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A Stress Model for Couples Parenting Children With Autism Spectrum Disorders and the Introduction of a Mindfulness Intervention

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Abstract

Parents of children with autism spectrum disorders (ASD) are at an increased risk for acute and chronic stress compared to parents of children with other developmental disabilities and parents of children without disabilities. It is plausible that the stressors of having a child with ASD affect the couple relationship; however, few researchers have focused on this dynamic within these families. In this article, we seek to develop a model for how stress operates in families with children with ASD. In developing this new stress model, we describe the characteristics of ASD, discuss stressors that are pronounced in families of children with ASD as supported by the literature, and highlight the limitations of Perry's (2004) model in application to this population. Our expanded stress model includes the addition of parenting couple resources and parenting couple outcomes. Finally, we demonstrate how to apply the model using a mindfulness intervention to promote positive outcomes and strengthen the couple relationship.

Keywords

Autism; developmental disabilities; family stress model

Parents of children with autism spectrum disorders (ASD) are at an increased risk for acute and chronic stress compared to parents of children with other developmental disabilities

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(DD) and parents of children without disabilities (e.g., Davis & Carter, 2008; Hastings, 2003). Researchers have demonstrated that this is in part a result of the severity and ongoing nature of the characteristics of ASD (Ingersoll & Hambrick, 2011). In addition, the stress of having a child with ASD can negatively influence the couple relationship (Meadan, Halle, & Ebata, 2010). For example, the divorce rate is higher among parents of children with ASD (23.5%) than among parents of children without developmental disabilities (13.8%; Hartley et al., 2010). Further, parents of children with ASD report lower relationship satisfaction than do all other parenting couples (Brobst, Clopton, & Hendrick, 2009). In other words, parents of children with ASD are more likely to experience divorce and decreased relationship satisfaction than are parents of children without disabilities. Further, as the divorce rates are higher among this population (Hartley et al., 2010), there is also a greater number of divorced parents coparenting their child with ASD.

It is plausible that the stressors of having a child with ASD affect the couple relationship; however, few researchers have focused on this dynamic within these families. In this article, we seek to develop a model for how stress operates in families with children with ASD. A previous model of stress has depicted predictors, moderators, and outcomes of parents of children with developmental disabilities (Perry, 2004). In developing this new stress model, we describe the characteristics of ASD, discuss stressors that are pronounced in families of children with ASD as supported by the literature, and highlight the limitations of Perry's (2004) model in application to this population. Our expanded stress model includes the addition of parenting couple resources and parenting couple outcomes. Although we focus exclusively on couples parenting children with ASD, the new model can also be applied to families and parents of children with other types of DD as well as other family structures (e.g., divorced coparents, multigenerational parenting). Finally, we demonstrate how to apply the model using a mindfulness intervention to promote positive outcomes and strengthen the couple relationship.

Autism Spectrum Disorders

Autism spectrum disorders are neurobiological disorders including autism, Asperger's syndrome, and pervasive developmental disorder–not otherwise specified (PDD-NOS; US Centers for Disease Control and Prevention [CDC], 2012). In the United States, approximately 1 in 88 children is diagnosed with ASD, with males (1 in 54) being diagnosed more frequently than females (1 in 252; CDC, 2012). The diagnosis of ASD is characterized by a variety of behaviors, including impaired communication, atypical or limited social functioning, and repetitive or self-stimulatory behaviors (American Psychological Association [APA], 2000). However, the severity and expression of these characteristics of ASD occur on a spectrum, which means that ASD symptoms may manifest differently across individuals. For example, a child with ASD may be highly verbal (which is often considered high functioning) but may not socialize well with others and engage in restricted, repetitive behaviors.

There is considerable overlap between the characteristics of developmental disabilities (DD) and the characteristics of ASD. However, there are some characteristics that are distinct to ASD and other characteristics that are more severe than those of DD. For example, the

impairment of a child's ability to relate to others is unique to the diagnosis of ASD. Notably, this characteristic has been associated with higher levels of reported parental stress (Davis & Carter, 2008). In addition, there are features of ASD that are more severe compared to other DD. Ventola et al. (2007) found that children with ASD had noticeable and consistent impairments on assessments of socialization skills, particularly joint attention skills, and were more impaired in certain aspects of communication, play, and sensory processing when compared to children with DD. Further, children with ASD were observably distinct from other children with DD in behaviors such as responding to smiles with a smile, joining adults in functional play, and initiating verbal and nonverbal requesting behavior (Trillingsgaard, Sørensen, Němec, & Jørgensen, 2005). Overall, it appears that children with ASD appear to display impairments in socializing behaviors that are more severe and distinct than in children with other DD. Considering these differences, it is important to understand how these characteristics of ASD might influence parental stress and the couple relationship.

ASD and Parental Stress

Parents of children with ASD report higher levels of parental stress than do both parents of children with other DD (e.g., Down syndrome, intellectual disabilities, developmental delays; Estes et al., 2009; Griffith, Hastings, Nash, & Hill, 2010) and parents of typically developing children (Brobst et al., 2009; Ingersoll & Hambrick, 2011; Montes & Halterman, 2007). For these parents, several factors increase the likelihood of stress, such as greater time demands associated with participation in various therapies (e.g., speech and language, occupational), which results in less time to attend to other matters (Sawyer et al., 2010). Further, there are certain characteristics of ASD that appear to be correlated with higher levels of parental stress. These include social impairment, self-regulatory problems, and most notably, problem behaviors. Children with ASD generally are withdrawn in social situations, are less likely to make eye contact with others, and are less likely to behave in other socially normative ways compared to children without disabilities (APA, 2000). As previously mentioned, the impairment of a child's ability to relate to others is a unique characteristic of ASD, which has been associated with higher levels of reported parental stress (Davis & Carter, 2008).

There also are characteristics that are associated with several diagnoses but may be more pronounced in children with ASD. For example, behaviors related to self-regulation generally are delayed or impaired in children with ASD (Davis & Carter, 2008). These behaviors increase the time and energy demands of caring for these children, thus leading to a greater likelihood of parental stress (Sawyer et al., 2010). However, problem behaviors appear to be the strongest predictor of stress among parents of children with ASD. These problem behaviors include acts of defiance and/or aggression, tantrums, and public outbursts (Estes et al., 2009; Hastings, 2003; Lecavalier, Leone, & Wiltz, 2006). Compared to parents of children without any developmental delay, mothers and fathers of children with ASD experience more intense child behavior problems and increased parental stress (Brobst et al., 2009).

In addition to child characteristics associated with ASD, more distal factors may also predict parental stress. One distal factor may be a reduction of informal social support. These parents may be less likely to receive informal social support given the nature of the child's disability. Perhaps the negative perception of the social and behavioral characteristics associated with ASD may prevent informal social networks from providing ongoing or consistent support. Stuart and McGrew (2009) found that a reduction of informal social support is associated with increased caregiver burden, which could lead to increased stress.

Another distal factor influencing parental stress may be the diagnosis process. Unlike other diagnoses, such as Down syndrome, in which a diagnosis is provided almost immediately, families of children with ASD generally endure lengthy and involved procedures before receiving a diagnosis (Braiden, Bothwell, & Duffy, 2010; Moh & Magiati, 2012). This process involves seeking opinions from multiple professionals, who individually attribute delays to a variety of factors. In turn, these experiences have been shown to increase the risk of stress for families of children with ASD (Moh & Magiati, 2012; Siklos & Kerns, 2007). Given the various sources of stress associated with ASD, these parents also must deal with the pileup of stress associated with the disability (Stuart & McGrew, 2009). Parents of children with ASD appear to experience a complex array of stressors that are both proximal and distal.

ASD and Couple Stress

Researchers have found common factors associated with couples who report being satisfied with their relationship, including dependability; stability; honesty; and a positive perception of themselves, their partner, and their relationship (Young & Kleist, 2010). Moreover, healthy communication skills and conflict management skills are the best predictors of long-term relationship satisfaction (Bradbury, Rogge, & Lawrence, 2001; Lawrence et al., 2008). In general, systems theorists tout that healthy interpersonal functioning within the family is characterized by the ability to adapt to stressful and changing situations and to maintain a balance between autonomy and closeness (Kerr & Bowen, 1988; Minuchin, 1974).

Couples parenting children with ASD report higher rates of divorce and separation than both couples in the general population and parents of children with other disabilities (see Risdal & Singer, 2004). Furthermore, while the divorce rate of parents of typically developing children declines after their children reach adolescence, the divorce rate of parents of children with ASD does not (Hartley et al., 2010). The ongoing probability of divorce illuminates a difference among parenting couples of children with ASD and parenting couples of typically developing children: Having a child with ASD may distinctively disrupt functions of healthy couple interactions continuously through the marriage and not only during times of family life transition (e.g., entry into parenthood).

Relationship satisfaction among couples parenting children with ASD tends to be lower than the general population (Risdal & Singer, 2004); however, the reason for this is not clear. When compared to parents of children without disabilities, both mothers and fathers of children with ASD report lower relationship harmony and agreement (Gau et al., 2012), which is a strong predictor of relationship satisfaction (Kurdek, 1993). This could suggest that there are patterns of interaction among this population that are different from those of

parents of other children and could negatively influence relationship satisfaction. Though parents of children with ASD tend to report lower relationship satisfaction (Risdal & Singer, 2004), others reveal that marital satisfaction can buffer against the stress of having a child with ASD (Risdal & Singer, 2004). In addition, even when controlling for coping style, relationship satisfaction among these couples is lower than that of the general population (Higgins, Baily, & Pearce, 2005). Perhaps typical coping styles may not be enough to buffer against the stress of parenting a child with ASD. Thus, it is important to understand what is most salient in influencing relationship satisfaction for these couples.

To the authors' knowledge, no study has specifically examined coparenting relationships among divorced parents of children with ASD. Saposnek, Perryman, Berkow, and Ellsworth (2005) developed a conceptual framework for individualized parenting plans for divorcing parents of children with special needs during the legal process. In this framework, they emphasized, "The parental separation and divorce exacerbates the symptoms of these children, [making] them harder to care for at a time when there are fewer resource to go around, and impacts the entire family in unique and often profound ways" (p. 566). Thus, coparenting during the divorce process may be particularly challenging for coparents' of children with ASD and their children's well-being.

We have described some of the specific stressors associated with parents of children diagnosed with ASD. In the following section, we discuss a model that addresses stress in parents of children with DD and follow with an explanation of why this model is limited in its application to couples parenting children with ASD.

Perry's Stress Model

Developmental disabilities include a wide variety of chronic, lifelong disorders caused by mental and/or physical deficiencies that affect everyday life experiences such as language, learning, mobility, self-help, and independent living skills (CDC, 2012). Common forms of DD include, but are not limited to, ASD, Down syndrome, intellectual disabilities, vision impairments, cerebral palsy, and hearing loss. Perry (2004) presented a stress model (see Figure 1) addressing the specific experiences of families of children with DD. This model was developed in response to the limitations of well-researched and well-published family stress models such as the ABCX Model (Hill, 1958) and the Double ABCX Model (Lavee, McCubbin, & Patterson, 1985). Perry (2004) stated that these models did not accurately capture the experiences of families with children with DD because of the implications that the outcomes of stress are dichotomous (adaptation or crisis). However, conceptualizing the experiences of these families through the Daily Hassles model (Kanner, Coyne, Schaefer, & Lazarus, 1981) may offer a more accurate perspective, as it captures ongoing and repeated daily stressors. Perry articulated a need for a model that encompassed the ongoing stress that families of children with DD endure.

Perry's (2004) model includes four core components: stressors, support, resources, and outcomes. The support and resource components act as moderators of the relationship between stressors and parental outcomes. Stressors are defined as objective and subjective child characteristics (e.g., cognitive or developmental level, frequency and severity of

maladaptive behavior) and other life stressors that all families experience (e.g., employment, financial strain). Resources include both individual resources (e.g., coping strategies) and the family system's resources (e.g., family functioning, marital satisfaction). Support includes actual or perceived informal social support (e.g., family, friends, social organizations) and formal supports and services (e.g., professional and paraprofessional interventions). Outcomes in this model are defined as positive (e.g., personal growth) or negative (e.g., depression).

As with any model, there are limitations to Perry's (2004) model. Perry intended for her model to include families of all developmental disabilities. The model is limited in its simplicity because (a) it does not account for how the intervening variables of resources and support might influence each other reciprocally, (b) it focuses on individual parental outcomes while neglecting the effect that a child's disability has on the relationships within the family system (e.g., the couple relationship), and (c) it lacks the credibility of being grounded in empirical evidence. Instead, the focus is on providing explanations from a clinical perspective without providing a review of the scientific literature. In the following section, we propose a model that expands on Perry's model and addresses these limitations.

Stress Model for Parents of Children With ASD

We present a stress model informed by the empirical findings from research on stress among couples parenting children with ASD (see Figure 2). As indicated by the literature cited earlier, it is evident that this population experiences a heightened level of stress and thus warrants a model tailored to their experiences. Though our model also may apply to families of children with other types of DD, our focus on families of children with ASD allows us to support our model using a more narrow and homogenous body of literature. We incorporate a more systemic perspective by including outcomes that are specific to both parents as individuals and parents as a couple. We further expand on Perry's (2004) model by emphasizing how intervening variables (i.e., support and resources) can interact with each other over time, compounding or collectively mitigating the stressors associated with having a child with ASD. Our model includes child characteristics as predicting variables, which include child behavior problems and parental perceptions of those behaviors. Individual parental outcomes and couple relationship outcomes serve as the dependent variables, and the interaction between them is depicted in our model. Supports and resources are intervening variables either buffering or exacerbating the effects of child characteristics on couple and parental outcomes. We discuss each of these components in the following sections.

Stressors

Child characteristics—As stated earlier, child social-relatedness issues, regulatory problems, and behavior problems increase the likelihood of stress in couples parenting children with ASD (Davis & Carter, 2008; Hastings, 2003; Estes et al., 2009; Lecavalier et al., 2006). However, much of the research on stress experienced by parents of children with ASD is based on maternal report. When considering both mother and father report, results of parental stress are mixed (e.g., Estes et al., 2009; Hastings, 2003), with mothers reporting more stress related to child behavior problems, regulatory problems, and conduct problems

(Hastings, 2003; Hastings et al., 2005), and fathers reporting greater stress in relation to externalizing behaviors (e.g., hitting; Davis & Carter, 2008). In addition, mothers report greater marital maladjustment than do fathers (Gau et al., 2012). It may be that mothers and fathers perceive different behaviors as problematic. For instance, a particular behavior may be viewed as noncompliance by a mother but experienced as play behavior by a father. If behaviors are perceived as problematic, these child characteristics may increase the likelihood of parental stress. However, the varying parental perceptions of these child characteristics are an area in need of additional research.

Because of the differences in parental perceptions of child characteristics, we have included subjective child characteristics in our model of parental stress (see Figure 2). There also may be characteristics unique to each child that potentially affect parental stress, such as severity of ASD symptoms and/or child age. In relation to the severity of a child's symptomology and parental stress, findings are largely inconclusive. Many researchers have suggested that the more severe the diagnosis, the more likely parents are to report higher stress (Ingersoll & Hambrick, 2011; Osborne, McHugh, Saunders, & Reed, 2008; Stuart & McGrew, 2009). Yet even parents of children with high-functioning autism report greater stress than parents of children with no developmental delay (Rao & Beidel, 2009). Also, parents of children 4 years old or younger who are diagnosed with ASD report significantly greater levels of stress than do parents of older children with ASD (Osborne & Reed, 2010). Objective characteristics, such as the child's symptomology and age, can affect stress in parents and thus have been included in our model as distinct stressors (see Figure 2).

Other family stressors—As evidenced in the literature reviewed thus far, most researchers who have studied stress among families of children with ASD have hypothesized and demonstrated that the presence of a child with ASD is associated with elevated levels of distress in parents. Though this hypothesis has proved accurate in many cases, it is incomplete given the lack of attention to additional sources of stress. Despite the likelihood that these families encounter many stressors (both normative and nonnormative) that are not directly related to the presence of a child with ASD, few have included this element to their studies. A notable exception was a study by Benson (2006), who found that both child symptom severity and stress proliferation (i.e., the tendency for stressors in one area of life to produce stress in other areas of life) were associated with depressive symptoms in parents. This study provides a more complete characterization of the process of stress parents experience by accounting for stressors not directly related to the presence of a child with ASD. In line with Perry's (2004) model, we believe that a complete characterization of the stressors experienced by parents such as work, finances, the presence of additional children, family structure, and other family issues must be considered when conceptualizing how parents of children with ASD experience stress.

Intervening Variables

Intervening variables can have an effect on how predictor variables influence outcome variables. In addition, these intervening variables can interact with one another, thus changing the effect of predictor variables on outcome variables. For example, although the dimensions of these variables are represented singularly in their effects in our model,

individual resources such as optimism have been shown to mediate the relationship between family support and certain outcome variables such as stress, depression, life satisfaction, and psychological well-being (see Ekas, Lickenbrock, & Whitman, 2010). In our proposed model, resources and support are identified as interaction variables, and we describe them in detail in the following sections.

Resources—According to family stress theory, resources play an integral role in how families adapt to stressful circumstances (McCubbin, 1979). Perry's (2004) model includes personal and family system resources as important elements that may affect the relationship between having a child with DD and positive and negative parental outcomes. However, in describing the effect of individual and family resources on parents of children with DD, Perry provides limited empirical justification for the inclusion of these variables in the model. The purpose of this section is to illustrate how various resources can influence the effect of having a child with ASD on parental outcomes. In addition, we expand Perry's model by including couple resources separate from resources that exist within the family as a whole. By so doing, we allow for differentiation between resources that are available to couples and those that are available to the entire family.

Individual resources—Perry (2004) described individual resources as "personality variables and cognitive coping strategies and beliefs, as well as more demographic factors (such as education and employment status)" (p. 7). Despite Perry's argument that few researchers have investigated the effect of individual resources on parents of children with DD, several researchers offer insights into how individual resources influence parents and families of children with ASD, especially with regard to coping strategies. Overall, it has been demonstrated that parents who use positive coping strategies (e.g., task-oriented coping, positive reframing) reduce the amount of negative outcomes and increase the amount of positive outcomes, whereas the use of negative coping strategies (e.g., emotion-focused coping, active-avoidance coping) is associated with increased negative outcomes (Dabrowska & Pisula, 2010; Dunn, Burbine, Powers, & Tantleff-Dunn, 2001; Lyons, Leon, Phelps, & Dunleavy, 2010; Pottie & Ingram, 2008). Thus, parents of children with ASD appear to benefit from using adaptive coping strategies such as reframing stressful situations, despite the challenges they experience. However, parents who adopt coping behaviors that that are avoidant and volatile seem to increase their risk for stress.

Beyond coping strategies, few researchers have investigated the effect of other individual characteristics (e.g., personality, education, employment status) on outcomes experienced by parents of children with ASD. However, Weiss (2002) found that having a hardy personality (e.g., believing that one can control or influence life events, feeling deeply involved in or committed to life activities, and anticipating change as an exciting challenge to further ones development; Kobasa, 1979) is an adaptive quality in mothers of children with ASD and other disabilities. With respect to gender effects, some evidence indicates that mothers are at an increased risk compared to fathers for negative outcomes associated with parenting children with ASD (Dabrowska & Pisula, 2010; Gray, 2002), Despite the limited research in this area, it appears that individual resources play an important role how couples parenting children with ASD experience stress.

Couple resources—Perry's (2004) model does not distinguish couple resources from overall family system resources. Our argument, however, is that within the family system, the marital subsystem is recognized as unique and deserving of specific attention. Couple resources are the characteristics that the dyad brings to the family system to reduce, exacerbate, or maintain stress. As previously discussed, relationship satisfaction acts as a buffer to the stress of parenting a child with ASD (Risdal & Singer, 2004). Additional examples of couple resources that may influence individual and relationship outcomes in parents of children with ASD could be those that have been shown to be influential among the general population for all forms of parenting dyads (e.g., separated or divorced parents, parenting grandparents, same-sex parents).

Other forms of couple resource could be the bidirectional influence of the partners' attitude and behavior. One study found that individuals' relationship competence is predictive of relationship satisfaction (Lawrence et al., 2008); thus, the relationship skills of one member of the dyad can influence the perceived quality of the relationship. Conversely, relationship satisfaction can influence individual well-being (Larson, Whitton, Hauser, & Allen, 2007). These studies together suggest a feedback loop, with individuals influencing the dyad and the quality of the dyad influencing the individual. For parents of children with ASD, this mutual influence may also occur. Mothers and fathers of children with ASD report greater stress when their partner struggles with depression and stress (Hastings, 2003; Hastings et al., 2005). If mothers and fathers can experience negative effects from their partner's mental health challenges, then the reverse may also be true; certain individual characteristics may predict positive outcomes in aspects of their partner's well-being.

In general, patterns of relational interactions can predict later relationship characteristics (Karney & Bradbury, 1995). For example, several studies highlight the influence of social and relationship competence on relationship satisfaction (e.g., Lamke, Sollie, Durbin, & Fitzpatrick, 1994; Lawrence et al., 2008). Also, communication skills coupled with conflict style predicts current and future relationship satisfaction as well as relationship dissolution. Couples with more effective conflict management skills also report high relationship satisfaction at a later point in time. If these findings are similar to couples parenting children with ASD, then qualities of the romantic relationship may act as a resource because these qualities influence the relationship outcomes.

As previously mentioned, there is limited literature that specifically examines coparenting relationships among divorced parents of children with ASD. However, Saposnek et al. (2005) suggest parenting classes for divorcing parents of children with intellectual disabilities (e.g., ASD) who cannot agree on important parenting decisions (e.g., diagnosing procedures, medical care, attending therapies for their child). Although these suggestions are very specific to a particular time in the divorce process, they point to the importance of effective communication among the coparents for the well-being of the child. This concept is echoed in the literature on coparenting among divorced parents of typically developing children (e.g., Baum, 2004, 2006; Crockenberg & Langrock, 2001; Roberson, Sabo, & Wickle, 2011). Quality coparenting for typically developing children is described as consisting of high coparent interaction (e.g., frequent of conversations between parents about the child); low coparent conflict (e.g., the frequency, hostility, and tension of

arguments about parenting, as well as differences in opinion over child rearing), and high coparent support (e.g., the willingness of parent to accommodate changes in visitation, whether both parents are helpful or act as resources to the other parent in raising their children; Ahrons, 1981). These different types of coparenting styles (conflicted, disengaged, and stable) are linked to different outcomes for children and parents (Roberson et al., 2011). Both the types of coparenting styles and the quality of coparenting may be useful in conceptualizing divorcing coparents of children with ASD.

Other family resources—Family resources can be viewed as resources that are available to and contribute to the well-being of the family as a whole. Family functioning, one type of family resource, has been conceptualized as the balance of cohesion and adaptability within a family unit (Olson, Portner, & Lavee, 1985). Altiere and von Kluge (2009) found that families of children with ASD with a cohesive style of family functioning use more positive coping behaviors than other styles of family functioning. In this way, cohesive family functioning appears to be a resource to families of children with ASD. However, further research needs to be done to replicate these results and verify such conclusions.

There are several other types of family-level resources to be considered that have not yet been researched in relation to stress among families of children with ASD. For example, other resources likely to be important for families of children with ASD are financial resources, which may be influential in determining a family's ability to utilize formal supports and services. Also, though additional children at times may cause increased stress for parents, siblings of children with ASD can also be a valuable resource to the family when they are old enough to help in ways that may provide moments of respite to the parents. Though siblings of children with ASD have been identified as at risk for distress and in need of additional support, practitioners also have emphasized the importance of considering their roles within the overall family system (Bloch & Weinstein, 2010).

Support—Perry (2004) states that informal and formal social supports and services are the main dimensions of support that exist in families of children with DD. We concur with this classification and offer empirical support specific to families of children with ASD.

Perry (2004) suggests that informal social support includes "emotional sustenance and/or tangible help actually received and/or perceived to be available from extended family members, friends, neighbors, social organizations, and religious communities" (p. 9). In general, an increase in informal social support among couples parenting children with ASD decreases the likelihood of negative outcomes such as stress (Dunn et al., 2001). Specifically, Benson (2006) found that informal social support from friends and family decreases stress proliferation and depressive symptoms among parents. Weiss (2002) found that esteem-boosting friendship predicts lower levels of depression and a greater sense of accomplishment with parenting among mothers of children with ASD. Finally, family, partner, and friend support can both directly and indirectly reduce negative parental outcomes while increasing positive parental outcomes (Ekas et al., 2010). Taken together, these findings suggest that certain forms of informal social support may be beneficial for parents of children with ASD.

As previously mentioned, however, couples parenting children with ASD may receive less informal social support, which can increase the burden placed on these couples (Stuart & McGrew, 2009). It has been speculated that the failure of social networks to consistently provide support is because of the socially unacceptable nature of some characteristics of ASD. Perhaps the lack of informal social support can exacerbate the experienced stress leading to negative outcomes. This proposition should be explored in future research.

Independent from informal social support, formal supports and services are also received by parents of children with ASD. According to Perry (2004), these include "professional or paraprofessional interventions, including education/treatment programs … and family interventions such as individual, marital, or family counseling, respite care, behaviour management training, parent support groups, and parents' organizations" (p. 9). In a meta-analysis of depression among mothers of children with DD, Singer (2006) demonstrated that formal supports and services can help reduce distress in these families. Similarly, among couples parenting children with ASD, formal supports such as respite services and school services have been shown to be particularly helpful in providing stress relief (Tehee, Honan, & Hevey, 2009). It is likely that families of children with ASD benefit from such supports in ways similar to families of children with other DD. However, to our knowledge, researchers have not yet attempted to differentiate between which specific types of formal supports and services may be more beneficial or preferable to these families.

Outcomes

In her stress model, Perry (2004) suggests that there are both positive and negative outcomes for families of children with DD. Parenting distress, including burnout, depression, and pessimism, involves the possible negative outcomes of having a child with DD. Further, there are possible positive individual outcomes for parents of children with DD, including personal growth. Perry states that this area is underresearched and recommends an increased focus on positive outcomes for this population. Informed by Perry's stress model, our model incorporates both positive and negative parental outcomes. Further, because we are emphasizing the marital dyad, we discuss outcomes that are specific to mothers, fathers, and relationship quality.

Parental outcomes—Much of the literature on the outcomes of parents of children with ASD is based on combined findings of mothers and fathers or focuses solely on the mothers' outcomes (e.g., Lickenbrock, Ekas, & Whitman, 2011; Siman-Tov & Kaniel, 2011). Recognizing that partners may experience stressors differently and that those experiences may uniquely contribute to the quality of their relationship, we reference, when available, findings elucidating specific mother and father outcomes in addition to parenting outcomes as a whole. Researchers primarily focus on psychological well-being (e.g., stress, depression, anger) as outcomes for parents; thus, we discuss the short- and long-term outcomes for parents of children with ASD in this regard.

Parents of children with ASD are at an increased risk of experiencing anger, depression, and anxiety in the period shortly after diagnosis (Benson & Karlof, 2009). Longitudinally, parents of children with ASD report different levels of well-being in relationship to the

severity of the children's behavior problems. In an interview 10 years after diagnosis, parents of children with ASD reported improvements in well-being when their child had fewer challenging behaviors as compared to more challenging behavior problems (Gray, 2002). In light of these studies, although parents of children with ASD are more likely to experience anger, depression, and anxiety shortly after diagnosis, over time parental well-being appears to depend in part on the severity of the child's behavior.

It is important to note that not all parental outcomes are negative. Positive and negative outcomes can exist simultaneously as the two are not mutually exclusive (Trute & Hiebert-Murphy, 2002). Positive outcomes include positive affect, psychological well-being, and life satisfaction. In some cases, mothers of children with ASD report experiencing the positive outcomes specifically when they have social support and are generally optimistic (Ekas et al., 2010).

Relationship outcomes—There are negative and positive relationship outcomes associated with this model. Given the high rate of divorce among couples of children with ASD (Hartley et al., 2010), we here address couple outcomes for both married and divorced coparents. For married couples, relationship disillusion, interpartner violence, and high conflict are considered negative couple outcomes. In general, members of intact families fare better than those in families that experience divorce and/or single parenthood (e.g., higher psychological well-being, fewer health problems, less social isolation, more financial stability; Amato, 2000; Amato & Keith, 1991). It is plausible to expect that families of children with ASD experience similar outcomes if the family remains intact. Positive relationship outcomes for parents of children with ASD have not been a specific focus of research. However, similar to personal growth (Perry, 2004), it is possible that couples may grow closer, improve their conflict resolution style, and reach a deeper understanding of themselves and their partners in relation to their child.

For divorced partners, coparenting relationships can have positive and negative outcomes. Positive outcomes generally result when coparents communicate effectively about parenting strategies and trust their fellow coparent in parenting decisions (see Roberson et al., 2011). However, negative outcomes stem from coparents who are frequently conflicted or disengaged. The anger and disagreement common in conflicted coparenting can disrupt child developmental outcomes such as regulation of affect and can prevent parents from developing a parental role separate from a spousal role (Baum, 2004; Roberson et al., 2011). For disengaged coparents, one or both parents are cut off from both the coparenting partner and the child, often because of the emotional pain of the separation (Baum, 2006).

For both married and nonmarried parenting couples, formal interventions may be able to promote positive relationship outcomes. However, parenting couples of children with ASD often experience particularly difficult thoughts and emotions as a result of the extreme nature of their child's disability (Blackledge & Hayes, 2006), and those thoughts and emotions are not necessarily validated in traditional cognitive and behavioral therapies (Singer, 1993). In addition, the ability to respond with empathy but still in an emotionally neutral manner demands both clarity of focus and attention, as well as the ability to manage emotions effectively (Benn, Akiva, Arel, & Roeser, 2012). As a result of successes in

addressing emotion regulation, attention, and mood disorders such as anxiety and depression (Baer, 2003; Greeson, 2009; Grossman, Niemann, Schmidt, & Walach, 2004), mindfulness may be one intervention that could effectively intervene with the heightened stressors associated with having children with ASD. In the second half of this article, we illustrate the utility of our model through the application of mindfulness intervention and practice.

Mindfulness

Mindfulness, rooted in Eastern contemplative traditions, is a state of consciousness in which one brings "awareness and attentiveness to immediate experience" (Grossman, 2010, p. 88). The basic concept of mindful awareness is found in a variety of philosophical traditions, including ancient Greek philosophy, phenomenology, existentialism in Western European cultures, and humanism and transcendentalism in the US cultural tradition (Brown, Ryan, & Cresswell, 2007). The term *mindfulness* is broadly defined as awareness, circumspection, discernment, and retention (Shapiro, 2009). In empirical studies, mindfulness most often is defined as "paying attention in a particular way, on purpose, in the present moment, and nonjudgmentally" (Kabat-Zinn, 1994, p. 4).

The basic assumptions pertaining to the condition of the human mind must be explained in order to understand the implications of the process and practice of cultivating mindfulness as a conscious state. The most foundational of these assumptions is that, in general, humans are unaware of experiences in the moment (Grossman, 2010). In addition, cognitive and emotional responses to these moment-to-moment sensory experiences occur so quickly following the experiences that they are perceived as simultaneous. Grabovac, Lau, and Willett (2011) stated:

> With the awareness of any object, there is a concomitant feeling tone. … Due to the rapid and transient nature of these feelings, constantly arising and passing away, they often go unnoticed and can serve as the key trigger to a chain reaction of thoughts (including emotions) and actions that can lead to suffering. This chain reaction of thoughts and emotions in response to these thoughts are referred to as *mental proliferation.* (p. 155)

Thus, individuals generally react emotionally with little discernment, which often leads to misperceptions of the situations (Grossman, 2010).

Bringing mindful awareness into our daily lives offers an alternative way of processing moment-to-moment experiences. Mindful awareness can be cultivated through mindfulness practice, a collection of exercises that when practiced on a regular basis promotes nonjudgmental attention to that which is taking place in the moment. Mindfulness practitioners come to the realization that once an experience is perceived through the senses; there are many possible ways to respond. Through perceiving experiences as they are taking place, one then responds in a way that is less emotionally reactive and more nuanced and attuned to the specific situation (Shapiro, Carlson, Astin, & Freedman, 2006). Consequently, the reduction of emotional reactivity leads to an interruption of the body's stress response, resulting in improved physical and psychological outcomes (Baer, Smith, & Allen, 2004; Grossman et al., 2004). To promote mindfulness practice, mindfulness interventions have

been designed to introduce participants to techniques in order to become more mindful in their daily lives.

The most commonly used intervention in empirical studies is Mindfulness Based Stress Reduction (MBSR), an 8-week program developed by Kabat-Zinn (1990). The classes are led by a trained mindfulness instructor, and participants meet weekly for 2.5 hours, with an extended day of practice between the sixth and seventh weeks. Weekly sessions include theoretical and didactic lessons about mindfulness and its impact on the body's physiological stress response, experiential practice of mindfulness techniques that generate increased attention and awareness, and group dialogue related to obstacles and challenges in implementing the techniques (Kabat-Zinn, 1990). Experiential practices include a breath awareness practice in which one brings attention to the breath as it naturally flows into and out of the body, directing attention back to the breath when one notices that the mind has wandered. Another exercise is a body scan, in which one brings attention to the physical sensations of the body beginning at the toes and continuing through to the head. Both the breath awareness and body scan are conducted slowly over a period of 15 to 45 minutes, for the participant to focus on the nuances of physical sensations and both mental and emotion processes. One session over the 8-week period is dedicated to mindful communication between individuals; this session can be extended to meet the needs of parenting couples, and specifically the needs of couples parenting children with ASD. This program has been adapted to specific populations before and could be adapted to the needs of couples parenting children with ASD. For example, given the stress on these parents, attending 8 weeks of this program may not be feasible. Therefore, a program adaption might include a reduction in the number of weeks and time spent in class or providing appropriate child care during the sessions.

Mindfulness With Couples in Families With a Child With ASD

Although research in mindfulness has increased dramatically in recent years, there have been strikingly few studies that address the implications of mindfulness practice on couple relationships, particularly as it applies to the stressors that couples face daily when parenting a child with a disability. There are several aspects of our stress model in which mindfulness may be most effective in improving individual and couple outcomes (see Figure 3). First, we explore the implications of mindfulness practice on individual well-being as an individual resource. Second, we discuss the potential benefits of mindfulness practice on the couple relationship as a couple resource. Third, we offer mindfulness as a formal intervention to improve individual and couple outcomes. Because of the limited research on mindfulness and families of children with ASD, we are including studies that sample parents of children with chronic conditions such as asthma, cystic fibrosis, and cancer, as well as those with ASD. Although we recognize that there are vast differences among the needs and challenges of these disparate groups, the findings of these studies can elucidate the possible outcomes that a mindfulness intervention may have on families with children with ASD.

Mindfulness as an individual resource—Parenting a child with a disability can be tremendously challenging, and the accumulation of the strain from these challenges over time can increase stress on parents and compromise their psychological well-being (Benn et

al., 2012; Cummins, 2001; Emerson, 2003; Hedov, Anneren, & Wikblad, 2002). Practicing mindfulness results in a significant improvement in individual emotional well-being (Baer, 2003; Greeson, 2009; Grossman et al., 2004; Hofmann, Sawyer, Witt, & Oh, 2010). In particular, mindfulness practice has been particularly effective in reducing anxiety (Kabat-Zinn et al., 1992; Miller, Fletcher, & Kabat-Zinn, 1995) and depressive symptoms (Fincune & Mercer, 2006; Kutz et al., 1985; Teasdale, 2004), the very aspects of well-being with which parents of children with ASD often struggle. A recent study with parents of children with ASD found that the stress level of parents who were randomized to a mindfulness intervention decreased to a greater extent than among those who were randomized to a parenting-skills intervention (Ferraioli & Harris, 2012). In another recent experimental study that investigated the impact of a mindfulness intervention on emotional well-being outcomes of parents and educators of children with disabilities, mindfulness had a mediating effect on well-being outcomes, including stress, anxiety, depression, personal growth, emotion regulation, self-compassion, quality of parent–child interaction, forgiveness, and empathic concern (Benn et al., 2012). Another mindfulness intervention study targeted stress levels of parents of children with chronic health conditions; this study reported a significant decrease in parents' stress post-intervention (Minor, Carlson, Mackenzie, Zirnicke, & Jones, 2006). Put together, these findings support the premise that mindfulness interventions show promise in helping alleviate stress and improving coping skills of caregivers of children with various health challenges.

In a correlational study that explored fathers' involvement with their children who had intellectual disabilities, greater mindfulness in fathers was associated with less avoidance of their children and more participation in child care (MacDonald & Hastings, 2010). This is an important finding, as there is appreciable evidence that father involvement is beneficial to children's healthy psychological development (Bronte-Tinkew, Carrano, Horowitz, & Kimukawa, 2008; Lewis & Lamb, 2003) and that fathers often are less involved than mothers in caring for children with intellectual disabilities (Bristol, Gallagher, & Schopler, 1988; Roach, Orsmond, & Barratt, 1999; Willoughby & Glidden, 1995). Implications of this finding are that mindfulness as an individual parent resource may be advantageous for the psychological development of the child, emotional well-being of the father, as well as alleviating the mother's child-care burden.

Acceptance and commitment therapy (ACT; Hayes, Strosahl, & Wilson, 1999) is a therapeutic approach that suggests that psychological suffering stems from psychological inflexibility. Psychological flexibility is therefore developed through "the ability to contact the present moment more fully as a conscious human being and to change or persist in behavior when doing so serves valued ends" (Hayes, Luoma, Bond, Masuda, & Lillis, 2006, p. 7). Through traditional mindfulness practices, the participant notices thoughts, feelings, and sensations without any attempt to change them. In this way, ACT is particularly applicable to the challenges of parenting children with ASD, because the parents' thoughts and feelings, though difficult at times, are not inappropriate to their situation. Challenging one's thoughts and feelings, or trying to change them, is likely ineffective and would lead to frustration on the part of the parents (Blackledge & Hayes, 2006).

In a study in which mindfulness practitioners implemented an intensive 2-day ACT workshop with parents of children diagnosed with ASD (Blackledge & Hayes, 2006), parents were led through exercises that helped them clarify their values and become aware of how their thoughts, feelings, and language deterred them from adhering to these values. Results demonstrated a decrease in depressive symptoms and psychological distress from pre- to post-intervention that were maintained at 3-month follow-up. Parents also reported an increase in self-esteem and active coping and a decrease in stress from pre- to 3-month follow-up (but not at post-intervention). Thus, parents of children with ASD may benefit from practicing mindfulness as it contributes to an increase in multiple aspects of well-being.

Other mindfulness researchers have specifically focused on the role of caregivers and their influence on the well-being of individuals with disabilities (Singh et al., 2004; Singh et al., 2006; Singh et al., 2010). In several studies involving caregivers of individuals with disabilities, the aim was not to directly investigate the potential reduction of caregivers' stress levels but rather to change the behavior of the individuals by altering the nature of their interactions with caregivers, which would then have an effect on the caregivers' stress levels. In one study, mindfulness training of parents of children with ASD resulted in a reduction of children's aggressive and self-injurious behaviors and greater compliance with parents' requests (Singh et al., 2006). A decrease in parents' stress as a consequence of this improvement in children's problematic behavior is plausible. However, this direct link needs to be investigated further.

Further evidence for mindfulness training effecting change in individuals with disabilities and thus attenuating the challenges of caregiving was reported in another study in which the researchers investigated the results of mindfulness training for caregivers of three adults with profound multiple disabilities on the level of happiness they experienced (Singh et al., 2004). Reported happiness of the adults with disabilities increased not only during the period in which their caregivers were receiving the mindfulness intervention but for 16 weeks post-intervention as well. Thus, it is evident that some aspect of the nature of the interaction between the caregivers and the individuals with disabilities has been altered through the caregivers' participation in the mindfulness training, thus resulting in greater happiness in the individuals with disabilities. Singh et al. (2010) suggest that the caregivers undergo an inner transformational change as a result of the mindfulness training that manifests across multiple settings; evidence for this transformation is indicated by the change of their interactions both with the adults with disabilities and with the caregivers' biological children.

Mindful practice appears to have a positive influence on the well-being of individuals who are parents of children with ASD through both direct (e.g., by lowering their own individual stress) and indirect (e.g., by decreasing child problem behaviors) pathways. These positive influences may have a particularly salient impact because mindfulness techniques learned in one setting appear to transfer to other settings. As parents of children with ASD report experiencing comparatively lower emotional well-being because of their own stress levels and their child's challenges, mindfulness techniques may offer a way to address those concerns.

Mindfulness as a couple resource—Mindfulness promotes receptive awareness and nonjudgment of oneself and others (Kabat-Zinn, 1990). Through mindfulness practice, mindful partners are more likely to listen to others' perspectives and are less inclined to be distracted by their own. Consequently, mindfulness has been proposed as a path to cultivating empathy and a disposition to forgive in the context of couples' relationships (Benn et al., 2012; Block-Lerner, Adair, Plumb, Rhatigan, & Orsillo, 2007), and, in fact, it has been associated with empathy in a study of couples (Benn et al., 2012; Wachs & Cordova, 2007). Being aware and attentive to the present moment in the absence of the pull of emotions would suggest that one is more able to identify his or her own emotions, and consequently more able to communicate them to others (e.g., Barnes, Brown, Krusemark, Campbell, & Rogge, 2007; Wachs & Cordova, 2007). Through closely observing the transitory nature of emotion states as they come and go in the present moment, one is better able to understand that these states are not fixed or solid, but rather merely one option in an array of possible responses to a situation. As such, it may be easier to tolerate emotions or situations that are distressing. In fact, skilled emotional repertoires, specifically those that pertain to identifying and communicating emotions, were shown to fully mediate the relationship between mindfulness and marital quality (Wachs & Cordova, 2007). This indicates that mindfulness promotes the development of identifying and communicating emotions to one's partner, which leads to improved marital quality. Not surprisingly, therefore, mindfulness has been shown to be associated with relationship satisfaction (Barnes et al., 2007; Burpee & Langer, 2005) and marital quality (Wachs & Cordova, 2007).

In the only mindfulness intervention study that we found in which couples were participants, couples were randomly assigned to either a control group or an intervention group (Carson, Carson, Gil, & Baucom, 2004). Positive outcomes for the intervention group included an increase in reported relationship satisfaction, relatedness, and acceptance of oneself and one's immediate experiences. Moreover, the amount of mindfulness practice reported by the couples was associated with the degree of positive relational outcomes (Carson et al., 2004). On the basis of these findings, it is evident that parents of children with ASD who interact with one another in a mindful way may experience outcomes that are considered couple resources (e.g., relationship satisfaction, reduced conflict), which may enable them to more effectively cope with the stressors of having a child with ASD. These parents might then be less likely to experience the subsequent stress pileup associated with relationship dissatisfaction, separation, and divorce (for a review, see Randall & Bodenmann, 2009).

Mindfulness as a formal intervention—Creating a mindfulness intervention for parenting couples of children with ASD could be accomplished by adapting the Mindfulness Based Stress Reduction program to meet the specific needs of these families. For example, the session on mindful communication between individuals can be expanded and addressed over several weeks, as mentioned earlier. Unique issues common to parenting couples of children with ASD can be presented in this context. As an example, after parents practice mindfully discussing a nonthreatening issue, they can be asked to address a more challenging subject (e.g., how to manage the child's behavior in public situations). Practicing mindful communication in this guided and supported format with a trained mindfulness instructor can help couples learn how to be present and attentive while actively

listening to each other. Couples can be encouraged to set aside time each day to practice not only individual mindfulness practices such as breath awareness and body scans but also mindful communication with each other. Moreover, in group dialogue, participants can address common issues that arise with having a child with ASD. Specifically, parents can focus on how to stay mindful and present in these challenging moments without reacting emotionally, and instead responding in a balanced and conscious manner.

The concept of nonjudgment and acceptance is integral to mindfulness practice. Throughout the 8-week MBSR program, participants are encouraged to accept in a nonjudgmental manner the emotions they are experiencing in the moment, recognizing that those emotions are part of the human condition and that they are by nature temporary and will pass. Parents of children with ASD experience mixed emotions about the best way to handle their child; the ability to understand that these emotions are natural and appropriate would offer relief to these parents (Sams, 2012). In other words, through an intervention that introduces them to mindfulness practice, parents of children with ASD can learn to accept themselves, including their imperfections and limitations, and approach their parenting with less self-judgment.

How might one empirically test a mindfulness intervention with parenting couples of children with ASD? Utilizing an experimental design with three groups, an intervention group would receive mindfulness training (including any adaptations made to fit with this population), an active control group would receive traditional couples' therapy, and a true control group would receive no treatment. Couples would participate in pre-intervention, post-intervention, and follow-up questionnaires with measures assessing perceived stress level, quality of life, and relationship satisfaction. Open-ended questions would be included at the end of the post-intervention and follow-up questionnaires for the intervention and active control groups. After the follow-up questionnaires have been administered, a subsample would be selected for couple interviews. This qualitative approach would elucidate the participants' impressions of the intervention and changes within the couple relationship.

Summary

Families of children with ASD experience greater stress than families of children with other disabilities and those without disabilities. Further, couples in these families seem to be particularly susceptible to stress, as evidenced by the increased divorce rate and decrease in couple relationship quality. We presented a model of stress that captures both the specific stressors of having a child with ASD and the need to understand how couple relationships can be affected by these stressors. We also proposed that a mindfulness intervention can alter the relationship between child characteristics and individual and relationship outcomes by influencing individual resources and couple resources, and by acting as a formal support.

There are limitations to our model and intervention. Our model is designed to be applied to parenting couples of children with ASD to closely examine the intricacies among this population. By limiting the population, we also have limited its generalizability. Recognizing that there is a wide range of characteristics associated with ASD and variety of

family types, this model may not be fully inclusive of the stresses encountered by parents of children with ASD. Moreover, as our model was developed from a review of pertinent literature, we cannot conclude that this model will hold up to empirical scrutiny. We also cannot state conclusively that this model is exhaustive, as it may not include all intervening and outcome variables that are associated with objective or perceived child characteristics.

We suggest that future research empirically validate this model either in part or in full. Particular components of this model that need further study are differences in parental perception of child characteristics, couple relationship outcomes, and positive individual parental outcomes. Though mindfulness has been shown to decrease the effects of stress associated with having a child with ASD (e.g., Singh et al., 2006), future research should study how mindfulness specifically operates within this model at the suggested points (see Figure 3). As previously suggested, we further recommend that future mindfulness research include a control group. Lack of an active control group has been cited as a limitation of previous mindfulness research (Grossman, 2008).

In general, the distinct couple stressors and outcomes associated with parenting a child with ASD have not been given enough attention in empirical research. However, the present model and proposed mindfulness intervention sought to move forward knowledge in this area. Though this model will need to be empirically tested, it is grounded in empirical research and will provide a usable model for practitioners and professionals that research or work directly with these families. The mindfulness intervention also provides an example for how to utilize the model in practice.

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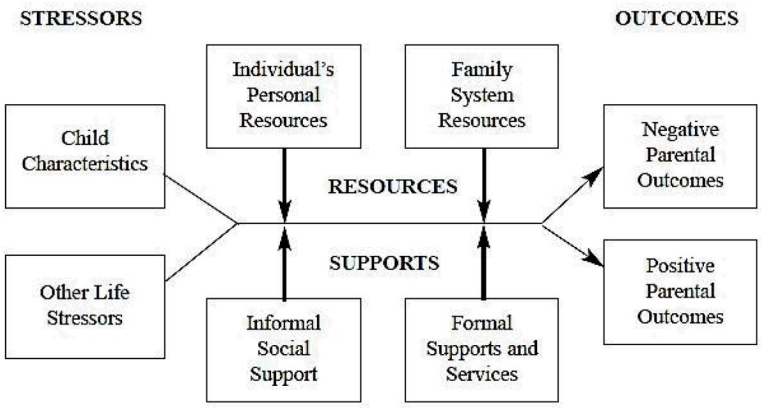

Figure 1.

Perry's stress model.

A model of stress in families of children with DD

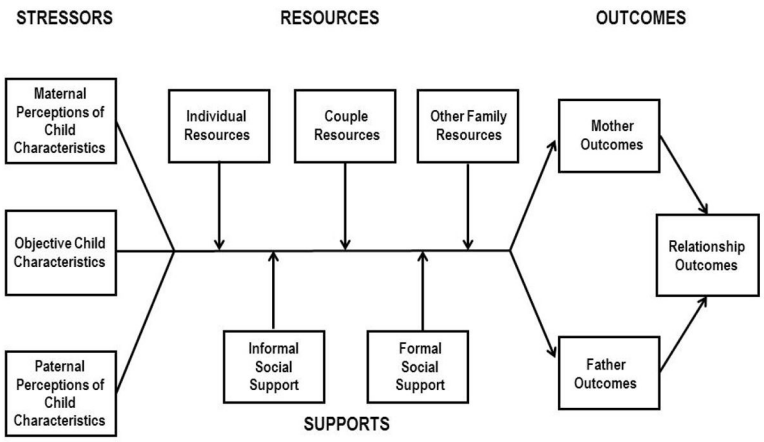

Figure 2.
Parents of children with ASD stress model.

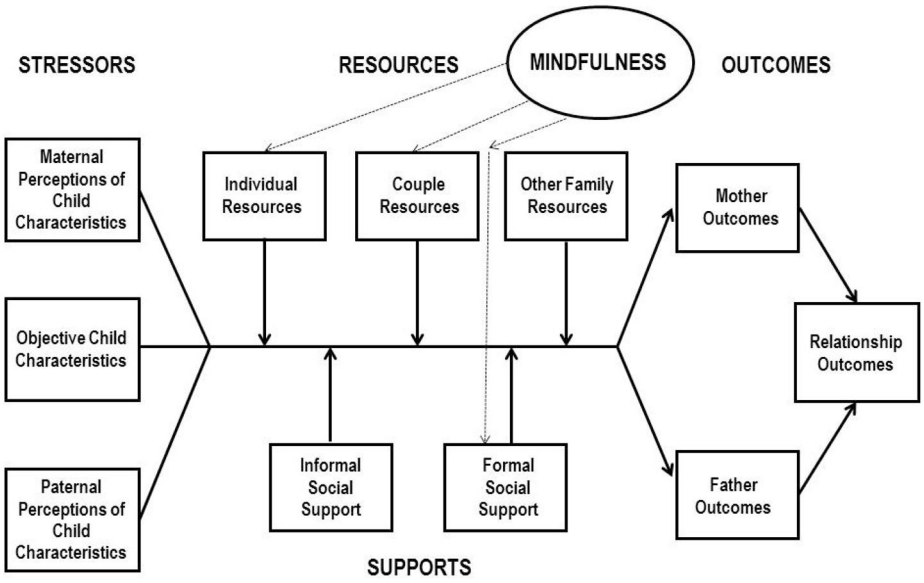

Figure 3.
Parents of children with ASD stress model with mindfulness influence.