

PRACTICE GUIDELINES FOR SPECIALISTS DEALING WITH PARENTS OF CHILDREN ON THE SPECTRUM

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Abstract: *Parents of children with Autism Spectrum Disorder (ASD) are known to present high levels of depression, anxiety, and stress. The impact of the diagnosis is clearly presented in the literature and refers to consequences affecting the couple and the family. The understanding of the psychological impact faced by the family leads to the highlighting of a new approach addressing an integrative treatment plan. In these contexts, the importance of specialist like family and couple therapist in order to help members stay connected and together is clear. Hence, for all the specialists dealing with families of children on the spectrum, it is very difficult to know how to efficiently help these families. All the specialists dealing with families of ASD children could benefit from having some ideas about the ways they could help. Furthermore, the current paper aimed to explore the exact impact of diagnosis and to offer some suggestions that could serve as guidelines in practice.*

Keywords: *Autism Spectrum Disorder; couple therapy; family therapy; parents; specialist; guidelines; practice;*

Introduction

The latest statistics suggest that the prevalence of Neurodevelopmental Disorders, especially of Autism Spectrum Disorder (ASD) has been constantly growing in recent years (Solomon and Chung, 2012; Christensen et al., 2018). Even if the understanding of ASD has changed in time, or any kind of disability, especially ASD represents a challenge for families and couples (Solomon and Chung, 2012). Consequently, in recent years the impact of ASD upon families and their quality of life has sparked substantial research attention.

After years of research we clearly know that in comparison to parents of typically developed children, parents of children on the spectrum present an entire list of consequences linked to the diagnosis. Among these we remind: low parental self-efficacy; anxiety related to the child's communication, motor and social skills; stress related to the cognitive difficulties of the child, mood swings of the child, lack of autonomy, hyperactivity, learning difficulties; fatigue; family conflicts; low family functioning; low marriage satisfaction; low quality of life and as mentioned before, high rate of divorce (Karst and Van Hecke, 2012; Smith et al., 2010; Kelly et al., 2008; Brobst, Clopton and Hendrick, 2009; Fond-Harmant and Gavrila-Ardelean, 2016; Gau et al., 2011; Hartley et al., 2011; Higgins, Bailey and Pearce, 2005). Despite knowing and acknowledging that such a family reality has its impact, specialists still face difficulties in supporting these families. First, it was not until recently the magnitude of the impact was recognized. Secondly, the years in which all the focus was upon the treatment of the child made specialist fall behind with the way the family could be helped. Thirdly, in some cases parents do not consider needing help, do not have enough money or time left in order to ask for help and enroll in therapy or any kind of support program reality which also made specialists fall behind with practice. Considering these facts, the paper aims to explore practical ways that could offer support for specialist in their work with families of children diagnosed with Autism Spectrum Disorder. We aim to provide suggestions that could inspire and support

specialists in their work. We begin by highlighting the impact of the diagnosis at an individual level, family level, and couple level and continue by exploring possible practical guidelines. The paper concludes by reinforcing the impact of the diagnosis and the main aspects to remember into practice.

Knowing and understanding the impact of ASD and the role of specialist

The depiction mentioned above reveals the complex impact of the diagnosis which ways of treatment that is still debatable (Karst and Van Hecke, 2012). We could see that the diagnosis has its impact at an individual level (depression, anxiety, fatigue), at a family level (family conflicts, low family functioning) and couple level (low marriage satisfaction, lack of trust, lack of emotional support). At the individual level, the risk of developing anxious or depressive symptoms is increased together with a higher level of stress (Lecavalier, Leone and Wiltz, 2006; Karst and Van Hecke, 2012). In one recent study we can see the comparison of 151 families of children with ASD with 113 families with typically developed children concerning the levels of psychopathology (Gau et al. 2012). The results were similar to others and suggested a high rate of depressive, anxious and obsessive symptoms, especially among mothers. Some other findings suggest that 33% of mothers of children with ASD and 17% of fathers were scoring high levels of depression and 6% of both groups were scoring high levels of anxiety (Davis and Carter, 2008). Additionally, couples face the challenge of staying together and even saving their marriage as statistics show that the rate of divorce is higher in families of ASD children (Karst and Van Hecke, 2012; Hartley et al., 2010; Freedman et al., 2012). Yet, when it comes to the impact upon the couple, we still lack understanding. In their paper Hartley and colleagues (2017) argument that we still miss information about the impact of impact of child-related challenges associated with ASD on other family dynamics and marital relationships while only knowing that this couple presents low marital satisfaction. Most studies analyzing the family and couple impact are limited to markers of marital stability (i.e., divorce/separation) or self-reported global marital satisfaction or marital adjustment (Hartley et al 2017). This gap in the literature is essential in the context of a systemic principle saying any stressor in one family subsystem influences the functioning of other subsystems (Cox et al. 2001) which would mean that what affects the child, affects the couple and vice versa.

Individual difficulties

The principal consequences of ASD are depression and anxiety. As a specialist in the field one could pay attention to the parents in order to recognize depression and anxiety and firstly listen parents, offer to understand and suggest seeking help. In order to recognize depression any specialist should pay attention to the behavior of the parents and their nonverbal language starting with the outfit and posture. In case signs are identified and seen repeatedly at any parent it is in any specialist duty to suggest the seeking of help, which could be a very hard mission. Despite the hardness it is essential to accomplish this hard mission as we know depression comes with considerable suicidal risk. In case of depression help should be found at a psychotherapist and/or at a psychiatrist.

In case of anxiety, any specialist should again pay attention to any sign and take into consideration that in many cases the main worry of these parents is referred to the child. Parents of children on the spectrum, as mentioned very often worry about the child's communication, motor, and social skills; the cognitive difficulties of the child, mood swings of the child, lack of autonomy, hyperactivity, learning difficulties. In these cases specialist could be opened to discuss with families about their worries and offer them the chance to participate in support groups where to find validation and empathy.

Family and couple difficulties

Although the complexity of the impact requires a complex psychological intervention, until recently all the focus was towards the therapy of the child (Karst and Van Hecke, 2012). Given the impact upon the couple and family one could think that the most appropriate specialist to help in these cases could be a family and couple therapist. Hence, until recently the impact was not clear in the literature and these cases belonged to the field of education specialists that helped with the therapy of the child. Consequently, even if the family and couple therapist could have had a unique and powerful contribution to this population, they felt and may still feel not authorized to work with these cases (Solomon and Chung, 2012). It is not until recently that the literature speaks about their contribution. Among all of these, some other factors may be involved. For example, the fact that in our country institutions – teachers and developmental specialist do not encourage families to undergo therapy may contribute to the poor involvement of systemic specialists in these cases. So to speak, family therapist seems to be not confident enough and not sustained by other specialists.

According to systemic specialists, the concerns faced by the family throughout the child's development include identifying that the child has a problem, gain a diagnosis, coping with emotional reactions to the diagnosis, taking treatment decisions, developing a support system (Neely et al 2012). While families struggling with the impact of the chronic situation, systemic therapists may contribute to family wellbeing (Gavrilă, 2008).

One potential contribution of a systemic therapist that could be considered by any specialist that deal with these families refers to supporting the family in exploring potential interventions for their child. In many situations, one parent could believe and consider that one intervention is more suitable, and another could consider something else. In such a situation, families could benefit from exploring the pros and cons of treatment options. Also, in other situations families may face one member that gives up his/her life in order to serve the child. A specialist could consider observing these situations and encouraging the family into action, into keeping up with their lives as usual as much as possible. They could also benefit from being encouraged to keep being involved in the community life which could help them keep a good level of satisfaction and wellbeing. In other cases, families may face a system that is more or less supportive of their situation. Consequently, specialist may help the family to speak up for their rights and needs and by offering to understand and promoting acceptance. Any specialist could also pay attention to the approach of the parents towards the siblings that most often are also affected. The most often situation is that the sibling receives less attention from the parents than the affected child. A specialist could observe the situations and encourage parents to spend time with their siblings (Gavrilă-Ardelean, 2014).

Specific interventions regarding emotions, grief, and meaning are essential and should be addressed by a family and marital therapist (Solomon and Chung, 2012; Neely et. al. 2012). Other specialists could help in this regard for example just by knowing, accepting and promoting the help of systemic therapists. Education opportunities for families could increase the chance to understand how to manage these situations (Goian, 2013). It has been demonstrated that social support can improve the capacity to face overwhelming events, becoming a protective factor for these situations (Tudorel & Vintila, 2018; Goian 2004). However, specialists should use specialized language with caution, as this can create a barrier between the professional and the client, sharing or receiving meaningless messages (Goian, 2010).

As far as the difficulties faced by the couple, we remind that until recently we do not fully understand the way in which the diagnosis affects the family dynamics. What could be intuitive is that each member of the couple faces the reality in a different way and reacts in a distinct way. Couples that do not have a strong and secure attachment style could be seen at risk in falling apart as they do not find support in one another at difficult times. As mentioned before what affects one subsystem, affects the other subsystem, in other words, parents, couple

partners, and children are all affected. Furthermore, specialist could pay attention to the couple dynamic, at any sign that could show that the relationship is at risk. It is well to know that the face conflicts regarding child-rearing, time spent together, and sexual satisfaction (Knapp, 2004; Weber, 2011), child issues, habits/personality; work; target child; other parenting; intimacy/commitment; relatives; leisure/friends; communication; money; chores and other (Hartley et al. 2016; Hartley et al. 2017). In case of any distress observed specialist should be prepared with a recommendation of couple therapist. In these regards, it is well to know that one form of couple therapy named Emotionally Focused Therapy (EFT) starts to show good results in the case of parents of children on the spectrum. Emotionally Focused Therapy was developed in 1985 by Johnson and Greenberg. Its goal is to diminish the couple levels of stress by developing a secure attachment style between the partners (Lebow et al., 2012) and in order to achieve this, the therapy views emotions as a means of change (Johnson, 2004). In their study regarding the effectiveness of EFT and ASD parents Lee, Furrow and Bradley (2017) revealed the relevant potential of EFT in the case of couples raising chronically ill children and that the parents of ASD children confront great relational distress. They included seven couples in the study and received 12 weeks of EFT treatment each lasting 75 minutes. Their findings highlighting the benefits of EFT in decreasing marital distress. Consequently, in the case of couple difficulties specialists could be prepared with names and phone numbers of specialist in the field of couple therapy. All of these could serve and result in saving one family, into helping members stay together.

Conclusions

The current paper aimed into offering practical guidelines that specialists could consider when dealing with families raising a child on the spectrum. The impact of such a diagnosis is complex and affects at an individual level (depression, anxiety, fatigue), at a family level (family conflicts, low family functioning) and couple level (low marriage satisfaction, lack of trust, lack of emotional support). Hence, it was not until recently that we understood the complexity of the situation and the need of a multifaced treatment plan. Given the circumstances, specialists and institutions could firstly be up to date with the information regarding the named impact and secondly be prepared with ways of helping families. Some of these ways that could inspire specialist and institutions refer to:

- Be prepared to recognize depression by paying attention to the behavior of the parents and their nonverbal language starting with the outfit and posture. Suggest parents seek help with a psychotherapist or psychiatrist.
- Pay attention to any sign of anxiety and take into consideration that in many cases the main worry of these parents is referred to the child. Discuss with families about their worries and offer them the chance to participate in support groups where to find validation and empathy.
- Supporting the family in exploring potential interventions for their child by exploring the pros and cons of treatment options.
- Encouraging the family into action, into keeping up with their lives as usual as much as possible. encouraged to keep being involved in the community life which could help them keep a good level of satisfaction and wellbeing.
- Help the family to speak up for their rights and needs and by offering to understand and promoting acceptance.
- Pay attention to the approach of the parents towards the siblings that most often are also affected and encourage parents to spend time with the siblings.
- Pay attention to the couple dynamic, at any sign that could show that the relationship is at risk and be prepared with a recommendation of a couple therapist.
- Knowing, accepting and promoting the help of a systemic therapist.

Using culturally adapted instruments to obtain robust and validated results (Tudorel et al., 2018; Vintila et al., 2018).

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