012). Thus, parent training and active engagement in the intervention process constitute a marker for best practice. Parents can be effectively taught to implement a broad range of intervention strategies (McConachie and Diggle, 2006), although meta-analytic findings indicate that not all types of parent involvement in treatment delivery equally facilitate positive treatment gains (Strauss et al., 2013).

Although the call for individualization of parent education programs is concurrently raised with the call for treatment individualization, there is very little research on how to best approach parent inclusion in treatment provision (Karst and Van Hecke, 2012). The role of therapists and clinical staff is no longer authoritarian when deciding treatment goals and intervention strategies (Charles, Gafni, & Whelan, 1999; Charles, Whelan, & Gafni, 1999) and a collaborative or partnership model, where staff and parent share information and work together in setting treatment goals throughout the treatment progress, is emphasized (Brookman-Frazee & Koegel, 2004; Turnbull, Blue-Banning, Turbiville, & Park, 1999). One method of fostering a collaborative partnership model is through the process of Shared Decision Making (SDM). Shared decision-making (SDM) is defined as an approach in which the clinician and patient go through all phases of the decision-making process together and in which they share the preference for treatment and reach an agreement on treatment choice (Charles, Gafni, et al., 1999; Charles, Whelan, et al., 1999; Jordan, Ellis, & Chambers, 2002). Forms of decision-making can be regarded as a continuum with two extremes – the ‘traditional medical model’ and the ‘informed medical model’. At the very best, the patient and clinician both bring information and values into their discussion, evaluate treatment options and together build a consensus on the treatment to implement (Charles, Gafni, & Whelan, 1997). Studies on SDM in clinical practice showed that improvement in parent satisfaction, adherence, and well-being had in common that the SDM interventions concerned treatment programs or contained more than one session (Joosten et al., 2014). Thus, SDM can be regarded most functionally as a collaborative process that flow in goal selection and treatment implication rather than as one or two isolated events in the very beginning of a decision towards a specific treatment option. Research has demonstrated that knowledge provision and knowledge acquisition, e.g. in form of parent training, do not sufficiently contribute to patient participation in decision making, when a perceived clinician–patient imbalance in the ability to use this knowledge is persisting (Joseph-Williams, Edwards, & Elwyn, 2014). Furthermore, there is evidence of frequent lacking readiness in patients to participate in decision

Download English Version:

<https://daneshyari.com/en/article/371210>

Download Persian Version:

<https://daneshyari.com/article/371210>

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