



Parenting Stress of Children with Autistic Disorder

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Received 2 June 2016; accepted 5 July 2016; published 8 July 2016

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Abstract

Parents of children with autistic disorder experience a unique form of stress that varies significantly according to socio-cultural contexts. This review aims to investigate the stress levels of parents with children with autistic disorder and identify variables that predict parenting stress. A search of CINAHL, Springer, Pub Med, and EBSCO databases between the years 2001-2015 was conducted using the following keywords: parent stress, impact stress on parent, child with autistic disorder, psychological well-being, and 35 articles out of 56 articles were included in this review. The literature showed that socio-demographic variables influenced parental stress levels. The highest levels of stress were reported for the cases: mothers younger than 30 years old, children younger than 6 years old, a recent diagnosis, low educational level, low monthly income. Additionally, a major impact of autistic disorder on parents in relation to their mental health and the family-child relationship was discussed.

Keywords

Parent Stress, Child with Autistic Disorder, Impact Stress on Parent, Parent Psychological Well-Being

Subject Areas: Nursing, Pediatrics, Psychology

1. Introduction

The term “autistic” and “autism” originate from the Greek word “autos”, which means “self”. Recently, autism as a term is associated with a neuro-cognitive development disorder [1]. Generally, autistic disorder has included several domains related to health, but the concept also initially included many other non-health related issues such as family, social background, and environment [2]-[4]. While the concept of autism is supported by the li-

terature to date, there has been no single and unanimously accepted definition [5]. Over the last 15 years, several definitions of autism have been provided. Most of them focus on psychological and social development [2] [6].

Stress is a particular response to the environment, where the individual appraises that certain demands are overextending resources, and thus threatening wellbeing [7]. Abidin [8] pointed out that the general stress experienced by parents would be the result of child-related characteristics, such as adaptability, care-taking demands and pervasive disruptive behaviors. In addition, autism results in change, including physiological, cognitive, emotional and behavioral changes and these changes persist throughout the lifespan [9] [10].

Children with autistic disorders experience a complex range of social, emotional and behavioral difficulties that present significant and ongoing concerns for parents [11]. Parenting a child with chronic disability is considered as a unique experience that is significantly different regarding to social and cultural contexts [12]. As such, these parents are often at risk of experiencing stress [13]. Parents of children with autistic disorder experience more negative psychological distress than parents with typically developing children. This psychological distress can range from confusion, feelings of helplessness, frustration, sadness, anger, and fear [14] [15].

2. Methods

2.1. Search and Screening Process

The literature search was conducted systematically based on previously tried and tested bibliography search strategies. These strategies included searching by keyword, selecting databases, and applying a limit to the search results and the number of articles extracted.

In order to find literature on this topic, the authors searched electronic medical and health care databases, including CINAHL; Springer; Ovid; Pub Med; Pro-Quest; and EBSCO host. However, the most relevant literature was found through EBSCO host.

The following search terms were used as keywords: “parent stress”, “impact stress on parent”, “child with autistic disorder”, and “psychological well-being”. Search terms consisted of four steps: 1) conduct systemic literature search, 2) appraise the quality of the selected articles, 3) review the articles to identify themes, and 4) organize the themes and critically analyze them. No restriction on article language was applied. **Figure 1** shows literatures screening process.

2.2. Inclusion and Exclusion Criteria

To narrow the scope of the review, a number of inclusion criteria were applied to select the relevant literature:

- 1) Articles identified as primary sources.
- 2) Articles that initially validated or used a previously validated measure of parenting stress.
- 3) Studies conducted only on child diagnosed with autism disorder.
- 4) Studies that measured the stress among parent who have child with autistic disorder.

Literature exclusion criteria were also employed such as: abstract, articles focusing on child with other disorders.

After application of the inclusion and exclusion criteria the search strategy identified 56 relevant articles, of which 51 articles were quantitative, 5 articles were qualitative. All of the identified articles were reviewed, and only 35 articles were included as they were deemed to be of relevance.

2.3. Data Extraction Method

The keywords “parent stress”, “impact stress on parent”, “child with autistic disorder” were used to screen all articles published in the medical health fields. An initial search of the mentioned database was carried out, followed by an analysis of the variables (parent gender and age, monthly income ,educational level marital status and child age and time since diagnosis) contained in the titles and abstracts and the index terms used to describe the articles. Furthermore, four criteria were used to evaluate the quality of selected articles: 1) articles publish in recent years, 2) context of the study is clearly described, 3) the main results are clearly presented, 4) the conclusion presents the results of study clearly.

3. Literature Review Themes

All of the identified relevant articles were extensively reviewed to identify themes related to parenting stress of

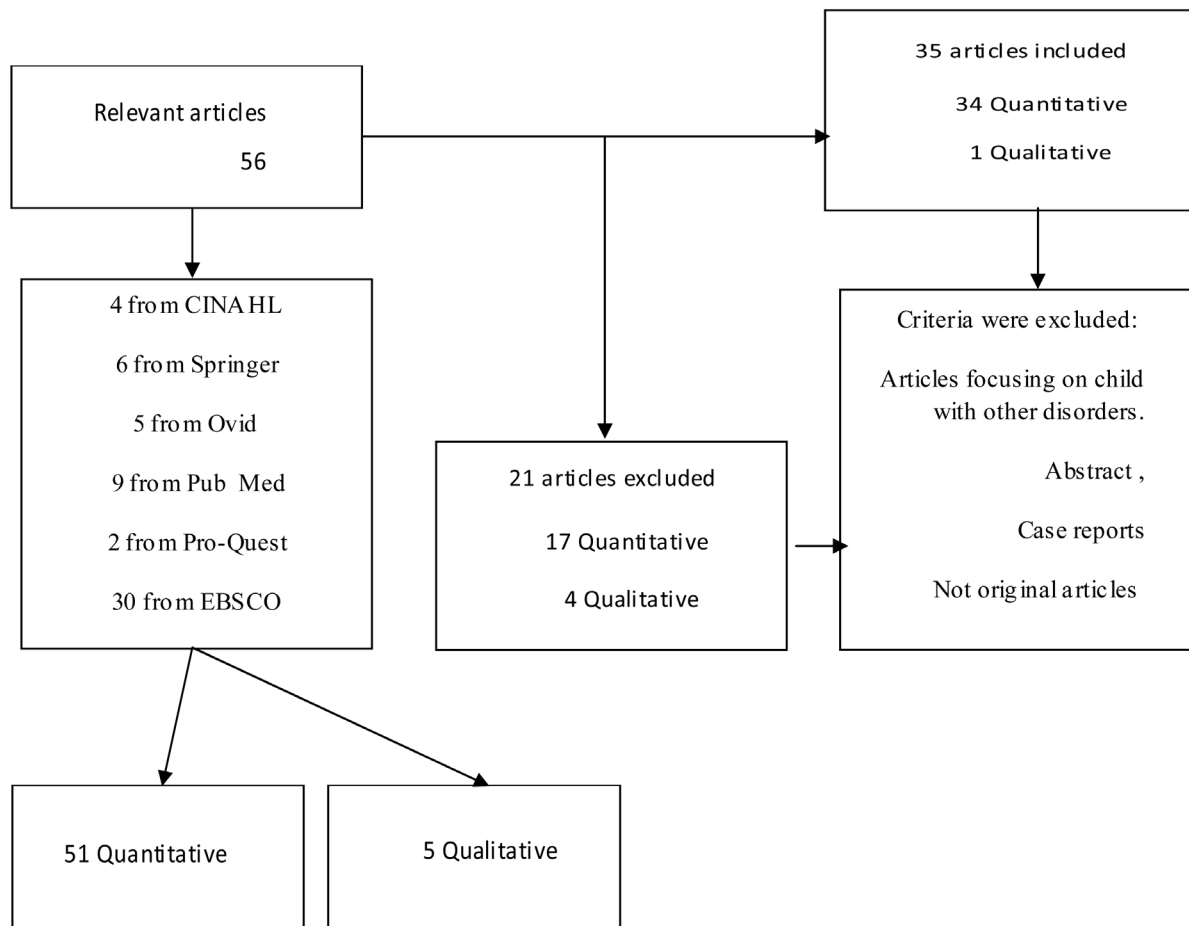


Figure 1. Literatures screening process.

children with autistic disorder. Two themes were identified: source of parenting stress, and impact of autism-related stress on parents well being.

3.1. Source of Parenting Stress

While it is expected that all parents experience stress as their children develop, the presence of certain factors, such as difficult child characteristics or a disability, can increase stress levels [4] [10] [11] [16]. The literature review explored factors associated with parenting stress of children with autistic disorder (*i.e.*, parent gender, age, child age, marital status, monthly income, and educational level).

With regard to parent's gender, numerous studies have found differences in the stress levels between mothers and fathers of children with autism. In general, mothers in comparison to fathers, tend to experience greater levels of caregiver stress. They reported having more obligations with regard to family management and spent more time in a direct caregiving role for the child with autistic disorder [11] [12] [17]-[21].

The association between gender and stress levels was examined by Hastings [17]. Eighteen mothers and 18 fathers of children with autism were involved in the study. The Questionnaire on Resources and Stress-Short Form (QRS-S) was used to assess parent's stress. The study revealed that mothers reported higher stress levels than fathers. In addition, the results indicated that mothers who were divorced were more affected than married mothers. Likewise, a study conducted by Tehee *et al.* [11] also pointed out that mothers were significantly more stressed than fathers. In addition, the results indicated that single mothers showed significantly higher level of stress than mothers living with their partners.

Consistent with the previous studies [12] [20], Soltanifar *et al.* [21] studied the different stress levels among fathers and mothers of children with autism. In their study, 42 couples with children aged between 2 and 12

years diagnosed with autistic disorder were interviewed using the Parenting Stress Index (PSI). Demographic information was collected using a questionnaire. The study revealed that mothers of children with autism had higher levels of parental stress than fathers. Overall, a review of the literature revealed that mothers showed significantly higher level of stress than fathers [11] [12] [20] [21].

Regarding to the age of the parent and their child, the literature suggests that parenting stress is associated with maternal age and child age. Koegel *et al.* [22] were the first researchers to study the relationship between maternal age and parenting stress. In the study, interviews were conducted with 50 mothers of children who were diagnosed with autistic disorder, with a mean age of 5.98 years old. Maternal age was measured as a demographic variable. The study results revealed that mothers younger than 30 years showed higher levels of stress compared with mothers older than 30 years. In addition, the results indicated that stress among mothers of children younger than six years was higher than mothers of children older than six years. Consistent with previous study [23], Duarte *et al.* [24] studied the association between maternal age and parenting stress. In the study, interviews were conducted with 31 mothers of children with autistic disorder with a mean age of 6.2 years. Mother's ages were divided into three groups; twenty to thirty years old, thirty one to forty years old, and mothers over 40 years old. The authors reported that mothers younger than 31 years reported higher levels of stress than mothers older than 31 years old. In addition, the results indicated that stress among mothers of children younger than six years was higher than mothers of children older than six years. Overall, a review of the literature concluded that mothers younger than 30 years old with children younger than six years diagnosed with autism experienced higher levels of parenting stress [22]-[24].

In regard to time since diagnosis and parenting stress level, Fleischmann [25] reported that the earlier the diagnosis of autism, the more parents suffer from high levels of stress. Keen *et al.* [26] focused on the stress related to the initial time of autism diagnosis. Their study revealed that early diagnosis was associated with higher levels of parenting stress of children with autistic disorder. In addition, the study results highlighted other sources of stress, noting the diagnostic and planning processes, that diagnosis takes a long time, care plans do not always include parental participation, and that many plans do not include intervention data. This is very stressful and is significantly associated with parents' stress levels. Similarly, Hastings and Johnson [27] conducted a study to examine the association between time since diagnosis and parenting stress levels. A total of 141 parents of children with autism participated in the study. The mean time since diagnosis was 13 months. The study results revealed that the early diagnosis of autism was associated significantly with high levels of parenting stress. Thus, a review of the literature confirmed that parents experienced stress when their children received an early diagnosis of autism [25]-[27].

In regard to educational level, financial status and parenting stress, Phetrasuwan and Miles [28] investigated sources of parenting stress in parents of children with autism in a descriptive correlation study. In this study the sample consisted of 108 parents who had children diagnosed with autism. The participants were asked to complete the Parental Stressor Scale (PSS), a Personal Questionnaire (Age, Ethnicity, Education, Income) and the Childhood Autism Rating Scale-Parent Version (CARS-P). Study results revealed that behavioral symptoms were the primary source of parenting stress. In addition, the study indicated that parents with lower education levels and low monthly income reported higher levels of stress. Similarly, Wang *et al.* [3] highlighted possible factors that increased stress levels in parents of children with autism. In their study, 150 parents of children with autism were included. Data about participants' demographic characteristics, stress level among parents, anxiety level, depression status, child's behavioral problems, financial status, and social support were collected through a questionnaire. The study revealed that mothers of children with autism faced high levels of stress and that stress was associated with levels of anxiety, depression, low monthly income, low educational level and the child's behavioral symptoms. In a more recent study, Samadi and McConkey [29] studied the variables that are associated with parental stress. In their study, 103 parents (58 mothers and 45 fathers) who had a child with autistic disorder completed the Short Form of the Parenting Stress Index. Educational level was measured as a demographic variable. The study results revealed mothers had significantly higher levels of stress than fathers. In addition, the results indicated that stress significantly correlated with lower educational levels of the parents. Overall, a review of the literature revealed that parents with lower education levels and low monthly income reported higher levels of stress [3] [28] [29].

Conversely, Benson [30] conducted a study to examine the relationship between educational level and parental stress levels. In this study, 68 parents of children with autistic disorder completed the stress subscale of the Effects of the Situation Questionnaire (ESQ). The study revealed that parents with higher levels of education

also had significantly higher levels of stress. These results were corroborated by a study by Dabrowska and Piusula [19]. They found that parents who were more educated reported significantly higher levels of stress compared to other parents who were less educated.

Extensive research has compared parents of children with autistic disorder to parents of children with and without disabilities. Commonly, studies have compared an overall measure of stress between parents of children with autistic disorder to those of parents of children with typical development [31]-[34] or those diagnosed with Down Syndrome, intellectual disability, and Fragile X syndrome [15] [16] [19] [35]-[38]. These studies have revealed that parents of children with autistic disorder experience higher levels of stress than parents of children with other types of disorders or disabilities.

Tomanik, Harris and Hawkins [14] reported the best predictor of high parental stress ratings is child inappropriate social behavior, including acting aggressively towards themselves or others, and/or engaging in repetitive or ritualistic actions. Consistent with the previous studies [18] [39], Osborne and Reed [40] investigated the relationship between behavior problems and parenting stress in a sample of 137 parents with children with autistic disorder using the Gilliam Autism Rating Scale (GARS) and the Questionnaire on Resources and Stress (QRS-F). The study revealed a strong relationship between parenting stress and a child's behavioral problems (Stereotyped Behaviors, Communication skill, Social Interaction, and Developmental Disturbances).

3.2. Impact of Autism-Related Stress on Parents Well Being

Parenting stress has been one of the most frequently researched aspects of family life among parents of children with autistic disorder [41]. The severity of the child's autism symptoms and behaviors has been consistently found to be a strong predictor of parenting stress [42]. Moreover, core symptoms, associated symptoms, and behavior problems associated with autistic disorder contributed significantly to negative parental wellbeing [43]. The following literature review has identified two aspects that impact on parents of children with autistic disorder. These include: the parent-child relationship, and parental mental health.

3.2.1. Parent-Child Relationship

Roles of parents and partners are challenging for most people especially challenging when extra time and effort are required in the parenting role [31]. Numerous studies have shown that children with autism affect the relationship between other family members. It has been shown that families of children with autism have lower marital intimacy and marital satisfaction [1]. Furthermore, emotional distress contributes to marital confrontation and dissatisfaction and increases potentiality for divorce, which in turn can be affected on a child [31].

Gender differences related to parents-children relationship have been identified. Kim and Mahoney [44] reported that mothers of children with autistic disorder showed strong relationships with children more than fathers and were not affected by child behavior and stress level. The association between marital satisfaction and the quality of the parent-child relationship was examined by Hartley *et al.* [45]. In their study, interviews were conducted with 91 married mothers and fathers. The authors found that marital satisfaction was an important predictor of parenting experiences, and mothers of children with autism showed close relationships with children more than fathers. These results were corroborated by a study by Hartley *et al.* [46] They found that mothers felt a closer relationship to their children with autism, rather than with the fathers.

Koren-Karie *et al.* [47] presented the idea that secure attachment among children with autistic disorder was associated with variance of developmental competencies and greater parental sensitivity, but not to the severity of clinical features of autism. Consequently, Hoffman and colleagues [32] studied the association between parent-child interaction and child behavior problems in 104 mothers of children diagnosed with autism. The authors reported that attachment was negatively impacted by the severity of autistic disorder symptoms. Similarly, Brobst and colleagues [31] conducted a study to examine the relationship between the child's behavioral problems and relationship satisfaction. In this study, interviews were conducted with 25 parents of children who have autistic disorder. Results indicated that parents of children with autism experienced lower relationship satisfaction which associated with intense child behavior problems. These results were corroborated by a study by Gau *et al.* [48]. They found that children with autism, who have a wide range of behavioral problems, negatively affect parent-child interactions.

The association between marital satisfaction and characteristics (gender, age, and intellectual disability status) of the child with autistic disorder was studied by Hartley *et al.* [49]. In this study, interviews were conducted

with 199 mothers. Family context variables, including the presence of other child with a developmental disability, education level, and household income, on marital satisfaction were also examined. The study revealed that behavioral problems of children with autism and household income had a significant effect on level of marital satisfaction and the quality of the mother-child relationship.

On the other hand, greater severity of autism significantly associated with higher levels of individual and family burden, Beurkens *et al.* [50] conducted a study to examine how severity of autism affects children's interactions (relatedness) and relationships with their parents. In their study, 25 parents of children with autism aged from 4 to 14 years were surveyed using the Parent-Child Relationship Inventory (PCRI), to evaluate the quality of relationships between parents and children, and the Autism Diagnostic Observation Schedule (ADOS). The study revealed that increased severity of autism adversely impacted on patterns of parent-child interaction but not on the quality of the parent-child relationship.

Conversely, Baker *et al.* [51] reported that mother-child relationship quality was not predictive of change in maternal symptoms of depression or child behavior problems. The relationship between psychological functioning, family communication, and parenting of the child with autistic disorder were studied by Montes and Halterman [52], a total of 772 parents of children with autism, who were 4 to 17 years of age, were interviewed. They found mothers of children with autism showed significantly strength in the parent-child relationship, social support, and stability of the household in the context of high stress and mental health issues.

3.2.2. Parent Mental Health

Parenting a child with autistic disorder has been associated with wide range of negative emotional outcomes [53]. Numerous studies have identified mental and physical health problems for parents of children with autism associated with high levels of stress [54]-[56]. Singer [57] examined and compared depression among parents of children with autistic disorder and parents of children without development disabilities, in a meta-analysis of 18 studies conducted between 1984 and 2003. Singer [57] analyzed findings from comparative studies of depression among parents of children with and without developmental disabilities. The study results revealed that parents of children with autistic disorder reported significantly higher level of depression compared to parents of children typically developing. Similarly, Olsson and Hwang [58] investigated depression among parents of children with autistic disorder and parents of children without disability. The study sample consisted of 216 parents of children with autism and 214 parents of children without disability. Depression level among parents was assessed by using the Beck Depression Inventory (BDI). The study results revealed that mothers of children with autistic disorder reported significantly higher levels of depression than mothers of children without autism and experienced distress more than fathers of children with developmental disabilities. In addition, the results indicated that single mothers of children with autistic disorder were found to be more vulnerable to higher level of depression than mothers living with a partner. Additionally, Gau *et al.* [48] compared depression levels among 219 parent of children with autistic disorder and parents of children with other disabilities using the BDI. The study confirmed that mothers of children with autistic disorder experience higher levels of depression and reported less than quality of life compared with mothers of children with intellectual disability.

Herring *et al.* [54] investigated the association between behavioral-emotional problems in children with autism and parental mental health. In their study, 23 parents of children with autistic disorder were included as participants. The parents completed a checklist on child behavioral and emotional problems, and a General Health Questionnaire. The results revealed that behavior and emotional problems have a significant impact on parent's mental health problems. Consistent with previous studies [56] [59], Weiss *et al.* [60] conducted a study to examine the relationship among child behaviors problem, mental health among parents, and psychological acceptance. Their study sample included 228 parents of children diagnosed with autistic disorder, between 6 - 21 years of age. The study results revealed that as the child's problem behaviors increased, parent's psychological acceptance decreased, resulting in an increase in parent's mental health problems. Overall, a review of the literature concluded that parents of children diagnosed with autistic disorder reported more mental health problems, compared with parents caring for a child with others intellectual disability [48] [54] [56]-[61].

4. Conclusion

Parents of child with autistic disorder considered a unique experience of stress that varied significantly according to socio cultural contexts, but mainly associated with type of disability that presented in their children. The review of previous studies results in investigation of the predictor variables of parenting stress, there was con-

sistency in the results regarding the association between parent gender, age, child age, recently time diagnosis, educational level, monthly income and marital status. All studies agreed that mother younger than 30 years old, child younger than 6 years old, recently time diagnosed, low educational level, low monthly income and single parent were related to high level of parenting stress of children with autistic disorder. However, numerous studies confirmed high educational level associated significantly with parenting stress. Additionally, the literature review identified a major impact of autistic disorder on parent regarding to mental health and family-child relationship. Consequently, all studies agreed that negative wellbeing, depression, anxiety, and negatively impact of family-child relationship were associated with autistic disorder. In contrast, numerous studies contradict in the result regarding impact of autism on family-child relationship, which reveals the increase of parents' relationship and their children with autistic disorder. Consequently, it is vital to identify decreases in wellbeing, heightened stress levels, and feelings of guilt among parents of children with autism to offer appropriate support and education to improve and increase their well being.

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