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The intervention priorities of parents of children with autism spectrum disorders in Iran

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ABSTRACT

When designing and implementing evidence-based programs for children with an autism spectrum disorder, the intervention priorities of parents are important criteria. Although studies in developed countries have explored parents' intervention priorities, there is a paucity of this kind of research in developing countries. This research explores the intervention priorities of 207 Iranian parents for their children with autism in Tehran, the capital of Iran. Participants with children between 2 to 21 years of age were asked to rate their intervention priorities from among 10 main categories. In addition, correlations between children's difficulties and parental intervention priorities were examined.

The results indicate that building social communication skills was the highest intervention priority for parents of Iranian children with autism, a contrast to typical current service provision in Iran. The results also substantiated that presence of social communication difficulties and challenging behaviors in children are typically correlated with parents' intervention priorities.

1. Introduction

The intervention priorities of parents of children with an Autism Spectrum Disorder (ASD) are important: understanding these and incorporating them into treatment and support programs is likely to increase parental acceptance, participation and satisfaction, and these factors are likely to lead to better outcomes for children. However, the priorities of parents in developing and developed countries may differ. This research seeks to understand the treatment priorities of parents in Iran, and to compare these with parental priorities reported in similar studies completed in developed countries. A secondary aim is exploring whether there is a correlation between parents' intervention priorities and their child's ability level.

Autism Spectrum Disorders are neurodevelopmental disorders that can be diagnosed by documenting difficulties in social communication skills and the existence of repetitive and stereotypical behavior (American Psychiatric Association, 2013). The most recent research literature indicates that the prevalence of ASD is increasing in most countries (Hill, Zuckerman, & Fombonne, 2015; Pellicano, Dinsmore, & Charman, 2014). This increase in prevalence is not believed to reflect a rise in incidence, but is instead derived from increased awareness and availability of diagnostic services (Rice et al., 2012). In Iran, the first study about the prevalence of ASD reported a rate of 6.26 in 10,000 (Samadi, Mahmoodizadeh, & McConkey, 2012), but a more recent study indicates that prevalence has reached 95.2 in 10,000 (Samadi & McConkey, 2015).

Parents and professionals try hard to find more effective and evidence-based interventions for their children or clients with ASDs

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(Guldberg et al., 2011; Hickerson, Finke, & Choi, 2014; Parsons, Lewis, & Ellins, 2009). One of the essential components of evidence-based practice is considering parents' priorities in designing and applying intervention or education programs for children with ASD (Melnyk, Gallagher-Ford, Long, & Fineout-Overholt, 2014). Therefore, when choosing effective intervention plans for children with ASD, the first step can be exploring and considering the intervention priorities of their parents (Guldberg et al., 2011).

In addition, the literature indicates that the core features of ASD in children can lead to behaviors that parents find challenging (Williams et al., 2012). These challenging behaviors can increase the level of anxiety and stress in parents of children with ASD in comparison to parents of children with other developmental disorders, and this may decrease parents' satisfaction with the effectiveness of intervention programs (Russell & McCloskey, 2016; Williams et al., 2012). This possibility is substantiated by research indicating that when parents are involved in the process of determining intervention goals for their children with ASD, the level of their anxiety and stress can decrease remarkably, and this can lead to increased satisfaction with the intervention programs used for their children (Bloch & Weinstein, 2009; Dunn, Cox, Foster, Mische-Lawson, & Tanquary, 2012; Guldberg et al., 2011).

Moreover, for professionals working with children with ASD, it can be vital to determine parents' intervention priorities (Lang, Regester, Rispoli, Pimentel, & Camargo, 2010), in order to select appropriate treatment goals (Bloch & Weinstein, 2009). If intervention plans for children are designed via reciprocal interaction between parents and professionals, this enhances both the effectiveness of those plans and parents' satisfaction (Petrina, Carter, & Stephenson, 2015). In fact, when professionals in developing countries want to move from traditional intervention approaches (i.e. only one-to-one sessions without parents' involvement) towards family-centered services that place parents as experts on their child's needs, they first need to explore the parents' intervention priorities and then consider these when designing and carrying out intervention programs (Dunn et al., 2012; Schaaf et al., 2015).

Most studies exploring intervention priorities or educational needs of parents of children with ASD have been done in developed or western countries. For instance, in research carried out by Spann, Kohler, and Soenksen (2003), 45 parents of children with ASD reported that social skills, communication skills, daily life skills and challenging behaviors were their intervention priorities. In another study done with 350 parents of children with ASD, improving social skills was reported as the highest priority (Whitaker, 2007). In addition, Pituch et al. (2011) explored intervention priorities for 90 parents of children with ASD, and reported that among ten determined skill domains, the parents selected social and communication skills as their first intervention priorities for their children. Schaaf et al. (2015) indicated that 32 parents of children with ASD in a qualitative study reported daily living, play skills and social skills as their highest priorities for intervention. Petrina et al. (2015) worked with 74 parents of "high-functioning" children with ASD aged 5–10 years, and reported that when given a choice of social skills, motor abilities, finding friends, academic skills and emotional behaviors as a focus, parents selected social skills as their first intervention priority and emotional behaviors as the second. In a study with 148 parents of children with ASD aged five to 15 years from three different eastern European countries, the parents reported social communication skills as their highest intervention priority (Preece et al., 2017). Finally, in recent research involving 3317 parents of children with ASD, participants indicated that social skills were the first priority for the parents (Lai & Weiss, 2017).

In spite of this existing research base, this area still needs more research, in comparison with other topics in ASD (Lang et al., 2010; Petrina et al., 2015), and especially in developing countries (Kelly et al., 2016; Samadi & McConkey, 2011). In developing countries, most studies about ASD focus on the prevalence or etiology of ASD. For instance, Kelly et al. (2016) reviewed articles published about ASD in several Middle East countries, and concluded that 56.6% were related to the etiology of ASD. In Iran, a developing country located in the Middle East, most articles about ASD published in recent years focus either on prevalence (e.g. Samadi & McConkey, 2015; Samadi, Mohammad, Ghanimi, & McConkey, 2016) or on specific intervention methods (e.g. Mohammadzaheri, Koegeel, Rezaee, & Rafiee, 2014; Abshirini, Khafaie, Bahrani, Rayshahri, & Khafaie, 2016), reflecting a focus on the needs of professionals rather than families or people with ASD themselves. The few studies involving parents of children with ASD in Iran focus on support services that parents might need (e.g. McConkey & Samadi, 2013; Samadi, McConkey, & Bunting, 2014). A cross-cultural study done regarding parents of children with ASD in Iran reported that among their ten main needs, Iranian parents needed time to spend with their colleagues and friends, or to receive supportive services to decrease their concerns about the future (Ahmadi, Zalani, & Amrai, 2011). None of these studies focused on exploring parents' intervention priorities for their child, or comparing these priorities with the priorities reported in developed countries.

2. Method

2.1. Questionnaires

To meet the aims of this study, a questionnaire that had been developed and used in a similar study in developed countries (Pituch et al., 2011) was translated into Farsi after getting permission from the original developers. This questionnaire surveys 54 behaviors, which are classified into 10 main categories. These categories are Self-care (6 behaviors), Domestic Living (4 behaviors), Community Living (4 behaviors), Job (3 behaviors), Recreational (4 behaviors), Motor (5 behaviors), Social (6 behaviors), Communication (7 behaviors), Academic (5 behaviors), and Challenging Behaviors (10 behaviors). The original developers remarked that these 10 categories and 54 behaviors had been chosen with regards to a review of scientific literature in the field of ASD and consideration of international organization guidelines (see Pituch et al., 2011, for more information).

Following forward translation into Farsi, a backward translation of this questionnaire in English was sent to the developers to ensure that key concepts had not been altered. However, there was a need to ensure that the content was also culturally valid. The original questionnaire included 54 behaviors, but after discussion between the researchers and the original developers, one behavior (finding an appropriate boyfriend and girlfriend) was removed from the social category, because in Iranian culture it is not common

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