FAMILIES FACING AUTISM SPECTRUM DISORDERS. LANDMARKS FOR MARRIAGE AND FAMILY THERAPISTS

Dalia STOICA
Department of Psychology, West University of Timisoara
Mihaela MINULESCU
Faculty of Communication and Public Relations, SNSPA Bucharest
Mona VINTILA
Department of Psychology, West University of Timisoara

Abstract: Current surveys picture the fact that the number of children diagnosed with Autism Spectrum Disorder (ASD) is on the rise. The complexity of the psychological impact faced by the family lead to a new approach to ASD addressing an integrative treatment plan which includes marital and family therapy. Having a child with ASD affects different domains of family and connects to a variety of chronic and acute stressors that affect marital satisfaction and functioning. In this context, marriage and family therapist could help the members connect to each other and create a new family story. Given the evidence, the need to better understand the types of interventions suitable to enhance the partner connection is clear. Furthermore, the current paper offers a comprehensive image of some possible therapeutic objectives in order to help as better families facing ASD throughout their life span.

Keywords: Autism Spectrum Disorder, couple therapy, family therapy, multifaced treatment plan, parents

Introduction

Current statistics referring to child psychopathologies suggest an epidemic of the Autism Spectrum Disorder (ASD) diagnosis. The prevalence of ASD seems to have constantly growing in recent years (Christensen et al., 2018; Solomon and Chung, 2012). Moreover, the definition of ASD has changed over time depending on different versions of DSM. On the other hand, beyond statistics and definitions, ASD represents a chronic condition which

inevitably impacts and affects the family functioning and their quality of life (Solomon and Chung, 2012). Researches in this area are relatively new in Romania, a region experiencing social and economic transitions, as well as changing patterns following the fall of the Iron Curtain (Swami et al., 2018, apud Matlak, 2014).

The considerable research attention given to the topic revealed some of the repercussions of the diagnosis upon the family. The most frequently highlighted effects are those of developing anxious and depressive symptoms and even obsessive-compulsive disorder, especially among mothers (Lecavalier, Leone and Wiltz, 2006; Karst and Van Hecke, 2012, Gau et al., 2012). Besides, the diagnosis comes together with different couple difficulties and even with a growing rate of divorce among families of ASD children (Karst and Van Hecke, 2012; Hartley et al., 2010; Freedman et al., 2012). Hartley and his colleagues (2010) compared parents of children with ASD with matched parents of children without disabilities and highlighted a 24% higher rate of divorce among parents of children with ASD. A complete description of the impact of such a diagnosis pictures an overwhelming situation as follow:

Low parental self-efficacy – refers to the fact that parents of children with ASD lack trust in their parental skills which leads to feelings of guilt and low involvement in the child development.
Anxiety related to the social behavior of the child, the level of communication, the child`s involvement in play and motor skills.
High levels of stress related to the cognitive impairment of the child, the child`s mood swings, the lack of autonomy, the hyperactivity, the lack of obedience, adaptation difficulties, communication deficit, learning problems, and social difficulties.
Depressive and anxious symptomatology
Fatigue and a high risk of developing health problems;
Low state of well being;
Frequent conflicts in the family that affect the diagnosed child;
Low marital satisfaction which affects the parental role and the diagnosed child;
High risk of divorce and high levels of divorce;
Low family quality of life.

(Karst and Van Hecke, 2012; Smith et al., 2010; Kelly et al., 2008; Brobst, Clopton and Hendrick, 2009; Gau et al., 2011; Hartley et al., 2011; Higgins, Bailey and Pearce, 2005).

Therefore, the above depiction describes the complex impact of the diagnosis which ways of treatment that are still debatable (Karst and Van Hecke, 2012). Even if this complexity requires a complex psychological intervention, until recently all the focus was towards the therapy of the child (Karst and Van Hecke, 2012). Yet, the understanding of the impact changed the perspective to highlighting the importance of family and couple therapy for parents of children on the spectrum.

While facing the complex described impact it became clear that these cases do not only belong to the developmental disabilities community, but also to systemic therapists. It was just the beginning of admitting the importance of systemic therapy in such cases. Some of the recent directions of treatment involved for example structural family therapy, double ABCX model, solution-focused brief therapy in order to ease marital dissatisfaction and parental stress (Smock Jordan and Turns, 2016; Brockman et al.2016). Given the evidence and the importance of the marital relationship for the parental role, the need to better understand the types of interventions suitable to enhance the partner connection is clear. Furthermore, the current paper offers an up to date image of the strategies presented as useful in the therapy of such families and concludes upon the importance of knowing some directions of intervention.

Landmarks for marriage and family therapist in cases of families facing ASD

The first challenge such a family faces is the journey to diagnosis, which can be long and frustrating winding from pediatrician, psychologist, and neuropsychologist (Neely et al.,2012). Afterward follows the hit shock of the diagnosis, in other words, the beginning of the discussed impact. Creating a complex and multifaced treatment plan for parents of children with ASD is the next required step. Until the magnitude of the impact was fully understood the entire focus when it came to the treatment was towards the therapy of the child. Later on, a new approach proposed the three-legged stool metaphor to described the necessary treatment plan in such cases. The non-profit organization Talking About Curing Autism (TACA) proposed the metaphor which refers to the three main parts of the treatment plan. The first leg of the stool I represented by traditional therapies for autism like Applied Behavior Analysis (ABA) or The Developmental, Individual Difference, Relationship-Based Model (DIR/Floortime), speech therapy and occupational therapy. The second leg refers to the biomedical interventions required for the medical concerns underlying autism. The third leg refers to the necessary family support. According to the approach, without concert to one of the three legs, the system of the child remains out of balance. Unfortunately, there is a high risk of this to happen because the parents tend to focus on the child no matter the distress they

face. It remains the specialist duty to create a comprehensive and multidisciplinary treatment plan involving emotional support for the family. Family therapist as a specialist working with the family system are the most suitable to support the parents. For this to happen, it is essential the family understands the other two legs of the stool and to possess resources in order to offer the emotional support. Current literature attention has been given to the strategies that can be used in the therapy of the families of ASD children.

Solomon and Chung (2012) explored how family therapists can make use of an integrative approach with parents of ASD children. They present three main domains of use in therapy described as an action, meaning, and emotion. The first presented domain refers to helping parents find ways to do their daily activities as well as they can considering the situation. More precisely this refers to helping parents when they feel they did not do enough, helping them organize their lives, support them in making use of self-care activities and support them in talking about the diagnosis with the typically developed siblings. All of these are aimed to reduce stress and increase resilience. The following domain involves facing the ”why” question that most frequently daunts parents of children on the spectrum. Most frequent parents believe the autism is the results of genes and curse the bad luck they had or may believe it was due to the decision they made about the child’s vaccines. All these narratives include anger and fault. Creating a narrative refers to helping the parent co-construct a story about their child and who they are. The other domain presented by the author refers to working with emotions, with the battle between fighting and accepting the diagnosis. The diagnosis is most often perceived and lived as a loss by parents. This means complex and powerful emotions must be handled by the parents that most often end up constraining the connection between them. Also, parents most commonly experience isolation because of the unpredictable behavior of the child.

Neely and the collaborators (2012) also presented some key roles they consider essential to be completed by the systemic therapist for the family to face the challenge of the diagnosis throughout the life span. The first role is to facilitate the family grieving by firstly discovering how the family grieves. The therapist may help the family by explaining that everybody grieves differently and that the process is ongoing. Also, the therapist may help the family talk about their grief. Another aspect is that the therapist could explore the interventions that are available for the child as the family often face an abundance of confusing information. Considering the importance of opinions, emotions, and trust on an intervention towards the effectiveness of the intervention. Following, the therapist may serve as a mediator for the family helping them advocate for themselves in the interaction with different institutions. Besides, it is essential to explore the feelings, emotions and beliefs

of the family. Exploring the emotions serves to diminish the fact that family members feel isolated also one from another and may benefit from the therapist that may offer permission for the family to talk about what is happening in the family. Exploring the family beliefs refers to exploring the roles are delegated in the family and the meaning of the diagnosis for the family members. Also, the therapist may help the family reach their full potential by reinforcing the positive aspects from their lives and encourage them to explore resources that can improve their lives.

In their article, Ramisch (2012) talks about the ABCX model as a way of helping families of children on the spectrum. The therapeutic tool could be used with families in order to asses and intervene. It refers to A – to pile up stressors and demands by obtaining a correct diagnosis for the child, exploring difficulties and financial hardships. Also, it refers to helping the family access and benefit from their inner and external resources (B). Following, families should gain from building self-confidence and develop coping strategies (C). Finally, the therapist may help in the proves of adaptation (X) which refers to all the effort made by the family. In other words, Ramisch (2012) simplifies the model by suggesting that the family therapist may: asses and develop a plan concerning family stressor; asses and develop a plan concerning resources and asses and develop a plan concerning coping strategy. This means that the therapist should know the stressors, the resources and the coping strategies of the family and develop o plan in order to improve and enhance them.

Conclusions

Families living with ASD face a wide variety of overwhelming challenges. In this context, the family therapist is a resource and can help the family face the stressor and enhance their resources. Thus, in order to obtain valid and robust results, studies should take into consideration to use a validated and culturally adapted instruments (Tudorel et al., 2018; Vintila et al., 2018). The family therapist should be one member of the therapeutic, educational and medical team (Gavrilă-Ardelean, 2008).

Parents of children with ASD are challenged by multiple emotions, beliefs, and hurdles and in order to better overcome and accept the reality by establishing. Establishing clear therapeutic objectives is therefore essential in the process. These could be referring to: *knowing the stressors of the family, exploring and enhancing resources and coping strategies, handle emotions, facilitating the grieving process, helping the family co-construct their story and identity and reinforce the positive aspects*. Hopefully, all of these will add to the experience of the therapist and will change the lives of many families.

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