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Parent Stress and ASD Severity: A Re-Examination

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Abstract

The purpose of the present research was to investigate the relationship between ASD severity, as assessed by GARS, and parent stress, as assessed by the PSI and the PSI Parent Domain subscales in particular. Studies suggest that parent stress rises to the severity of a young child's ASD for reasons related to the challenges of parenting and managing severe autistic behavior compared to moderate or mild levels. The participants were parents seeking Early Intensive Behavior Intervention (EIBI) services from a university-based program between 1996 and 2018. A total of 46 mothers and fathers (23 mothers, 23 fathers) and their respective 23 children participated. The present results suggest that a young child with mild ASD ma enable his parents the luxury of spending less time, effort and worry about managing behavior, leaving more time to spend instead on either their own well-being, and/or learning how to manage their child's behavior more effectively.

Dedication

This work is dedicated to my husband Mark and my son Caleb. Through all the long hours, sleepless nights, and some tears, you both encouraged, loved, and supported me wholeheartedly.

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I would like to express my gratitude to my advisor Dr. Patrick Ghezzi who guided me through this process, as well as all my lab mates who supported and assisted with this work. Especially, Marisela, Morgan, and Ainsley who without any hesitation would lend an ear, offer feedback, and encouragement. I will be forever grateful.

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Parent Stress and ASD Severity: A Re-Examination

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Introduction

The purpose of the present study was to re-examine the relationship between the severity of Autism Spectrum Disorder (ASD) and the level of stress experienced by parents of young, pre-school-aged children with ASD. The statistical correlation between the two variables is positive, as might be expected, and appears to be mediated by the difficulties inherent in managing a young child's severe, as opposed to mild, autistic behaviors (Baxter et al., 2000; Benson, 2006; Benson & Karlof, 2009; Brie, 2014; Estes et al., 2009; Hastings & Johnson, 2001; Hayes & Watson, 2013; Hodapp et al., 1998; Huang et al., 2013; Lyons et al; Osborne et al., 2007; Pastor-Cerezuela, 2016; Pisula et. al., 2010; Robbins et al., 1991; Soltanifar et al., 2015).

The severity of a young child's autistic behaviors and the difficulty of trying to manage them may not be the only source of a parent's stress, however. Dumas and her colleagues (Dumas, 1984; Dumas & Wahler, 1983) and Tarbox et al., (2016) make the point that parenting occurs under circumstances that include relations with spouses, children, friends, relatives, neighbors, business associates and medical personnel, to name a few. "Research and intervention," according to Dumas & Wahler (1985), "may need to broaden their unit of analysis to not only mother-child interaction but also, at the same time, to the interactions that mother and children have with other members of their environment" (p. 16).

Robert Wahler (1980), the first behavioral researcher to advance this point of view, reported that low-income parents who experience tense relations with family members commonly experience stressful relations with other people such as social and mental health professionals. Compared to low-income parents who enjoy positive working relations with social and mental health professionals, parents who experience negative relations with these people are more likely to abandon treatment. These parents, reported Wahler, interpret their interactions with social and mental health workers as aversive, and believe that the difficulty they have managing their child's behavior is not their fault but instead the fault of the social and mental health workers.

Wahler, Dumas, Tarbox and their colleagues take the position that multiple sources of stress exist for parents, and that the behavioral effects of stress appear in the context of managing their child's autistic behavior(s). While the urgency of managing autistic behavior in the home every day and with minimal success is an obvious source of parent stress, these authors contend that it is not necessarily the only or even the main source. Marital disharmony, limited finances, legal problems, an unrewarding career and so forth all have the capacity to elevate the stress that a parent already experiences while managing their child's autistic behavior(s).

The present study sought to re-examine the hypothesis that the level of parent stress is a function of the severity of a young child's autistic behavior. The test of this hypothesis involved Abidin's 2014 Parent Stress Index (PSI), which identifies sources of stress that lie outside of the child domain *per se* and that lie instead in the parental domain as a matter of personal health, happiness and life fulfillment. A working assumption, in the light of research by Dumas, Wahler, Tarbox and colleagues, was that

high PSI stress scores in the parental domain do not necessarily predict a positive relationship with ASD severity, and vice versa.

Dumas and Wahler (1983) invoke J. R. Kantor's concept of "setting events" as a means to conceptualize research and practice on the effects of stress on parenting. We shall take a moment to examine the concept and its relevance to the present study.

Stress and Setting Events

Kantor (1958) defined setting events as "the immediate circumstances that influence which stimulus-response relationships will occur (p. 95)." Bijou and Baer (1961) greatly clarified the definition by distinguishing a setting event from a stimulus event. A stimulus event, according to Bijou and Baer, involves discriminative, reinforcing and punishing stimuli, while a setting event constitutes, "a stimulus-response interaction, which, simply because it has occurred, will affect other stimulus-response relationships which follow it" (p. 21).

It is worth noting from the start that there is a rather vague distinction between setting events and motivating operations (MO) in the behavior analysis literature. These terms are often used interchangeably, and often invoked to account for the same phenomenon. The MO concept, which originated from radical behaviorism, encompasses a class of environmental variables that temporarily alter the effectiveness of another class of things, objects, people and events in the environment as reinforcing or punishing (Nosik & Carr, 2015).

This is consistent with Bijou and Baer's definition of a setting event. The concept originated from interbehaviorism independently of radical behaviorism as a means of accounting for essentially the same phenomena to which the MO concept is applied.

Lewon and Hayes (2014) provide numerous examples of how emotional circumstances can influence a temporally extended series of behaviors. The response to a Monday morning traffic jam, for example, would be different if the driver learns that she just won the lottery, as opposed to hearing that she just lost her job.

Another everyday instance of the effects of a setting event occurs when a parent scolds a young child for missing the bus because he took too long getting ready for school. The child arrives late to the classroom, sullen, unresponsive and unable to stay on task for the entire morning. To say that the earlier episode with the parent altered the child's "mood" and that this mood-altering event, in turn, affected the child's behavior later in the classroom captures the meaning of a setting event.

We shall set aside the distinction between motivational operations and setting events and move on to describe the types of setting events that Bijou (1996) identified, as follows: physiological, physical, and sociocultural. He emphasized the most obvious effects of each type on an individual's behavior. He further emphasized that the three types interact constantly with one another and, of course, with the prevailing stimulus and response events in the environment. Strict distinctions between the three types are difficult to maintain, in other words, as there is plenty of overlap from one type to another type of setting event. The three types are nonetheless helpful for purposes of the present study, and thus deserve additional attention.

Consider, first, physical setting events. These pertain to the sights, sounds, smells and sensations that arise in a given environment and that influence the effects of stimuli on behavior. The bright lights, loud sounds and pungent smell of fireworks on July 4th would qualify as a physical setting event, provided that an individual's behavior is

affected by the festivities and that the affects persist as a function of the festivities. A mother at the July 4th celebration, for instance, sees that her young son with ASD is highly agitated during the fireworks display and sees that he remains agitated long after the event is over. For her part, she sees the influence of this type of setting event on herself as a parent during and after the fireworks. She might indulge her son more than usual, or alternatively, she might be more strict than usual. In any case, it is plain to see that the event altered the "stimulus-response relationships" (aka: behavior-environment relations) in the moment and in the aftermath of the moment for herself and her young child.

A second type of setting event, termed physiological, includes illness, sickness, injury, disability, fatigue, deprivation, cycles (e.g., sleep, menstrual, circadian), and strong feeling states. Strong feeling states, as Skinner (1957) noted, predispose an individual to interact with the environment in a certain way. A person in love who views the world through "rose-colored glasses," for instance, suggests a positive influence of this type of setting event. Angry, bitter or resentful feeling states suggest a negative influence. Physiological setting events, in any case, affect behavior in the sense of altering behavior-environment relationships in the present and in the future.

Stress, conceived by Bijou as a physiological setting event, is bound to affect parenting. As Dumas and Wahler (1985) point out, how a parent interacts with their child is partially related to the child's current behavior and partially related to the emotional experience a parent brings to the interaction from a previous interaction with the physical, social, or personal environment. Faced with the distressing news that her mother is losing her battle with cancer, for instance, and faced with her child's

troublesome behavior, a mother of a young boy with ASD would undoubtedly parent her son in this moment and later much differently then she would had the news been better. This type of circumstance and the feelings of stress it provokes illustrates the magnitude of the influence of a physiological setting event on behavior-environment relations, in this case, parent-child interactions.

The most common type of setting event pertains to sociocultural conditions. These include the vast expanse of customs, traditions, practices and social habits of people living as a group under the auspices of a cohesive culture. According to Bijou (1996), these setting events "require prescribed forms of behavior taught on the basis of contingencies by parents, teachers, and others" (p.151). A young child entering church with her mother, for example, may whisper or stop talking as a function of her mother enforcing the contingencies maintained by church authorities and followed religiously by the parishioners, including herself and her child. It is easy to see that a parent of a young child with ASD in the same situation and faced with a child that screams and shouts in church would experience considerable stress. It may be difficult to see, however, that additional sources of stress are present. The fact that her child is unable to follow rules, the fact that she is unable to teach her child to follow rules, and the fact that she is unemployed adds more stress to an already stressful situation. The effects of this collection of sociocultural setting events involving yet another instance of undesirable behavior and yet another reminder of the mother's inability to manage her child may persist, for example, as animus toward her child after she and her son leave church and head for home.

The three types of setting conditions, as Bijou (1996) observed, may function differently for different people and at different times and in different circumstances for the same person. Bothered by a headache (physiological) and irritated by the sound of television (physical) upon entering her apartment and seeing a past due rent notice (sociocultural), a mother may lash out at her young son with ASD for reasons that have little to do with her child per se.

In theory, isolating the effects of these setting conditions, alone or in combination with one another, will lead to a clearer understanding of parent stress. In practice, it should also lead to improvements in intervention strategies whereby parents learn how to manage the stress in their lives.

Thus far, we have emphasized that parent stress, conceived as a physiological setting event, arises from several sources. Apropos to the definition of a setting event, behavior-environment relations under the auspices of this type of setting event will be affected during and in the aftermath of the event. The confluence of managing severe autistic behavior and the stress that creates for a parent and the stress a parent brings forward from a previous event(s), as Wahler, Dumas, Tarbox and their colleagues point out, sums to a level of parent stress that is greater than either source of stress alone.

Most researchers agree that the greatest source of stress for parents of a young child with ASD is child behavior management. A child with severe autistic behavior, on this view, is more difficult to parent than is a child with mild autistic behavior. While we do not dispute this claim, our working assumption is that it is not the only source of stress and that for some parents, it might not even be the greatest source of stress in their lives. That said, we now turn to a discussion of child behavior management and parent stress.

Stress and Child Behavior Management

Research shows that parents who regularly and sincerely reinforce their young child for following rules and instructions generate harmony and equanimity within the family (Isabella, Belsky & Von Eye, 1989; Parpal & Maccoby, 1985; Schaffer & Crook, 1979; Westerman, 1990). Conversely, studies show that parents who reinforce compliance and rule following haphazardly or insincerely and who punish their young child for noncompliance and a disregard for rules generates discord and stress in the family (Dumas, 1984; Dumas & Wahler, 1985; Wahler & Dumas 1986). The majority of parents fall into the latter group (Bornstein, 2002), and the reasons for this are actually quite clear.

There is a propensity, according to Barkley (1997; see also Latham, 1994), for parents to pay less attention to their child's positive behaviors, on the one hand, and to pay more attention to their child's negative behaviors on the other hand. A behavior analysis of Barkley's contention (Cooper et al, 2007) would claim that parents are prone to reinforce their child's negative behavior(s) by attending to it, relative to, and at the expense of, their child's positive behavior(s). In real life, this can mean frequent negative behavior(s), on the one hand, and infrequent positive behavior(s) on the other hand. This combination of circumstances can be a steady source of stress for any parent, naturally, yet adding a young child with ASD and a suite of negative behaviors to the mix can be overwhelmingly stressful.

Consider a mother of a young child with ASD who comforts her son each time he fusses, whines, cries or tantrums. His negative behavior stops when she attends to it, plus he is more affectionate toward his mother at these times than at any other time of the day

or night. Part of what is happening here, explains Barkley (1997), is what behavior analysis call "attention-maintained behavior" (Iwata, 1982). The comfort the young child receives from his mother when his behavior is negative or unwanted, on this analysis, positively reinforces the child's negative behavior. What this means in real-world terms is that the child's fussing, whining, crying and tantruming will continue to occur in the future until the contingency between the child's negative behavior and his mother's response to it changes.

The other part of what is happening in this example, explains Barkley (1997), pertains to the mother's behavior. Her child's negative behavior stops, and it stops because she attends to it. This is what behavior analysis call "escape-maintained behavior" (Iwata, 1982). The reinforcer for the attention she gives to her son's negative behavior, on this analysis, is that it stops the behavior. This qualifies as "negative reinforcement" so long as she continues to comfort her son in response to his negative behavior in the future, and so long as his negative behavior stays stopped after she attends to it.

There is a second source of reinforcement for the mother in Barkley's (1997) example. Physical affection is infrequent in young children with ASD (Siegel, 1996), and thus it is entirely reasonable to assume that the affection the mother receives from her young son is a powerful positive reinforcer for the comfort she gives him at these times. The addition of this contingency to the negative reinforcement contingency complicates matters for the mother and child alike, and unless the contingencies of positive and negative reinforcement change, the mother will continue to comfort her son in response to his negative behavior, and his negative behavior, in turn, will continue to occur.

The main point here is that parents can create stress for themselves by unknowingly reinforcing their child's negative behavior(s). This simple fact is laden with the potential for months of frequent, lengthy, and severe episodes of negative behavior(s). Overwhelmed by their child's negative behavior(s) and faced with the stark truth that they are incapable of managing it properly, it is easy to see why parent stress and ASD severity are so closely related.

This, then, is how stress and child behavior management come together to form the central hypothesis of the field, namely, that ASD severity co-varies with the level of parent stress. Additional sources of stress are both possible and probable, as we noted before, and include a long list of sociocultural setting events, ranging from parents with conflicting views on behavior management, child development and family values to parents with financial difficulties, legal troubles, medical problems and insurance issues. It is entirely reasonable to assume that these added sources of stress interact with one another, as Wahler (1997) explained, and to hypothesize, as Wahler did, that the interaction can influence how a parent manages the behavior of their young child with ASD.

A significant variable in this regard, and one that we examined with the PSI in the present study, is social isolation. The stigma and embarrassment of negative behavior(s) in social settings, for example, can keep parents of a child with ASD at home for long and uninterrupted periods. As Dunn et al., (2001) noted, "Parents often choose isolation over the frustrations of taking their child out in public."

Staying home all the time as a means of escaping or avoiding the social consequences of a young child's negative behavior(s) might resolve the problem at first,

however, it can be a costly plan over the longer term. Relationships with people outside the immediate family can suffer from neglect, relationships with family members can suffer from overexposure, and cultivating new relationships is out of the question. Research confirms that parents experience elevated levels of stress under these conditions compared to parents that maintain relationships with friends, relatives, and neighbors (Bailey et al., 1994; Bowers & Gesten, 1986; Bristol & Schopler, 1983; Chay, 1993).

Another significant variable, and one that we also examined with the PSI in the present study, pertains to "role restriction." Raising a young child with ASD can place great demands on a parent's time and energy, thereby restricting the time and energy they have to pursue other interests and activities. High scores on this variable, alone but especially in combination with high scores on social isolation, can add considerably to the level of stress a parent experiences while managing their child's autistic behavior(s) throughout the day and evening.

A third variable that we examined with the PSI relates to the general health of a parent. The toll that raising a young child with ASD can take on a parent's physical fitness is underreported, and yet it seems that a parent's stamina and endurance could suffer, and that the capacity to resist, withstand and recover from an illness or injury could weaken as well.

The parental domain of the PSI includes social isolation, role restriction, and the health of a parent along with four additional domains, competence, attachment, depression, and spouse. We shall take a moment to describe the PSI in detail and to describe the four additional domains of the PSI.

The PSI

Formal, standardized testing is commonplace in studies on parent stress, and the PSI is among the most widely used test today. Developed in 1976 by Richard Abidin for use with children ranging in age from 1 month to 12 years, the PSI is tailored for identifying potential sources of stress in and outside the family (Abidin, 2012; Johnson, 2015). It is a self-report, Likert-type test with 120 questions divided into two domains, Child Characteristics and Parent Characteristics.

The Child Characteristics domain includes subscales on Adaptability, Mood, Acceptability, Demandingness, Reinforces Parent, and Distractibility/Hyperactivity. The Parent Characteristics domain subscales include Competence, Isolation, Attachment, Health, Role Restriction, Depression, and Spouse.

Child Characteristics. There are six subscales in this domain, as follows, and with a brief description of the interpretation of high scores for each subscale.

1. Distractibility/Hyperactivity (DI): High scores in this domain suggest a child with over activity, distractibility, restlessness, and a short attention span.

2. Adaptability (AD): High scores in this domain are associated with (a) perseveration and an inability to change from one task to another without emotional responding, (b) sensitivity to changes in sensory stimulation, (c) avoidance of strangers, and (d) difficulty calming down after being upset.

3. Reinforces Parent (RE): High scores in the domain suggests that a parent does not experience the interactions with their child as a source of positive reinforcement.

4. Demandingness (DE): High scores in the domain suggests that the parent sees the child as placing too many demands on their time and energy.

5. Mood (MO): High scores in the domain suggest that the child frequently cries and does not display signs of happiness.

6. Acceptability (AC): High scores in the domain suggest that the physical, intellectual, and emotional characteristics of the child do not match the parent's expectations for their child.

Parent Characteristics. There are seven subscales in this domain, as follows, and with a summary statement concerning high scores for each one.

1. Competence (CO): High scores in the area are associated with parents who lack knowledge in child development and behavior management skills.

2. Isolation (I): High scores in the domain suggests that the parents are socially isolated from their peers, relatives, etc.

3. Attachment (AT): High scores in the domain suggest that the parent does not feel close to the child and may suggest a real or perceived inability to understand the child's wants and needs.

4. Health (HE): High scores in the domain suggest difficulty maintaining, or returning to, good health with a good diet, regular exercise, medication, etc.

5. Role Restriction (RO): High scores in the domain suggests that the parent views their role as limiting freedom to maintain an individual identity and a normal lifestyle.

6. Depression (DP): High scores in this domain suggest clinical depression.

7. Spouse (SP): High scores in the area suggest that the parent lacks the support of the other parent or partner in managing the behavior(s) of their child.

Exploring the relationship between these measures of parental sources of stress, on the one hand, and a measure of ASD severity, on the other hand, was the primary purpose of the present research. Before we turn to a more detailed description of the study, we turn for a moment to the Gilliam Autism Rating Scale, or GARS for short.

The GARS

The GARS, currently in its third edition, is widely used to assess the likelihood of ASD in people ranging in age from 3-to-22 years old. The format is a Likert-style questionnaire completed separately by each parent or caretaker under the supervision of a professional worker.

There are three editions of the GARS. The first edition (Gilliam, 1995) was divided into four domains: (1) Stereotypic Behaviors, (2) Communication, (3) Social Interaction, and (4) Developmental Disturbances. Given the totality of responses to the questions, an Autism Quotient (AQ) was calculated. The quotient ranged from below 69 to above 131+. Seven levels of ASD "likelihood" were identified and, in turn, taken as evidence for the severity of ASD, as follows: Very Low (≤69); Low (70-79); Below Average (80-89); Average (90-110); Above Average (111-120); High (121-130); and Very High (131+).

The GARS-2 (Gilliam, 2006) eliminated the Developmental Disturbances domain, added a Parent Interview domain, and kept the three original domains from the first edition. An Autism Index (AI) replaced the AQ, and the old seven levels of ASD "likelihood" (and thus severity) were reduced to three levels, as follows: (1) Unlikely (≤69), (2) Possibly (70-84), and (3) Very Likely (83+).

The GARS- 3 (Gilliam, 2014) is the response to recent changes in the definition of ASD in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013). This third edition of the GARS is divided into seven domains, as follows: (1) Restricted/Repetitive Behaviors, (2) Social Interaction, (3) Social Communication, (4) Emotional Responses, (5) Cognitive Style, (6) and (7) Maladaptive Speech. The AI Autism Index is retained, and so is the ASD "likelihood" dimension, which is newly tied to the level of support a child might need in meeting the demands of daily living, as follows: Unlikely (≤54), no supports needed; Probable- (55-70), minimal support needed; Likely (71-100), substantial support needed, and; Very Likely (≥101), very substantial support needed.

Purpose

The purpose of the present research was to investigate the relationship between ASD severity, as assessed by GARS, and parent stress, as assessed by the PSI and the PSI Parent Domain subscales in particular. One outstanding feature of this study is the participation of a relatively large number (46) of mothers and fathers. The working hypothesis throughout was that high scores on the PSI do not necessarily predict high scores on the GARS, as previous research might suggest, nor do low scores on the PSI necessarily predict low scores on the GARS. This purpose served the objective of working toward a coherent conceptual and practical understanding of stress in the life of a parent of a young child with ASD.

The study poses several specific questions, as follows:

1. Previous research shows a positive correlation between ASD severity and parent stress. To what extent does the study confirm this finding?

2. To what extent do mothers and fathers differ with respect to ASD severity and parent stress?

3. The Parent Domain of the PSI contains three sub-domains that reflect the three sources of stress that we identified previously as social isolation, role restriction, and health. To what extent do these three sub-domains correlate with ASD severity?

4. To what extent do mothers and fathers differ with respect to ASD severity and social isolation, role restriction, and health?

Method

Participants

The participants were parents seeking Early Intensive Behavior Intervention (EIBI) services from a university-based program (UNR Early Childhood Autism Program, ECAP) between 1996 and 2018. A total of 46 mothers and fathers (23 mothers, 23 fathers) and their respective 23 children participated. All the children were male and ranged in age from 2-to-7 years old (see Table 1 and Table 2 for additional details). The inclusionary criteria for parents included married couples residing in the same household and living with a young (7 years old or under) male child with ASD. Completing the PSI and GARS and supplying pertinent demographic information during the intake process were also part of the inclusionary criteria. One set of parents with a young girl were excluded in order to maintain a homogeneous sample of all male children with ASD.

Materials and Data Analysis

ECAP senior staff conducted an initial, routine assessment with each couple and their child. The purpose was to obtain information relevant to deciding whether to provide home-based services. This early assessment yielded demographic data for each parent, GARS scores for each child, and PSI scores for each parent. (See Table 1). The GARS and the PSI were administered, scored, and interpreted according to the requirements set forth in their respective manuals (Abidin, 2012; Gilliam, 1995, 2006, 2014).

A Microsoft Excel 2010 Data Analysis Tool Pack recorded, stored and organized the GARS and PSI scores. The same software calculated and recorded Pearson Correlation Coefficients between GARS scores, as an objective measure of ASD severity, and PSI scores for mothers and fathers within the Child and Parent Domains and their respective sub-domains.

Results and Discussion

Table 1 shows the demographic information obtained from the 46 mothers and fathers and their respective children. The average age of the 23 mothers was 37 years, 8 months (range: 29 to 47 years), and the average age of the 23 fathers was two years older at 39 years, 1 month (range: 31 to 50 years). The average age of the 23 children was 4 years, 3 months (range: 2 years, 2 months to 7 years, 8 months) and the average number of children in the home, including the young child with ASD, was 2.2 (range: 1 to 4 children). The parents reported that they had received or were receiving non-ABA services (e.g., occupational therapy, speech therapy, social skills training) for an average 12 months (range: 0 to 53 months).

One highlight in Table 1 is the average number of children in the home, which included the young child with ASD. As far as child behavior management and parent is concerned, it seems reasonable to assume that more children in the home means more behavior to manage, which in turn could serve as a setting condition for a relatively greater level of stress and therefore relatively more stressful parent-child interactions. The contribution of the number of children in the home to parent stress, parenting and child behavior management, in any case, is an open question and one that is not among the set of four questions investigated in the present study. The potential role of this variable as a confounding variable in the present study, however, is worth acknowledging and worthy of future research on the effects of the number of children in the home of a young child with ASD.

A second highlight in Table 1 pertains to the average duration of non-applied behavior analytic (non-ABA) therapies. The average is somewhat deceiving in that some parents (n=6) reported receiving no services at all. For those that did, the average was about one year and consistently mainly of speech and occupational therapies provided privately in a clinic and/or in public school. It seems reasonable to assume that the positive effects of these therapies were minimal, and further that the level of parent stress would track this variable. In any case, other relationships in the current study were explored, and thus the relationship between non-ABA therapies and parent stress, parenting, and child behavior management remains an open question and, for present purposes, a question for future research to answer.

Table 2 lists the GARS percentile scores for each child with ASD. The sole purpose for these scores was to assign parents to one of three groups according to the

verbal rating attached to their child's GARS score. The range of percentile scores for the Mild ASD Severity Group (Mild) was >1-24, for the Moderate ASD Severity Group (Mild), 25-50, and for the Severe ASD Severity Group (Severe), 51-<99. On this basis, seven married couples (7 mothers, 7 fathers) were assigned to the Mild group, 10 couples (10 mothers, 10 fathers) to the Moderate group, and six couples (6 mothers, 6 fathers) to the Severe group. Table 2 also shows the gender, ages and age ranges for each child in their respective parent group.

It is significant that all 23 children in the present study were male. A well-known finding is that boys with ASD are roughly four times more prevalent than girls with ASD (Baron-Cohen S, et al., 2020). The fact that only boys and their parents participated in the present study raises the question whether the results and their implications pertain only to young, pre-school-aged boys with ASD or may be extended to young girls with ASD. The proper response at this time, in our view, is to restrict generalities to young boys and to call for research on the effects of gender on parent stress, parenting, and child behavior management.

Table 3 shows the PSI Child Domain Total percentile scores for mothers and fathers within their respective group assignments. The Child Domain Total score represents an average of the percentile scores of each sub-domain in the Child Domain. The most significant aspect of these data is the consistency in the scores across the three levels of ASD severity. This contrasts sharply with the GARS scores, which coalesced around the three levels. That the PSI scores are insensitive to ASD severity is an issue in this study, one that either supports the notion that ASD severity does not necessarily

predict the level of parent stress, or that the PSI itself is not equipped to discriminate between mild, moderate, and severe levels of ASD.

Table 4 shows the demographic information for each of the three groups of parents and their respective children. In the Mild group, the average age of the mothers was 37 years, 1 month (range: 34 to 47 years), while the average age for the fathers was 37 years, 7 months (range: 35 to 41 years). The average age of the boys in the Mild group was 3 years, 9 months (range: 3 to 4.11 years). The average age of the mothers in the Moderate group was 37 years, 1 month (range: 31 to 45 years), the average age for the 10 fathers was 39 years, 8 months (range: 35 to 46 years), and the average age of the boys was 4 years, 7 months (range: 2.4 to 7.8 years). For the Severe group, the average age for the mothers was 36 years, 2 months (range: 29 to 45 years), the average age for the fathers was 39 years, 5 months (range: 31 to 50 years), and the average age of the boys was 3 years, 9 months (range: 2.2 to 5.11 years).

The information contained in Table 4 shows that the three groups of parents were relatively homogeneous in terms of average maternal and paternal age. Fathers were uniformly older than their spouses by about 2 years, and the range of ages, with the exception of fathers in the Mild group (35-41 years), were similar across the three groups. The boys in the Mild and Severe groups tended to be youngest, at 3.9 years, followed by the boys in the Moderate group, at 4.7 years.

The extent to which parental age is a factor in parent stress, parenting and child behavior management is an open question. The effects of parental age, as a confounding variable in the present study, appear to be minimal.

The differences between the ages of the children between the three groups were 8 months, respectively. The extent to which the age of a child is a factor in parent stress, parenting and child behavior management is another open question, and one that also bears on the present study as a potential confounding variable. The effects of child age are probably minimal in this study, especially for comparisons involving the Mild, Moderate, Severe groups, with an average difference of 8 months between the two.

The age and gender of a young child with ASD, the ages and gender of a child's mother and father, the number, age and gender of siblings all constitute sociocultural setting factors. As a point of discussion, age, gender and the mere presence of a sibling are "hollow" variables insofar as the learning processes involved in their respective effects on behavior are absent (see Baer, 1970). On the playground with his young son and daughter, for example, a father might engage in more rough and tumble with his son than he does with his daughter. This difference is not due to the children's gender per se, but rather to the contingencies of reinforcement and punishment and the relevant setting factors that prevail for each individual at the time. The father's behavior in this example could be under the influence, for instance, of the belief that boys inherently prefer rough and tumble play compared to the preference girls inherit for milder play. In any case, an analysis of behavior would "fill in" the gender-based account with a functional account of the relevant contingencies, setting factors included.

We turn next to the first question of the four we posed in the study, that is, the extent to which the present results confirm findings from previous research that shows a positive correlation between ASD severity and parent stress. Table 5 and Table 6, and Figures 1, 2, and 3 contain the data relevant to the answer.

Table 5 and Table 6 show the correlation coefficients for the mothers and fathers, respectively, in the Mild, Moderate, and Severe groups in relation to their scores in the Child Domain of the PSI. The strongest correlations, according to previous research on the positive relationship between the severity of autistic behavior and parent stress, would involve high PSI scores and high GARS severity scores, and the weakest, low PSI scores and low GARS severity scores. This was not the case in the present study.

Figures 1, 2, and 3 convey this conclusion in graphic form. Shown in Figure 1 are the correlations coefficients for mothers and fathers in the Mild group. The correlations are mostly positive yet weak. This could be interpreted as supporting previous research on the relationship between mildly autistic behavior (low GAR score) and low levels of parent stress (low PSI score) were it not for the fact that the correlations for mothers and fathers in the Moderate Group (Figure 2) and the Severe group (Figure 3) are also positive yet weak.

Contrary to previous research, then, the present study suggests that the severity of autistic behavior in young boys may minimally affect parent stress. Judging from the Child Domain Total PSI percentile scores shown in Table 3, the level of stress for 43 of the 46 parents in the study was well above the average (55-60) for parents of a child with a developmental disability. The homogeneity of scores on the PSI across the three ASD severity groups, needless to say, makes finding a meaningful correlation with ASD severity impossible. The GARS scores, on the other hand, yielded the heterogeneity sufficient to create the three ASD severity groups shown in Table 2. One speculation here is that the PSI is insensitive to ASD severity, as defined by GARS.

The extent to which mothers and fathers differ with respect to ASD severity and parent stress, the second question we posed in the study, is also addressed in Tables 5 and 6 and in Figures 1-3. Studies suggest that mothers experience a greater level of stress than do fathers of a young child with ASD (Rodrigue, 1990; Brie, 2014; Soltanifar, 2015). That finding gains limited support from the current study. The correlation coefficients shown in Figure 1 for the mothers and fathers in the Mild group vary the least across the sub-domains of the PSI, while the correlation coefficients for parents in the Severe group shown in Figure 2 vary the most, particularly in the Distractibility/Hyperactivity and Mood subdomains. Differences between parents of a child with severe autistic behavior might be magnified in the light of the demands the child places on one parent or the other, and in the light of crying and other negative emotions that a child with severe ASD may display. A child with mild or moderate ASD, on the other hand, might affect both parents' level of stress in roughly equal measure. In any case, the answer to the question regarding the relationship between ASD severity and the level of stress in mothers and fathers is there is no relationship because the great majority of parents in the present reported high levels of stress regardless of the severity of their child's ASD.

The third question, the extent to which social isolation, role restriction, and health within the Parent Domain of the PSI relate to ASD severity, is addressed in Tables 6 and 7 and in Figures 4-6. The correlation coefficients shown in Figure 4 for the Mild group are at or near-zero levels across the three domains, suggesting that these particular domains are negligible sources of stress for parents in this group. For parents in the Moderate and Severe groups, however, the correlations are more diverse, and negative or strongly negative in most cases. In this regard, it is perhaps most noteworthy to find that

parents of a young child with either moderate or severe ASD may experience *less* stress as a matter of social isolation, according to these data.

This result may seem counter-intuitive, however, parents of a young child with ASD may form social relationships with other parents and children with ASD over time and this may serve as a remedy for isolate behavior. To the extent this is the case, it may account for the finding that mothers in the Moderate group, compared to fathers, experienced less stress in the isolation domain. Mothers ordinarily take the lead in locating services, speaking to providers, making friends with other parents and so on, and it is conceivable, if not likely, that mothers will encounter more people more often and thus develop more social relationships than fathers develop in the context of parenting a young child with ASD.

This last point raises the fourth a final question in the present study, the extent to which mothers and fathers differ with respect to ASD severity and social isolation, role restriction, and health. Tables 6 and 7 and Figures 4-6 contain the relevant data. The variation in the correlation coefficients for mothers and fathers in the Mild group, shown in Figure 4, was smaller across the board compared to the correlations for mothers and fathers in the Moderate and Severe groups. For those two groups, as Figures 5 and 6 show, those two groups, the greatest differences between mothers and fathers in the Moderate group was Isolation ($r = -.77$ for mothers, $r = .09$ for fathers), and in the Severe group, Isolation for mothers ($r = -.14$) and fathers ($r = -.91$) and Role Restriction ($r = .35$ for mothers, $r = -.65$ for fathers).

The correlation coefficients in Figure 6 for fathers in the Severe group are strong and negative, indicating that a high level of ASD Severity is linked to a low level of

stress both in Isolation (r = -.91) and Role Restriction (r = -.65). With respect to Isolation, the fathers in the Severe group resemble the mothers in the Moderate (Figure 5) group insofar as they both experience *less* stress than their counterparts within each group do.

One speculation here is that a father of a child with severe ASD may be more engaged in locating services, speaking to providers, making friends with other parents and so on compared to fathers of a child with moderate severe ASD. With respect to Role Restriction, it is conceivable that fathers of a young child with severe ASD experience a clarification of their role as a parent and consequently experience less stress in this domain.

General Discussion

The purpose of the current study was to re-examine the relationship between parent stress and ASD severity. Studies suggest that parent stress rises to the severity of a young child's ASD for reasons related to the challenges of parenting and managing severe autistic behavior compared to moderate or mild levels. This relationship finds no support from the present study. The stress experienced by the parents in the study was unrelated to the severity of their child's ASD; in fact, virtually all parents in the study experienced high levels of stress according to their PSI Child Domain scores.

As to the relationship between parent stress and sources of stress that lie within the parent domain, the present study offers mild support for the idea that parents of a child with mild ASD are less affected by circumstances related to isolation, role restriction, and health compared to parents of a child with moderate or severe ASD. The parents of these latter children, according to the present study, actually experience *less*

stress in these domains, not more. This relationship held true for mothers and fathers alike in the moderate and severe groups.

These findings are consistent with the points made by Wahler, Dumas, Tarbox and their colleagues. They take the position that parents of young children with ASD face two sources of stress in their lives, managing their child's behavior and maintaining their own life circumstances apart from their child. The present results suggest that a young child with mild ASD may enable his parents the luxury of spending less time, effort and worry about managing behavior, leaving more time to spend instead on either their own well-being, and/or learning how to manage their child's behavior more effectively.

As to why the present results differ from past studies on parent stress and ASD severity, it is possible that the PSI is ill equipped to discriminate between different levels of stress within the population to which this study pertains, that is, predominantly white, upper middle-class parents of young, white pre-school-aged boys with ASD. The fact that the parents in this study arrived with aspirations of gaining entry into a university-based EIBI program (ECAP) adds another element of specificity to the population. Important, too, is the fact that the test-retest reliability is rather low for the Child Domain of the PSI at $r = .63$ (compared to $r = .91$ for the Parent Domain), and that the construct validity for the PSI, according to Johnson (2015) is "sparse."

Additional research is needed on the vitally important topic of how raising a young child with ASD affects people in their role as parents and family members, on the one hand, and in their role, on the other hand, as individuals and community members. Identifying the sources of stress from these domains will enable parents and practitioners alike to avoid or mitigate the negative effects of stress while working on developing

alternative sources of positive stimulation in and away from the home. Kantor's concept of setting events gives this research and practice the theoretical direction needed to maintain a consistent and coherent scientific narrative on these matters in the future.

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Appendix

Table 1. Demographic information on parents seeking UNR ECAP services, 1996-2018.

Demographics	Average (years)	Range
Mothers age	37.8	29-47
Fathers age	39.1	31-50
Childs age	4.3	2.2-7.8
Number of children in home	2.2	1-4
Duration of non-ABA therapies	1.0	0-4.3

Table 2. GARS percentile scores, ASD severity group assignments, gender and age in years and months for each of the 24 children.

Child	Score Mild (Range:>1 – 24)	Gender	Age
A	1	Male	4
B	1	Male	6
C	2	Male	3.3
D	5	Male	4.11
E	8	Male	2.11
F	16	Male	3
G	21	Male	5.3
	Score Moderate (Range:25-50)		
H	25	Male	2.4
I	32	Male	5.1
J	32	Male	3
K	32	Male	6.8
L	35	Male	7.8
M	39	Male	4
N	39	Male	5
O	39	Male	5
P	50	Male	4.7
Q	50	Male	3.2
	Score Severe: (Range:51-<99)		
R	65	Male	2.2
S	65	Male	4
T	70	Male	5
U	73	Male	2.8
V	75	Male	4.6
W	99	Male	5.11

Table 3. PSI Child Domain Total Percentile Scores and Ranges for Mothers and Fathers in the Mild, Moderate, and Severe Groups

Mild	Mothers PSI CD Total (Range: 7-98)	Fathers PSI CD Total (Range:13-99)
A	7	13
B	98	99
C	93	65
D	87	93
E	98	93
F	45	90
G	98	95
Moderate	**Mothers PSI CD Total (Range:73-99)**	**Fathers PSI CD Total (Range:67-99)**
H	73	67
I	99	83
J	97	93
K	98	73
L	98	98
M	95	95
N	97	98
O	87	83
P	93	93
Q	98	99
Severe	**Mothers PSI CD Total (Range:75-99)**	**Fathers PSI CD Total (Range:30-99)**
R	99	99
S	75	75
T	95	95
U	75	30
V	98	99
W	95	95

Table 4. Average age and age range, in years and months, for mothers, fathers, and children in the Mild, Moderate, and Severe groups.

Group	Avg. Age Mother	Range	Avg. Age Father	Range	Avg. Age Child	Range
Mild (n=7)	37.1	34-47	37.7	35-41	3.9	3-4.11
Mod. (n=10)	37.1	31-45	39.8	35-46	4.7	2.4-7.8
Severe (n=6)	36.2	29-45	39.5	31-50	3.9	2.2-5.11

Table 5. Mothers PSI Child Domain and GARS Severity Correlation Coefficients

PSI Child Domain	Mild	Moderate	Severe
Distractibility/Hyperactivity	0.25	0.16	-0.34
Adaptability	0.33	0.22	0.31
Reinforces Parent	0.00	0.06	0.10
Demandingness	0.10	0.50	0.28
Mood	0.24	0.37	-0.11
Acceptability	0.36	0.18	0.44

Table 6. Fathers PSI Child Domain and GARS Severity Correlation Coefficients

PSI Child Domain	Mild	Moderate	Severe
Distractibility/Hyperactivity	0.09	0.41	0.28
Adaptability	0.53	0.50	0.01
Reinforces Parent	0.25	0.47	0.22
Demandingness	0.33	0.39	0.10
Mood	0.21	0.49	0.35
Acceptability	0.40	0.09	0.43

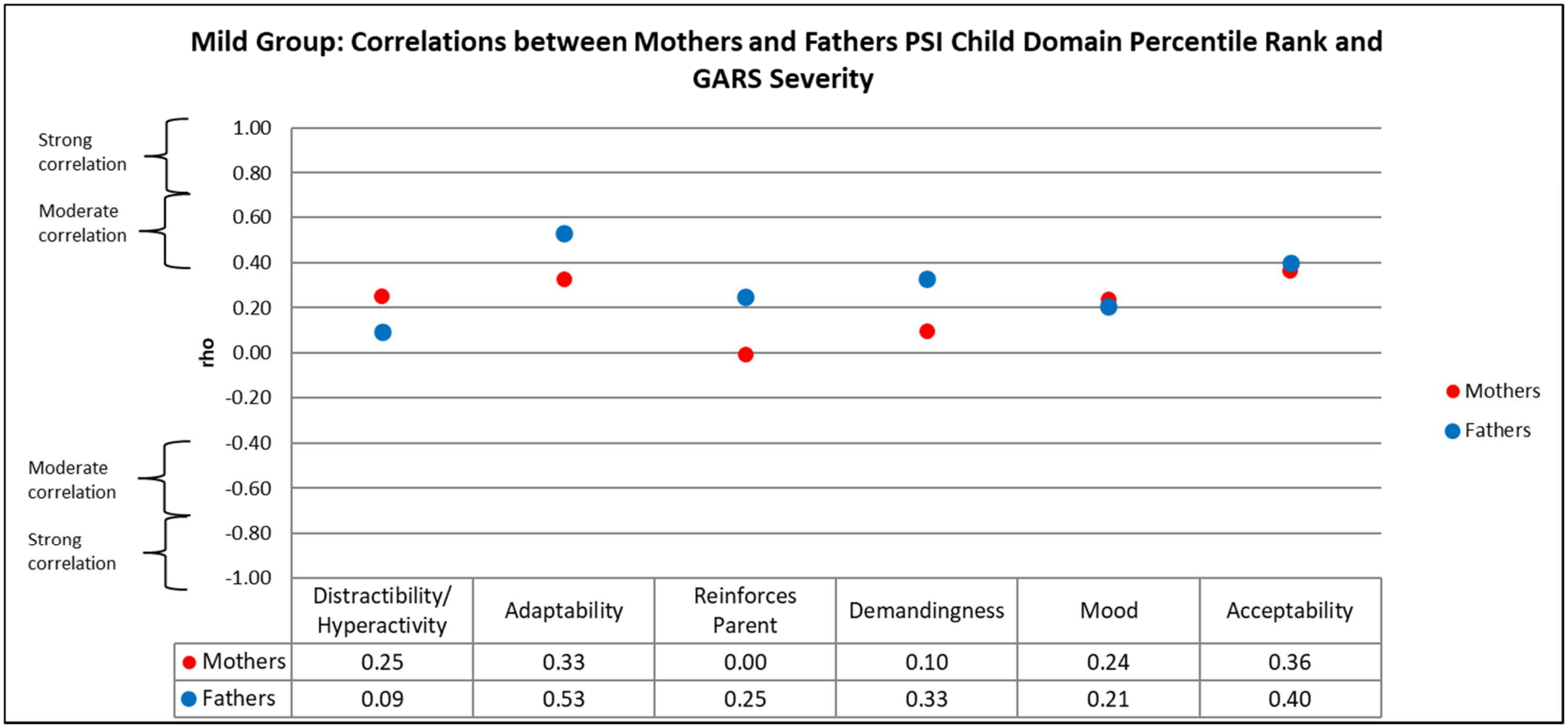

Figure 1. Pearson Correlation Coefficients (rho) for mothers and fathers in the Mild ASD Severity Group and in the Child Domains of the PSI.

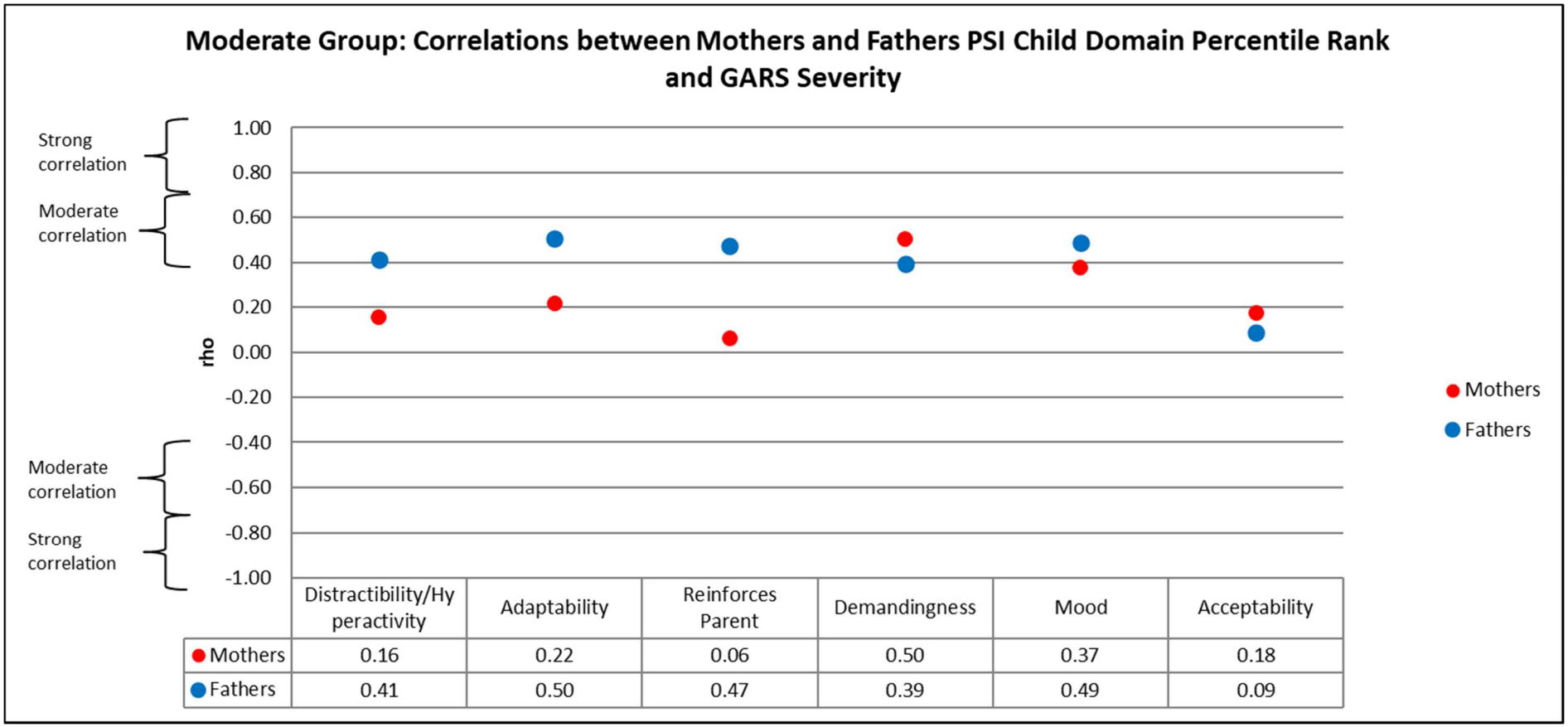

Figure 2. Pearson Correlation Coefficients (rho) for mothers and fathers in the Moderate ASD Severity Group in the Child Domain of the PSI.

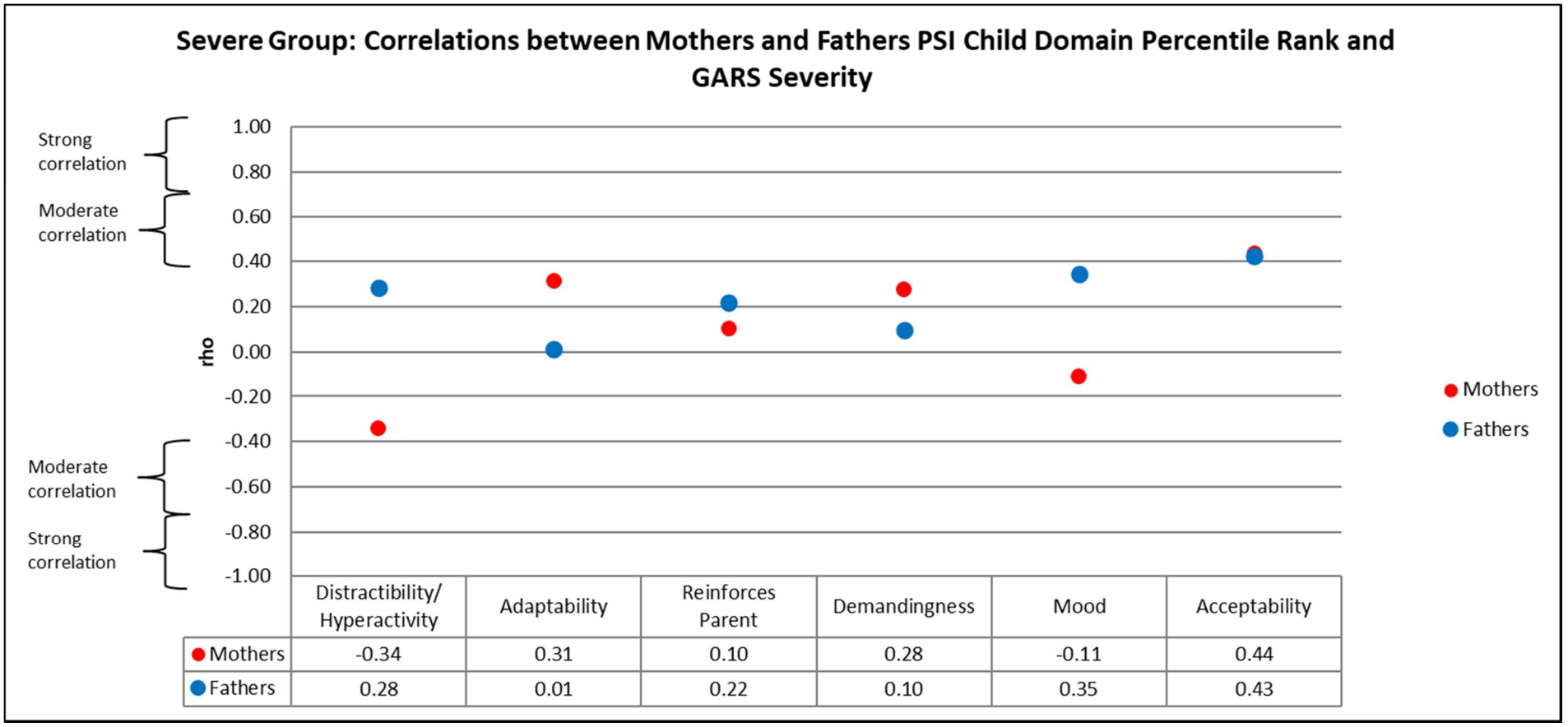

Figure 3. Pearson Correlation Coefficient (rho) for mothers and fathers in the Severe ASD Severity Group in Child Domain of the PSI.

Table 7. Mothers PSI Parent Domain and GARS Severity Correlation Coefficients (Isolation. Role Restriction, and Health

PSI Parent Domain	Mild	Moderate	Severe
Isolation	0.29	-0.77	-0.14
Role Restriction	-0.12	-0.09	0.35
Health	0.15	-0.41	0.26

Table 8. Fathers PSI Parent Domain and GARS Severity Correlation Coefficients (Isolation. Role Restriction, and Health

PSI Parent Domain	Mild	Moderate	Severe
Isolation	0.01	0.09	-0.91
Role Restriction	0.12	-0.32	-0.65
Health	0.07	0.29	-0.02

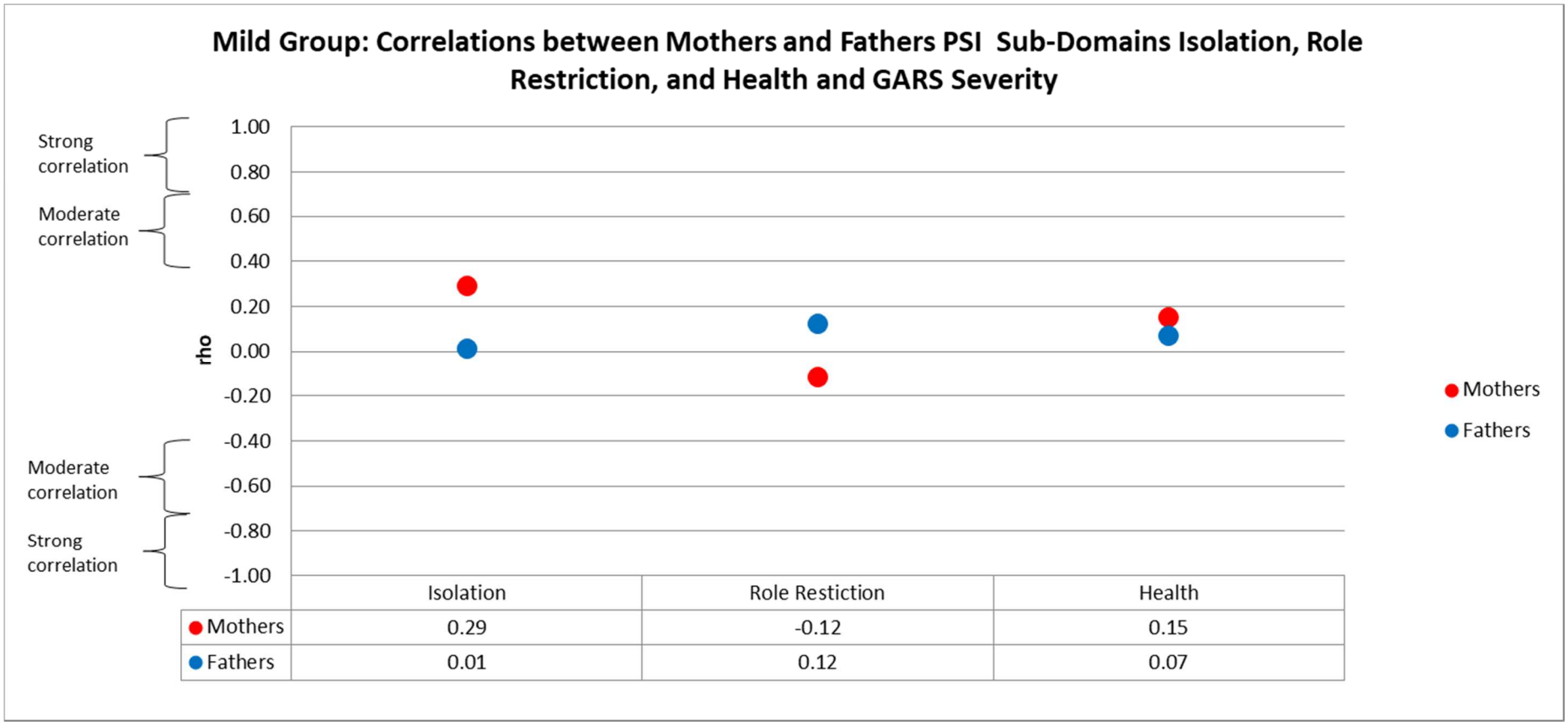

Figure 4. Mild group correlations between mothers and fathers PSI scores in the Isolation, Health, and Role Restriction sub-domains.

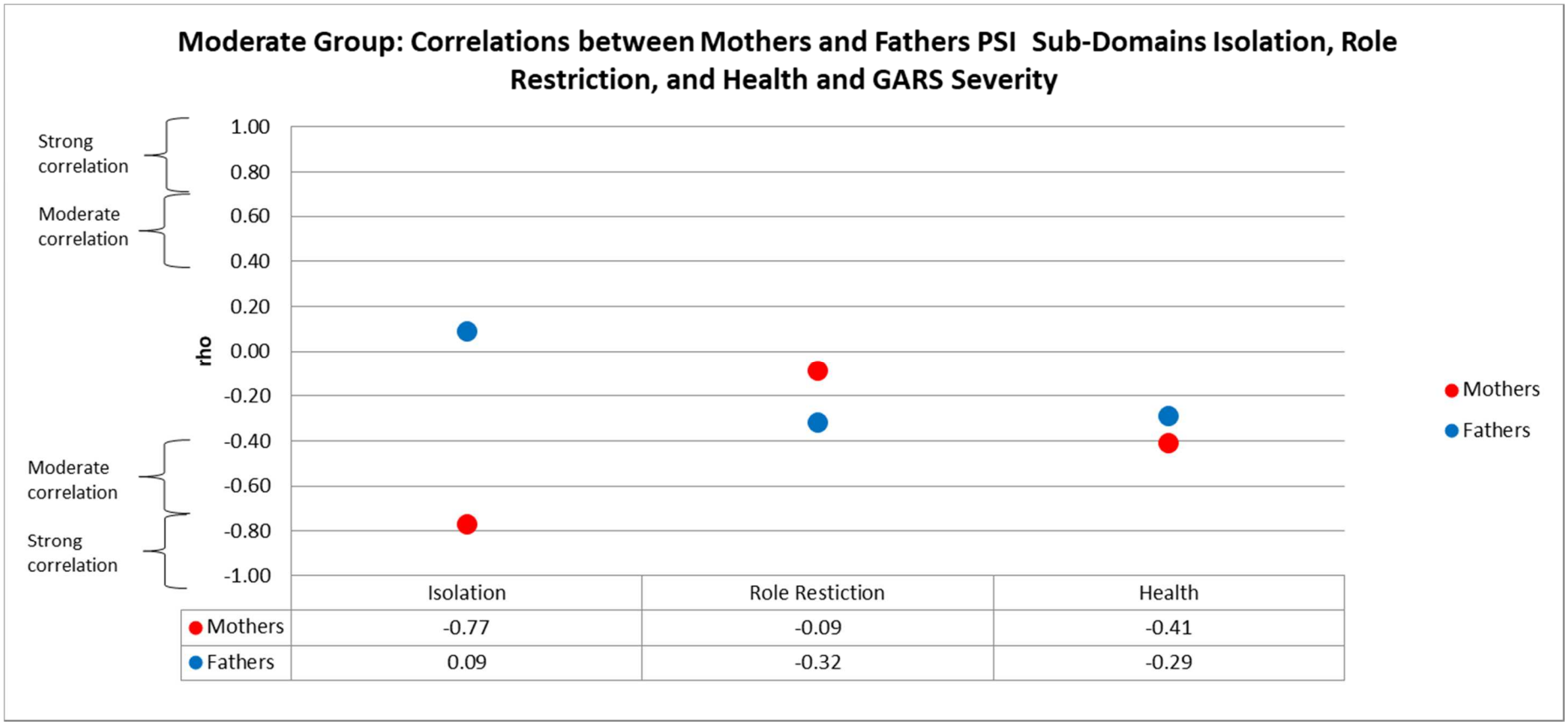

Figure 5. Moderate group correlations between mothers and fathers PSI scores in the Isolation, Health, and Role Restriction sub-domains.

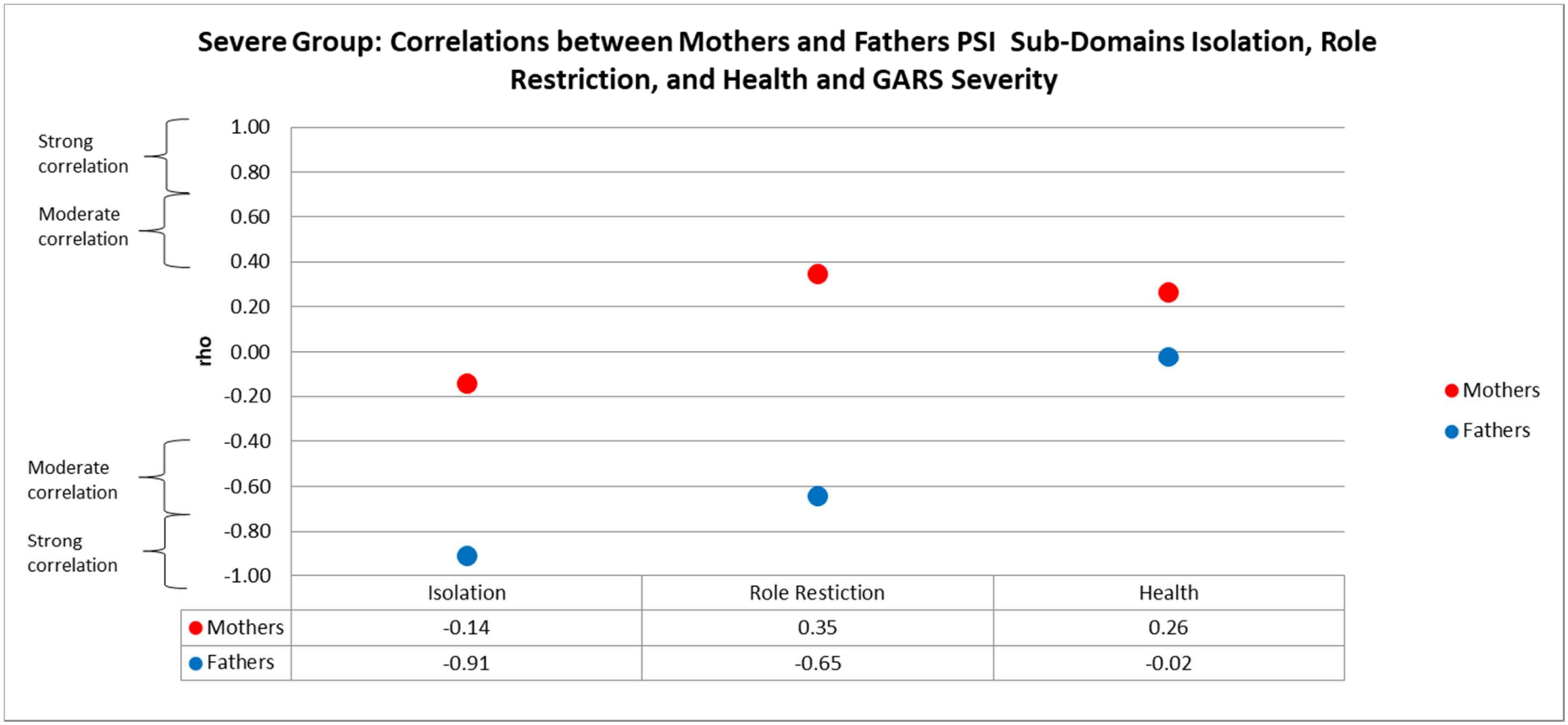

Figure 6. Severe group correlations between mothers and fathers PSI scores in the Isolation, Health, and Role Restriction sub-domains.