

Families With Children Diagnosed With Autism: Implications for Counselors

Isanely Guerrero Kurz¹

Abstract

This article explores struggles faced by parents with children diagnosed with autism (ASD). Experiences of parents are examined through identification of stressors, maladaptive coping, and negative emotions. Current counselor education research is presented on how counselors may work to help this population, including topics in supervision, multicultural and ethical competency, and need for integrative health care. Behavioral and supportive interventions used in working with children with ASD and their families are discussed.

Keywords

autism, families, counselor education, evidence-based practice

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that can be described as deficits in social interactions and communication which can often lead to expression through challenging behaviors (Haakonsen Smith et al., 2017). The manifestation of these behaviors can vary from mild to severe. The prevalence of ASD in the United States was reported to be 1 in 59 in 2018, while the lifelong cost of caring for an individual on the spectrum and intellectual disability was US\$2.4 million (Buescher, Ciday, Knapp, & Mandell, 2014; Center of Disease Control and Prevention, 2018). As the number of children with ASD increases, so does the number of caregivers promoting their child's development. Studies have shown that parents of children with ASD are likely to experience concerning levels of stress compared to parents of other developmental disabilities (Al-Khalaf, Dempsey, & Dally, 2014). Parents suffer significantly due to the demands of parenting a child with ASD; therefore, there is a high need for the development of more effective services for children with ASD and their parents (Bitsika & Sharpley, 2004). There is scarce research on competent services for counselors working with families with autism, despite the growing research on stressors parents face. In order to provide appropriate counseling services for these populations, counselors must attempt to understand the lived experiences of families of children with autism accessing mental health services. Counselors should consider their role in improving outcomes for families and their children with ASD through evidence-based treatment and training. Additionally, there are implications for research in counselor education to employ effective strategies in supervision, utilize multicultural and ethical skill, and advocate on behalf of integrative health care. These approaches are discussed in depth.

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Overview of Families With Autism

Family and Marital Challenges

Parents of children with ASD experience high levels of stress that can affect their psychological well-being and family and marriage systems (Serrata, 2012). As their children grow older, it may be more difficult to manage behaviors and communication barriers. Families may experience severe stress and overwhelming emotions through these daily challenges faced with their child. Furthermore, the emotional and financial challenges that are involved in managing their child's treatment plan can become even more complex if the family also has a typically developed sibling (Solomon & Chung, 2012).

Due to the stressors faced, parents may engage in more maladaptive coping such as criticizing themselves, venting negative emotions, and possibly distracting themselves from solving problems (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Lai, Goh, Oei, & Sung, 2015). Other families may feel shame in constantly needing to explain and educate others about autism (Gorlin, McAlpine, Garwick, & Wieling, 2016). One study in particular found that increased levels of parenting stress were associated with increased levels of depressive symptoms, but often, mothers of children with ASD who have increased depressive symptomatology do not seek psychotherapy (Beer, Ward, & Moar, 2013).

¹ The University of Texas at San Antonio, San Antonio, TX, USA

Corresponding Author:

Isanely Kurz, University of Texas at San Antonio, 501 W. Cesar E. Chavez Boulevard, DB 4.226, San Antonio, TX 78207, USA.

Email: isabarker19@yahoo.com

Within the family structure, parents with children diagnosed with autism generally face more difficulties in their marital relationship than those without (Hartley et al., 2017; Tomeny, Baker, Barry, Eldred, & Rankin, 2016; Walsh & O'Leary, 2013). In particular, some fathers admitted to experience the impact of their child's autism indirectly, through the stress experienced by their partner (Gray, 2003). However, support factors outside of the marriage are predictive of marital quality for both husband and wife (Harper, Dyches, Harper, Roper, & South, 2013).

Families may also experience severe isolation from others because of their inability to leave home due to their child's needs. Isolation can also occur through feeling unheard by medical and health providers who lack knowledge about autism and feeling shamed by the public when their child's behaviors are misunderstood. Additionally, parents report feeling isolated from their child because of their lack of communication and developmental delay (Gorlin et al., 2016). As a result of these feelings, families rely heavily on the support of others for emotional and physical support.

Sibling Challenges

Siblings of children with ASD also have adjustment problems (Hastings, 2003; McHale, Updegraff, & Feinberg, 2016). Siblings of children with autism serve a unique role in presenting their brother or sister with numerous opportunities for interaction (Braconnier, Coffman, Kelso, & Wolf, 2017). Additionally, positive sibling relationships are linked to increased self-esteem (Braconnier et al., 2017; Milevsky, 2005). However, having a sibling with ASD may also have negative effects on the sibling relationship. Due to social deficits of ASD, siblings may experience less warmth and closeness when the child with ASD presents behavioral problems (Braconnier et al., 2017). Ross and Cuskelly (2006) identified aggression as one significant stressor within sibling interactions where one sibling has ASD. Furthermore, the most common reaction to aggressive behavior was anger. Siblings may have difficulty with internalizing problems and a lack of understanding in how to handle difficult behaviors from their brothers or sisters (Ross & Cuskelly, 2006).

Protective Factors and Coping Strategies

Family units with a child with autism may require members of educational, therapeutic, and medical professionals to collaborate helping parents access all the support and resources needed for them and their child. A study by Lock, Bradley, Hendricks, and Brown (2013) found that members involved in a parent-professional networking group reported high levels of satisfaction with the increased knowledge and understanding of research-based interventions for their child but wanted more one-to-one contact to discuss their child. Some of the perceived benefits from being involved in the network were increased parental understanding, empowerment, knowledge, and camaraderie (Lock, Bradley, Hendricks, & Brown, 2013).

Another study found that social support resources formed by family, friends, and significant others was the most important predictor of social support perceptions in families with a child who has ASD (Meral & Cavkaytar, 2012). Families may also differ in problem-focused or emotion-focused means of coping. Perhaps families will rely on service providers or some on religion or focusing on their child's positive qualities (Gray, 2006). This information may be useful in how service providers, or counselors in particular, may choose to work with this population. Counseling professionals should consider the effects of not only the child diagnosed but on the entire family system and how their working with this population could add to or reduce their stress.

Counselor Education in Autism

There have been few articles published in counselor education journals discussing the population of clients with autism or their families. One study concluded that there was a need for more research understanding the roles of counselors working with clients who have ASD and their families (Layne, 2007). In reality, many counselors will find themselves working with parents who have a child with autism or their child diagnosed with ASD. Williams and Haranin (2016) discussed the need for training during professional education to provide a foundation for clinicians to develop confidence and skills to work with children with ASD.

Few studies proved to be helpful in working with the autism population. For example, one study found that family counseling may be helpful in early counseling sessions to increase family knowledge of ASD and prioritizing goals within the family structure (Lock et al., 2013). Implementing positive help-seeking behaviors may require change and acceptance within the family unit and how they react to stressful situations. Evaluating relationships within the family may also be helpful in identifying healthy patterns of behavior versus unhealthy ones.

Although there has been a huge gap in research between counseling and families and children with ASD, significant implications for counselors who have an active role with this population exist. Ennis-Cole, Durodoye, and Harris (2013) shared the advocacy and multicultural competencies for counselors to use to support families with ASD. Specifically, competencies such as personal awareness, cultural knowledge, and using appropriate skills for working with families with autism are discussed. Counselors and other mental health professionals hold a unique position to inform teachers, parents, and other professionals about the struggles that families with children with ASD face and how they can provide culturally sensitive services. Models and presentations for improving the identification of ASD should be shared in larger community settings to create a social action movement for awareness and public recognition.

In a larger picture, family access to telecommunication services where they can receive attention and intervention for their child through telephone or via webcams can help families who

have difficulty with transportation or work-related issues. Thinking outside the usual and catering to the client's needs may help to alleviate stressors parents face when having a child with ASD. Health agencies may also consider recruiting and hiring staff who are from diverse backgrounds that share culture and language with clients. They may also require that their staff is trained on multicultural issues and culturally sensitive practices.

Treatment and Intervention With Autism

There is a number of evidence-based practices and interventions used for treatment. Research aimed for counselors concerning evidence-based treatments toward working with families and autism is scarce. Some studies have evaluated the impact of mindfulness-based interventions in reducing stress and increasing well-being of parents of children with ASD (Cachia, Anderson, & Moore, 2015). Conner and White (2014) found that increasing maternal mindfulness decreased stress levels while controlling for the effect of child behavior problems. The use of emotionally focused couple therapy reported increased marital intimacy through treatment of couples raising a child with ASD (Lee, Furrow, & Bradley, 2017).

Cognitive–Behavioral Therapy

Cognitive–behavioral therapy (CBT) is an evidence-based practice that places emphasis on thoughts and behaviors to improve mood and overall functioning (Lock et al., 2013). CBT has been effective in treating anxiety in young persons with ASD (Reaven, Blakeley-Smith, Culhane-Shelburne, & Hepburn, 2012; White, Schry, Miyazaki, Ollendick, & Scahill, 2015). In individuals with autism, emotional dysregulation can be internalized through anxiety, depression, or obsessive-compulsive disorder or externalized through difficult behaviors (Wood, Klebanoff, Renno, Fujii, & Danial, 2017). A modified version of CBT was created to address social and adaptive deficits, poor motivation, school issues, and comorbidity. Parents also participated in sessions to help facilitate treatment progress and generalization in multiple settings. For example, parents helped to schedule peer activities and implement reward systems at home (Wood et al., 2015). A similar study adapted a CBT manual for children with ASD to address poor social skills, attention, and motivation through building independence and friendships, mentoring programs, and child's reward systems. Authors modified traditional CBT and address deficits in ASD. Teachers and parents were necessary in the skills acquisition phase of treatment to address disruptive behaviors and provide cues for adaptive skills in everyday settings (Wood et al., 2009). This program provided these individuals with focused goals and reduced anxiety for children with ASD. It is important to acknowledge the important role that parents and families have in the treatment of individuals with autism in continual progress and generalization to multiple settings.

Applied Behavioral Analysis

The scientific study of principle of learning and behavior, or applied behavioral analysis (ABA), has provided interventions that produce comprehensive and lasting results in autism (Foxy, 2008). This empirically evaluated treatment is effective in reducing inappropriate behaviors and increasing learning, communication, and appropriate behaviors (Rosenwasser & Axelrod, 2001; U.S. Department of Health and Human Services, 1999). The seven dimensions of ABA are as follows:

- Applied: interventions that work with problems of demonstrated social importance
- Behavioral: interventions that recognize measurable behaviors
- Analytic: objective or responsible for the occurrence or nonoccurrence of behavior
- Technological: intervention can be replicated and implemented by other researchers
- Conceptually Systematic: derived from specific and identifiable theoretical base
- Effective: produce socially significant results
- Generality: operate in different environments and continue after formal treatments end (Baer, Wolf, & Risley, 1968).

These principles are used to guide analysis and practice of ABA. ABA is composed of many different treatment approaches including shaping, chaining, fading, extinction, and more. Professionals who work under the principles of ABA are well-versed and equipped in implementing a wide variety of procedures as well as having an understanding on which the procedures are based. In addition, professionals are trained to understand under what conditions they can use the interventions (Leaf et al., 2016).

ABA interventions should be flexible in application to clients with a variety of needs. One systematic strategy derived from ABA is Discrete Trial Training (DTT). This intervention includes instruction from the therapist, response by the learner, and a punishment or reinforcement facilitated by the therapist (Radley, Dart, Furlow, & Ness, 2015). For example, a therapist may break a desired skill into smaller components for the client until they can effectively master the entire skill. A child may be taught to first correctly hold their toothbrush before applying toothpaste, turning on the faucet, and finally brushing their teeth. Application of DTT is recommended in the child's natural environment, so that learning is generalized and applied to more than one environment. DTT can improve social skills, language, and academic skills leading to life-altering changes within an individual with ASD (Leaf et al., 2016). Children with different functioning levels may require variations of intervention and treatment time and steps.

Implications for Counselors

Autism is a lifelong diagnosis that affects the entire family. Although there are few research studies within counseling

literature addressing interventions for working with these clients, maladaptive behaviors and deficits in communication can greatly impact the family's structure and well-being. Families may engage in negative coping styles that can directly influence stress, anxiety, and depression (Boyd, 2002). Furthermore, children with autism may be affected by comorbid conditions of anxiety and depression. Counselors are necessary in helping families manage behavioral problems and daily challenges for parents and their children. Targeting specific symptoms such as inappropriate speech, difficult behaviors, and dysregulated emotions can be targeted through the use of adapted CBT (Reaven et al., 2012; Sung et al., 2011; Wood et al., 2015).

Counselors may also choose to work in behavioral health-care settings where they will become familiar with behavioral interventions and working within the autism population. Specializing in therapies such as ABA can also help counselors to gain specific access within the autism population and appear more marketable through competitive job opportunities. As the demand for behavioral analytic services rises, the need for more qualified Board Certified Behavior Analysts (BCBAs) will be needed to help support families through their journey with autism (Dixon, 2014). Counselors must be mindful of the appropriate education, training, and supervision necessary for working in new specialty areas, such mentioned in the ACA Code of Ethics, Code C.2.b (American Counseling Association, 2014). Counseling programs may consider advertising an ABA certificate as elective courses for those interested in working with autism populations and their families. Continuing education in ABA may be useful in working with clients who seek behavioral therapy for treatment and can be helpful for counselors to utilize a therapeutic relationship alongside behavior principles. In addition, counselors should seek partnerships with BCBAs who may see clients with autism on a daily basis. Consulting with professionals from different fields may help in considering new perspectives to daily struggles within families with ASD. An interdisciplinary approach may be beneficial to improve outcomes for individuals with ASD while maintaining a professional relationship with other disciplines (Brodhead, 2015). Promoting the safety and well-being of clients with ASD and their families should be the greatest priority for all professionals helping this population. This includes the implication of systematic training for professional interactions between interdisciplinary teams to meet the needs of individuals on the spectrum while maintaining professional relationships (Brodhead, 2015).

There are several professionals involved in ensuring the safety of individuals with autism such as teachers, doctors, nurses, BCBAs, social workers, parents, families, and many more. Counselors have also contributed to some growing research in helping this population through advocacy and support. However, more research is necessary to identify the support that families with children diagnosed with ASD need and how counselors are needed in working with this population. Moreover, the author has considered evidence-based practices, ethical and multicultural issues, and formalized counselor

education for supporting children with ASD and their families. As the population of autism continues to ascend, counselors may find themselves considering new specialties for working with children with ASD and their families. Familiarity with how to approach best treatment methods such as ABA and CBT may help counselors to provide useful services to families or advocate on behalf of clients who may have no knowledge of this diagnosis.

Ethical and Multicultural Issues

In addition to the evidence-based practices mentioned previously, counselors should continuously seek treatment modalities that are empirically sound and grounded in theory as mentioned in the ACA Code of Ethics, Code C.7.a (American Counseling Association, 2014). The roles that counselors have in working with this population may be inconclusive, although there are responsibilities in advocacy and support that are needed. Supports may lie in advocacy for increased state and federal funding to support early intervention and for counseling services for children with autism and their families (Layne, 2007).

Counselors who find themselves working with families and their children with autism must also consider the family's cultural values and how they may differ or align with mainstream culture (Lock et al., 2013). As the rise of ASD and comorbidity affects children, family beliefs about causes must be considered when a family is initially diagnosed. An accurate diagnosis is necessary across all cultural groups, so that a child may receive early intervention through evidence-based treatments (Ennis-Cole, Durodoye, & Harris, 2013). Counselors working within a cultural group who believe their child will outgrow language and social skill deficits may need to evaluate their approach to this topic. Furthermore, ethnic minorities are underrepresented when referred to autism institutions (Ennis-Cole et al., 2013).

Acceptance of treatment and diagnosis is important when considering multicultural populations and their willingness to seek professional treatment. Counselors should be willing to incorporate different modalities of intervention and theory of practice. Lastly, religious beliefs may be considered when incorporating treatment planning and meeting the needs of families with different backgrounds (Sue & Sue, 2008).

Training and Supervision

Formal training is necessary for clinicians to gain confidence and applicable skill when working with this population. In particular, university graduate programs may consider providing special certifications for students who are interested in working with children with ASD. Integrating autism and behavioral curriculum in addition to hiring faculty with this professional expertise will enhance the opportunities for leadership within the counseling autism community. Furthermore, advocacy for more integrated behavioral services would help to conveniently deliver services for individuals with autism

and their families. As more professionals make connections and partnerships through integrative services, barriers to service delivery and incompetent training will reduce. Access to supervision with a professional who has expertise in ASD has also been found to be lacking (Williams & Haranin, 2016). Through specialized and foundational training beginning at the graduate level, supervisors with experience in autism can train others to be competent and confident in working with future clients. In addition, counseling professionals gaining a specialization in autism will make themselves marketable to the public in specialized training and supervision services.

Conclusion

With the most recent update from the Center for Disease Control (2018) estimating that the prevalence has increased by 15% within 2 years, enormous implications for government policy to increase individualized support for individuals with ASD are pressing now more than ever. As counselors, we have an obligation to advocate for clients who are underserved and at risk. Clients with autism may suffer from comorbid disorders such as anxiety and depression. Their families may also suffer significantly due to the responsibilities of raising a child with ASD. Counselors must be aware of how to effectively implement different methods of helping these clients through use of evidence-based practices such as ABA or CBT. Furthermore, counselors should be mindful of the perceptions they have toward people with developmental disabilities and how that can impact their work with them. In addition to having an autism diagnosis, clients have embedded cultural, social, and personal values that should be validated and listened to.

Incorporating multicultural and ethical competencies into counseling practice is necessary for applying knowledge in a comprehensive and holistic manner. The Association for Multicultural Counseling and Development outlines competencies each counselor should possess including self-awareness of one's own attitudes and beliefs, specific knowledge of the group they are working with, and cross-cultural skills relevant to diverse groups and effective counseling (Arredondo et al., 1996). Counselors and counselor educators provide services to persons with autism by attempting to see the world through their eyes and use this perspective to teach others how to be of service. While there is no cure to autism, if society can understand what people with ASD go through and what their families face, then they can design models and theories on how to assist in overcoming challenges once diagnosed. Through understanding of how they make meaning, we may then understand their cause and how to initiate change.

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