



Predictors of parent stress in a sample of children with ASD: Pain, problem behavior, and parental coping

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ABSTRACT

Studies have shown that children with ASD have increased severity and incidence of pain symptoms compared to typically developing children and children with other disorders. Pain has also been shown to act as a setting event for problem behavior. Further, problem behavior is one of the biggest impediments to quality of life for families and highly relates to parent stress. This study examined pain and problem behavior as predictors of parent stress and also examined how parenting style interacted with pain and problem behavior to influence parent stress. Results showed that problem behavior was a moderating factor between pain and parent stress and there was a significant interaction between pain and problem behavior predicting stress. An overprotective parenting style also moderated the relationship between pain and parent stress and there was an interaction between the two factors predicting stress. Implications are discussed in terms of treatments that focus on children's behavior and parenting behavior in order to improve quality of life in families of children with ASD.

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1. Introduction

Autism spectrum disorder (ASD) is a heterogeneous disorder comprised of deficits in communication and language skills, social skills, and repetitive behaviors. Due to the heterogeneous nature of the disorder, many researchers have focused on biological explanations for differences in the expression of ASD. A recent model proposed by Herbert (2005) is that ASD is a “whole body” disorder resulting from gene–environment interactions that affect a person's entire body, not just the brain. Herbert argues that people with ASD experience widespread, pervasive changes in their brain and body tissue due to chronic pathophysiological processes including neuroinflammation and oxidative stress.

This model has implications regarding the reasons that individuals with ASD often experience more medical problems like gastrointestinal disorders, allergies, seizure disorders, sleep problems, hormonal imbalances, metabolic abnormalities, and recurrent infections (Bauman, 2006). Evidence suggests that pain from various medical problems can adversely impact the effectiveness of behavioral interventions for individuals with autism (Carr & Herbert, 2008; Carr & Owen-DeSchryver, 2006). Physical illness and pain has detrimental effects to multiple areas of functioning including child problem behavior, parent stress, family quality of life (QOL), and parent coping strategies.

Currently, the relationships between pain, problem behavior, parent coping, and parent stress have not been studied in relation to one another; rather, these variables tend to be studied separately. In order to bridge this gap the goal of the

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present study was to test how pain, child problem behavior, and parent coping interacted to predict parent stress. A second goal was to assess whether problem behavior and parent responses to children's pain moderated the relationship between pain and parent stress. First we will review the extant research on the relevant variables including pain, problem behavior, parent coping, and parent stress in ASD populations.

1.1. Problem behavior and care-giver stress

In ASD populations problem behavior has been shown to be a primary predictor of parent stress. Problem behavior often results in increased stress for family members, isolation from the community, and exclusion from educational settings, social relationships, and typical home environments (Koegel et al., 1992; Lucyshyn, Dunlap, & Albin, 2002). Floyd and Gallagher (1997) compared problem behavior severity across children with mental retardation and chronic illness and demonstrated that severity of behavior problems rather than disability type was a stronger predictor of parent stress. When a child engages in problem behavior it can disrupt the entire family and make it more difficult to complete daily care-giving tasks. A study by Plant and Sanders (2007) found that problem behavior during care-giving tasks was the primary predictor of parent stress in a sample of pre-school aged children with developmental disabilities (DD). Not surprisingly, problem behavior made it more difficult to complete care-giving tasks such as bathing, feeding, supervising child activities and managing child behaviors, thus increasing parent stress surrounding those day-to-day tasks. In addition, researchers have demonstrated that parents of children with ASD experience heightened stress compared to parents of typically developing (TD) children or children with other disorders (e.g., ADHD, mental retardation; Baker et al., 2003; Hastings, 2002; Lee, Harrington, Louie, & Newschaffer, 2008; Tomanik, Harris, & Hawkins, 2005).

Furthermore, parenting stress has been related to many negative outcomes including marital distress, depression, coercive parenting, and drop-out from parent training interventions and thus is an important factor when utilizing family interventions for children with ASD. Additive stressors in one area of life that increase secondary stressors in other areas are termed stress proliferation and have been recently studied in parents of children with ASD (Benson, 2006, 2009). Stressors such as severe family disruptions, social isolation, and increased parenting demands (Fox, Dunlap, & Powell, 2002; Hastings, 2002; Koegel et al., 1992) can then lead to other negative outcomes like marital problems, depression, and lack of parenting efficacy; this supports the idea of stress proliferation (Benson, 2006).

Stress can also lead to increased child behavior problems and in turn, a coercive parent-child interaction style (Bor, Sanders, & Markie-Dadds, 2002). A coercive parent-child interaction occurs when the parent gives the child a command in which the child responds with non-compliance or some form of problem behavior and the parent either gives up on the request or the parent responds with aversive behavior (e.g., yelling, getting angry). In the first scenario, the child's problem behavior is negatively reinforced and in the second scenario the parent's aversive behavior is negatively reinforced, both of which serve as maintaining factors of maladaptive behaviors.

Another negative outcome related to parent stress is increased drop-out from interventions, as shown in one study, parents with higher stress were less likely to attend group therapy for their children than parents with lower stress (Andra & Thomas, 1998). Further, parents who experience high levels of stress or other psychological symptoms like depression might not be able to follow through with intervention procedures for their child (Schreibman, 2000).

1.2. Pain and care-giver stress

When a child experiences pain, physical illness, or discomfort, parents tend to experience increased role demands and are required to attend to or try to ameliorate the child's pain. Much of the research on pain and care-giver stress has focused on samples of individuals with medical disorders like cystic fibrosis (CF) or children and adolescents who report chronic pain symptoms. Research on pain and parent stress does not tend to focus on children with ASD. Only recently has pain and illness been of interest in the ASD area due to evidence of its increased prevalence (Eccleston, Crombez, Scotford, Clinch, & Connell, 2003; Quittner et al., 1998). Chronic pain has been shown to relate to increased stress in parents of TD children and it also has a negative impact on QOL for the family (Hanson & Hanline, 1990; Hunfeld et al., 2001). In a related study, Hunfeld et al. (2001) showed that mothers of adolescents with chronic illness had restrictions in social life and difficulty coping with the stress of the adolescent's pain.

Care-givers are required to be more intensely involved with a chronically ill child and may experience role strains as well as increased stress due to the constant demands to take care of a child that is sick (Krulik et al., 1999). Role strains and parent stress due to child illness was shown cross-culturally, where mothers of chronically ill children reported significantly higher stress than a normative sample and their stress seemed to be directly related to child rather than parent factors (Krulik et al., 1999). Mothers from four countries including the United States, Jordan, Israel, and Japan reported increased stress due to child illness factors, which indicates a robust finding that transcends various cultures. Furthermore, recurrent pain can have widespread effects on multiple areas of individual and family functioning, including sleep, school, social activities, and physical activities and can also negatively affect emotional functioning (Palermo, 2000). One study on adolescent chronic pain showed that parents displayed more depressive symptomatology and higher parental stress when they had a child with chronic pain (Eccleston et al., 2003).

In a sample of children with CF, a disorder comprised of chronic medical problems, parents of children with CF experienced much higher levels of stress and parental role strain than parents of children without a chronic illness (Quittner

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