

Exploring Factors Contributing to Perceived Stress Among Parents Having Children with Disability: A Literature Study

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Abstract

According to UNICEF's report, nearly 240 million children worldwide suffer from any form of disability. Upbringing children with disabilities has dramatically impacted the people surrounding the children, particularly the parents. Studies reported that parental stress might increase when having children with disabilities as these parents feel obligated to rear their children while facing various tough conditions, from financial to psychological burdens. The present paper aimed to identify factors contributing to parental stress perceived by parents having children with disability. The method conducted in this current study was a literature review. The literature has been searched through google-scholar and research-gate using keywords: coping strategies to parenting stress, parenting stress, and emotion regulation to parenting stress. The results of eighteen studies reviewed revealed evidence that internal and external factors may contribute to the level of parental stress. The internal factors that emerged contributions were emotional- regulations and coping strategies. These implied that parents with higher emotional regulations and positive coping strategies might have lower parental stress. In comparison, external factors contributing to parental stress were social support and child behavior problems. Studies reviewed in the paper may give insights to parents having children with disability or people working with parents who have children with disabilities, i.e., counselors and teachers.

Keywords: Parental stress, emotional regulation, coping stress, social support, children with disability.

Introduction

Over one billion people are estimated to have any form of disability. Disability has been found to have a risk on a human rights issue. People with disability have often been subject to multiple violations concerning their rights, including acts of violence, abuse, and disrespect because of their disabilities (WHO, 2020). Disability can be experienced at any age stage, either in children or adults. Nearly 240 million children have a disability (Unicef, 2021). A child with a disability needs special health care services for catching up and nurturing their development. Children with a disability may also face barriers, stigmatization, and discrimination when accessing health services. Children with a disability, such as ASD (autism spectrum disorder), have developmental disorders characterized by impairments in communication and social interaction and

show limited and repetitive interests and behaviors (Kandari, 2017). A child with ASD has reportedly been having several more typical behaviors than others concerning the number of behavioral symptoms, such as hyperactivity, impulsivity, aggressiveness, self-injury behaviors, and temper tantrums (Lyons, 2009). These characteristics have impacted the child and their parents, enhancing their stress levels.

Parental stress can be defined as an experience of distress or discomfort that results from demands associated with the role of parenting (Hayes, 2013). Studies showed that parents with children with ASD had significantly higher stress levels than individual distress on normal parental stress (i.e., Paynter, 2013). Many studies have shown that having a child with ASD is consistently a predictor of parental stress (Lyons, 2009). McQuillan and Bates' study revealed

that the hardness of handling behaviors in children with ASD impacted parenting stress and harsh reactive parenting (Deater-Deckard, 2017). Parents who experience stress will decrease their effectiveness in taking care of their children. A study has shown the many factors that influence parental stress, such as race/ethnicity, marital status, gender and sexuality, temperament and personality, and the caregivers of children with special developmental and health needs (Deater-Deckard, 2017).

Parents of a child with a disability experience daily stressors, everyday challenges, and caregiving demands that characterize their routine child-rearing responsibilities (Deater-Deckard, 2017). In this regard, social support plays an important role in parental stress. Social support has been proven to negatively correlate with mothers' stress over children with special needs (Ati, 2018). This finding would mean that social support may lower parental stress among these mothers. In contrast, family dysfunction and lack of social support may lead these mothers to divert energy away from managing everyday living and their ASD child's related needs and intervention demands. This will subsequently make them lack sufficient resources to meet parenting demands, increasing their stress consequently (Zait, 2016). OthAnotherudy revealed child's problem behaviors positively mediated parenting stress levels. Externalizing problem behaviors of children with ASD, e.g., disruptive behaviors and conduct problems, were prominently and consistently correlated with parenting stress over time, while internalizing problem behaviors, e.g., emotional but not peer problem, was, however, a weak and inconsistent predictor of parenting stress (Siu, 2018). Parents need special health services and support to deal with and bring up their children. While sustaining the right nurture, parents must cope with the right path to manage their stress, such as coping strategies and emotion regulation. A study has shown various means of coping strategies utilized by these mothers, and 81% of these were reported to be helpful (Kiami, 2017).

Coping helps decrease the strain of parental stress when having children with ASD. Coping is categorized into emotion-focused coping and problem-focused coping. Emotion-focused coping is used to manage feelings of distress. In contrast, problem-focused coping is used to deal with the stressor by doing something as a solution or changing one's perception of the certain stressor (Miranda, 2019). A family uses coping strategies to do preventive action, including utilizing family resources and developing new behavior to reduce the impact of stressful events (Dwirexsi, 2018). A study found that mothers who utilized more active coping strategies (i.e., solving a problem, getting help, or constructing positive meanings) and relied less on disengaged coping strategies (i.e., avoiding problems and the emotions associated with them), either at the time of diagnosis or over time, experienced lower levels of parenting stress (Zait, 2016).

Furthermore, coping utilization has been found to impact good emotion regulation effectively. Emotion regulation is the capacity to influence one's experience and expression of emotion (Rutherford, 2015). Emotion regulation has been widely conceptualized as the internal and external processes involved in initiating, maintaining, and modulating the occurrence, intensity, and expression of emotions to accomplish one's goals. Parents with poor emotional regulation tend to perceive parenting responsibilities as more stressful than those with better emotional regulation (Hu, 2019).

A broad view is useful because emotion regulation has been operationalized in various ways, typically within specific domains such as construal, i.e., reappraisals of situations, and emotions temperament and personality, and physiology, i.e., vagal tone (Deater-Deckard, 2015). These domains are rarely done and might be impacted by parenting stress. Therefore, parents need a great deal of emotion regulation and the right coping strategies to manage their stress. The impact of parental stress on a child with ASD can be bothersome. Parents tend to have

emotional changes (i.e., angry and crying easily), get strain conditions, and have less sensitivity to the child's needs and services.

Moreover, parents might hurt their children. When they surpass the mentality of the children or injure them purposely, without getting environmental support or protection or emotional bonding perceived by the children, they would suffer from toxic stress (Ghaisani, 2022). This paper aims to investigate and describe studies tapping various factors contributing to perceived stress among parents with children with disability, specifically autism spectrum disorder (ASD). Moreover, this paper will describe which factors revealed robust effects on parental stress. It is hoped that the findings reported in the current article will provide insights into the factors related to parental stress and, subsequently, may help them to cope with the right emotion to manage their stress when raising their children with ASD.

Method

This study used a systematic literature review research method. The research began with a search of the literature using search machines such as Google Scholar, Research Gate, and PubMed. The keywords used were "parental stress", "parenting stress", "Autism", "ASD", and "Disability". The literature used in the current article was studies conducted in various countries, and 18 kinds of literature were included in the final review.

The first screening began using those keywords and excluded the other criteria (i.e., not published peer-reviewed journals, doctoral dissertation, master's thesis, and undergraduate thesis). The second screening process was targeted period range (i.e., 11 years range for literature publication). Therefore, the current article only included 18 articles for further analysis (**Table 1**).

Results

A total number of 18 articles ranging from 2011 to 2021 were finally analyzed and summarized (see

Table 1 for details). Out of these 18 studies, twelve were empirical, five were literature reviews, and one was a qualitative research study. The total sample of participants (N) included were 1,935 parents (as participants of those studies).

The results revealed that positive reappraisal and problem-focused coping were the most used coping strategy for parents of children with ASD (Dardas, 2014; Gona, 2014; Kiami, 2017; Ni'matuzahroh, 2022). One specific intervention used by parents for their children was the diet strategy. Several participants thought that avoiding certain foods given to children with autism could control the autistic behaviors of their children. Some professionals seemed to advise parents on issues of diet (Gona, 2016). They tended to control sugar consumption to decrease the hyper level of their ASD children. A parent who utilized more active coping strategies, i.e., solving a problem, getting help, or constructing positive meanings, and relied less on disengaged coping strategies, i.e., avoiding problems and the emotions associated with them, experienced lower levels of parenting stress (Zait, 2016), while confrontative coping was the least frequently used coping strategy.

The three common coping strategies frequently reported as ineffective were explaining the family situation to others, eating abruptly, and getting angry easily. None of these strategies solve the problems when raising children with ASD and may be categorized as maladaptive coping strategies (Kiami, 2017). In addition, greater use of active-avoidant coping styles would also be linked with increased psychological distress across each family system level (Paynter, 2013).

Emotion Regulation

Parents' difficulties managing their emotions were positively related to their parenting stress. For example, when a parent reported arduous emotion regulation, both parents reported having higher perceived stress when raising their children with

ASD. Specifically, Chinese parents with greater emotion regulation difficulties reported suffering more parenting stress. Parents with higher stress levels reported overprotection/control, less affection,

and less optimal bonding with their children (Hu, 2019). Emotion regulation can be affected by parents' age, meaning that the mature age of the parents, the greater their emotional regulation (Ikasari, 2017).

Table 1. Coping Strategies and Regulation Emotion to Parental Stress

Author(s)	Years	Country	Topic	Sample (N)	Method	Diagnosis
Bariola, et al	2011	Australia	Child and Adolescent Emotion Regulation: The Role of Parental Emotion Regulation and Expression	-	Literature Review	-
Cuzzocrea, et al	2015	Italy	Parental stress, coping strategies and social support in families of children with a disability	50	Empirical Research	Disability
Dardas	2014	Jordania	Stress, Coping Strategies, and Quality of Life among Jordanian Parents of Children with Autistic Disorder	184	Empirical Research	Autism
Gona, et al	2016	Kenyan coast	Challenges and coping strategies of parents of children with autism on the Kenyan coast	103	Qualitative Research	Autism
Hsiao, Y-J	2017	USA	Parental Stress in Families of Children With Disabilities	-	Literature	Disability
Hu, et al	2019	China	The Mediating Role of Parenting Stress in the Relations Between Parental Emotion Regulation and Parenting Behaviors in Chinese Families of Children with Autism Spectrum Disorders: A Dyadic Analysis	422	Empirical Research	Autism Spectrum Disorder
Iswinarti	2020	Indonesia	Cognitive Emotion Regulation: Its Relationship to Parenting Stress	428	Empirical Research	Disability
Ikasari, et al	2017	Indonesia	Hubungan Antara Regulasi Emosi Dengan Stres Pengasuhan Ibu Yang Memiliki Anak <i>Cerebral Palsy</i>	50	Empirical Research	Cerebral Palsy
Kiami, et al	2017	USA	Support Needs and Coping Strategies as Predictors of Stress Level among Mothers of Children with Autism Spectrum Disorder	70	Empirical Research	Autism Spectrum Disorder
Miranda, et al	2019	Spain	Parenting Stress in Mothers of Children With Autism Without Intellectual Disability. Mediation of Behavioral Problems and Coping Strategies	52	Empirical Research	Autism Spectrum Disorder
Ni'matuzahroh, et al	2021	Indonesia	The Association between Parenting Stress, Positive Reappraisal Coping, and Quality of Life in Parents with Autism Spectrum Disorder (ASD) Children: A Systematic Review	29	Literature Review	Autism Spectrum Disorder
Paynter, et al	2013	Australia	The double ABCX model of family adaptation in families of a child with an autism spectrum disorder attending an Australian early intervention service	43	Empirical Research	Autism Spectrum Disorder
Paynter, et al	2016	Australia	Recognising the "forgotten man": Fathers' experiences in caring for a young child with autism spectrum disorder	26	Empirical Research	Autism Spectrum Disorder
Putri, et al	2021	Indonesia	Parenting Stress, Social Support and Parental Characteristic in Parents of ASD Children	50	Empirical Research	Autism Spectrum Disorder
Rutherford, et al	2015	USA	Emotion regulation in parenthood	-	Literature Review	-
Ng, et al	2021	China	Potential Factors of Parenting Stress in Chinese Parents of Children With Autism Spectrum Disorder: A Systematic Review	24	Literature Review	Autism Spectrum Disorder
Yu, et al	2016	China	Prevalence of Maternal Affective disorders in Chinese Mothers of Preschool Children with Autism Spectrum Disorders	121	Empirical Research	Autism Spectrum Disorder
Zait, et al	2016	Canada	Impact of personal and social resources on parenting stress in mothers of children with autism spectrum disorder	283	Empirical Research	Autism Spectrum Disorder

Social Support

Studies have shown that social support has an important domain predictor to influence parents' stress levels. Low emotional support for parents of a child with ASD was strongly related to lower psychological well-being and enhanced parenting stress levels (Putri, 2021). Family dysfunction and

lack of social support may lead parents to divert energy away. This may be effective by insufficient resources to meet parenting demands, resulting in increased stress (Zait, 2016). When parents cannot gain enough support from their family, they need to gain other support from outside. It would be helpful that they could gain support sources, i.e., friends,

professionals, extended family, parenting support, i.e., advice on problems specific to their child, and help with childcare. These were supportive predictors of most dimensions of parental stress (Hsiao, 2017).

Child Behavior Problems

Children with ASD tend to show inappropriate social behavior, aggressive towards themselves or others, conduct repetitive or ritualistic actions, and show marked impairment in language, communication, eye contact, and affection. Their lack of affectionate response could be emotionally painful for their mother and may lead to increased psychological distress (Yu, 2016). These behavior problems can be classified into two types, namely, externalizing, and internalizing types of behaviors. Furthermore, there is a strong correlation between parenting stress and externalizing behaviors problem in children with ASD, such as hyperactivity, aggression toward others and themselves, repetitive/stereotyped behaviors, and delinquent behavior. The internalizing behavior problems, such as withdrawal, anxiety, and inhibition, were evident and relatively stable in children with ASD. Nevertheless, these problems may not cause severe parental stress or arouse parents' attention like externalizing behavior problems (Ng, 2021).

Discussion

This study aimed to review studies reporting various factors contributing to perceived stress among parents having children with disability, particularly children with autism spectrum disorder (ASD). Based on the 18 published studies examining the influence factors of parenting stress, several vital factors can be categorized into two domains, internal and external. Internal factors stemmed from the inner part, such as parents (coping strategies and emotion regulation) and children (child behavior problems). Other external factors came from the environmental dimension, i.e., social support from others.

Coping strategies are revealed as the most significant internal factors, as it comprises a series of

actions or a thought process used to handle a stressful or unpleasant situation or modify one's reaction to it. Four major coping dimensions are utilized in parenting children with ASD, including avoidance, problem-focused, positive, and religious coping (Ng, 2021). Problem-focused coping was the most robust coping strategy among parents of a child with ASD. Problem-focused coping is used to deal with a stressful situation or change the situation to remove its stressful impact, such as by acting (Obeid, 2015). A study found that positive and problem-focused coping is associated with fewer stress levels (Miranda, 2019).

Furthermore, emotional regulation has it contributes to parental stress. Individuals with emotion regulation (ER) could manage their emotional responses in various situations to get stable internal emotions, i.e., less anxiety, depression, and hostility. Emotion regulation may be crucial when chronic stressors cause sustained emotional arousal that otherwise would interfere with healthy functioning (Deater-Deckard, 2015). Parents troubled by emotional regulation were more likely to perceive parenting stress. This condition was associated with fewer optimal bonding behaviors, more over-protection of the children, and even less care for their children (Hu, 2019). In addition, social support is needed for parents to get the right sources and services. The study has shown that family support affects parenting stress. Strong family support would decrease parenting stress among mothers who have children with disabilities in general (Fikriyyah, 2018). Another study revealed that high or increased levels of social support predicted a decrease in parenting stress, while high or increased levels of family dysfunction predicted increased stress (Zait, 2016).

From now on, the child's problem behavior was a contributing factor to parental stress. A study indicated that children's problem behaviors were related to less maternal positivity and more negativity (Poria, 2014). Autism spectrum symptoms were positively associated with parenting stress; the child's problem behaviors mediated the relationship. Parents of children with externalizing problem

behaviors (e.g., hyperactivity and aggression) reported comparable levels of impact and stress as high as those of children with ASD (Siu, 2018).

Strategies Resilience in Anticipating Parental Stress

Based on the literature review findings, some contributing factors influence parental stress. Those factors can be divided into two categories, internal and external. The internal factor was coping strategy

and emotional regulation of parents. Meanwhile, external factors were social support and child behavior problems. Parents need to get the right cope to manage their stress when raising a child with ASD. Great emotion regulation and the right coping stress might decrease the stress level of parents of children with ASD. Table 2 describes factor strategies parents can use, particularly those with children with ASD (**See Table 2**).

Table 2. Factor Strategies

Coping Strategies	Emotion Regulation
Help parents develop new positive coping strategies (e.g., task-oriented coping) by organizing parent counseling groups	Knowing the emotion and response of the body and accepting the emotion
Social Support	Child problem behaviors
Provide parents with some information and resources about ASD	Find out the children's behavior and consult with a professional to get the right cope

Conclusion

Parental stress is defined as an imbalance of parental perceptions between the demands of parenting and available resources. The experience of bringing up a child with ASD can be stressful. There are many factors contributing to parental stress along the processes. These factors can differ into some categories, such as parents coping strategies, emotion regulation, social support, and child behavior problems. Each of the factors may have different results. For example, problem-focused coping will decrease parental stress, and less social support from parents will increase the stress level. The implementation of these results provides several references for parents of children with ASD. Good management of emotion regulation and great coping strategies may decrease stress levels. Getting social support from others will emphasize knowledge regarding the way to handle children with ASD.

Furthermore, the child's behavior problem will be resolved by the parents.

A limitation of the current review was that it only focuses on some factors contributing to parental stress being investigated within the time range of the last ten years and limits on the issues of coping strategies, emotion regulation, social support, and child behavior problems. Further research can examine other variables that influence parental stress.

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