

Families of Children with Autism and Stress: A Scoping Review

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Abstract

The American Psychiatric Association defines autism spectrum disorder as a developmental lifelong disorder that includes challenges in social communication and repetitive behavior, like spinning in a circle or hand-flapping, and restricted interests [1; 14]. As a result, parents of children with autism can have high levels of stress from the symptoms associated with autism compared to parents of typically developing children or parents of children with other disorders [24]. This review organized the research literature on the coping responses of parents of children with ASD using the Double ABCX model of stress and coping. The OneSearch database at Indiana University Bloomington was used to find the related studies based on the inclusion and exclusion criteria. The search identified 3341 results between 1989 and 2022, with 12 results meeting the inclusion and exclusion criteria. The findings of the 12 results were organized into the categories of the Double ABCX model which were stressors (A) (e.g., living circumstances, social and financial status, and not having necessary resources), resources (B) (e.g., written emotional disclosure), perceptions (C) (e.g., deficits in child's immune system) and crises or strain (X) (e.g., engagement coping strategy and social support). Studies that addressed strain and coping strategies, especially for our targeted age group, were the most while studies that addressed resources and perceptions were the least, so we recommend having further research on caregivers' resources and different perceptions.

1. Introduction

The American Psychiatric Association defines autism spectrum disorder (ASD) as a developmental lifelong disorder that is characterized by challenges in social communication, repetitive behavior (e.g., spinning in a circle or hand-flapping), and restricted interests [1]. In schools, ASD can manifest as a lack of direct social attention, lack of social learning skills (e.g., attending and responding to social cues,) and lack of imitation [6]. Restricted interests can include an intense focus in a specific activity or topic, and difficulty with redirecting attention [18]. The National Institution of Mental health defines ASD as a developmental and neurological disorder that affects people's learning, behaviors, and communication with others [22]. Historically, ASD has been more commonly

diagnosed in boys than girls [14]. The worldwide prevalence of ASD has been increasing since the 1990s [22].

ASD is known as a spectrum because there is a wide range of differences in the symptoms that people with autism show [22]. The symptoms of ASD show in the first two years, but specialists can also diagnose autism at any age [22]. The most common symptoms of ASD are inconsistent eye contact and difficulty with changes in routines [22]. People with ASD can also have strengths like learning things in detail, and being knowledgeable in math, science, art [22] and technology (Jia et al., 2022).

The causes for ASD are not entirely known [14]. However, studies indicated that there are genetic factors that could work with environmental factors to result in autism [22; 14]. Some of the genetic factors that raise the chance of having ASD are the higher age of the parents, the child's gender, and the family health history [14]. Environmental factors may include exposure to toxins during pregnancy, premature birth, lack of oxygen during childbirth, and umbilical cord difficulties [14].

It is recommended to start therapy sessions with health care providers as soon as the child is diagnosed with ASD which decreases the difficulties that may face in the future [22].

2. ASD and the Family

Because of the symptoms associated with ASD, parents of children with ASD can have high levels of stress compared to parents of typical developmental children or parents of children with other disorders [24]. In general, parents experience hardship between supporting their child and enhancing his independency, especially in the transition period of time. That's applied as well to parents of children with ASD but with higher stress and tension, and the difference in parents' responses regards their child with ASD would be based on the child's characteristics, and the family's social relationship [24].

Parenting stress can happen because children with ASD require specialized care and specific resources [24]. The demands may cause parents to question their parenting skills. This is exacerbated when parents are blamed for their children's behavior or disorder [24]. Parents' stressors become higher when the child with ASD in their teenage ages, they have a complicated relationship with the child, find

difficulties adjusting daily routines and activities, experience stigma, and behavioral challenges [24].

According to Schiltz et al. (2022), Cadman et al. (2012) found that kids with ASD who are between 5-9 years old are the most causing of burden and stress to parents compared to other disorders such as ADHD, and then, parents of children with ASD have higher stress [24].

In addition, studies indicate that parenting efficacy is lower, on average, among parents of children with neurodevelopmental disorders compared to other parents of typically developing children because of parents' depression, bad sleep habits, the child's age and behavior, and difficult experiences with the service system which lead to parents stressors [24]. The home environment is very important for the family to maintain family behavior and sustainability, so unsettling household context increase problem behaviors of the child with ASD and then parents stress [24]. Having a child with ASD and other developmental disorders is the most challenging and stressful for parents [24].

The purpose of this scoping review is to organize the findings across multiple studies regarding families' responses to caring for children with ASD. This review will organize the research literature using the Double ABCX model of stress and coping.

3. Double ABCX Model

The Double ABCX model comes from the families system theory, and this theory takes the position that a family is always seeking equilibrium. The purpose of the Double ABCX model is to help us understand families' responses to stressors and the outcome of those responses [19].

The Double ABCX model has four main components. The letter A is used to represent stressor events, which can be defined as a transition or life event that affects the family social system and impacts its unity and equilibrium [19]. For example, changing the family members' roles in caring for another family member with a medical condition or other healthcare need, or other financial family demands affects the family's balance and routine [19].

The B component captures resources that the family can use to mitigate the impact of the stressor [19]. These resources can be defined by the ability of the family to prevent the change in their social system, as they face obstacles and transitions that threaten the family's balance [19], [20].

C component represents how the family defines the stressor [19]. This included the personal family perspective, how the family defines a specific stressor, and estimates their demands to bring up the family to balance. A family might or might not be influenced by any stress based on their point of view [19]. For example, accepting the i as a blessing

would decrease their stress and easiest their adaptation [19]. Additionally, redefining a stressor by the family and giving it a new meaning can help the family to reduce the burden of an issue, clarify the case and make it more able to be solved, and encourage the family's social and emotional duties [19].

The final component is factor X which is the family crisis [19; 20]. Crises can happen when the family disequilibrium is not corrected and the disbalance disrupts the family [19]. Stressors may not lead to crisis if the family was able to use the available resources efficiently, as shaped by their perceptions of the stressors and resources [19]. The interconnection between these components produces positive or negative adaptation [19].

The Double ABCX model is a good fit for this scoping review because it can address stressors faced by families raising a child with ASD and how families respond. According to Brannan et al. (2003), the Double ABCX model can be used to describe families' responses to life stressors when they are caring for a child with emotional and behavioral disorders. [7]. In addition, previous research has used the Double ABCX model to study the stressors of families who care for a child with autism spectrum disorder (ASD) [20; 21].

By framing the previous literature within the Double ABCX model, we will summarize research findings regarding stressors, resources, perceptions, and coping among families caring for children with autism spectrum disorders. In addition, we will identify family coping strategies described in the extant literature.

4. Methods

Onesearch at Indiana University database was used. Using the advanced search, we used the following terms to search abstracts: "stress" or "strain" or "tension" AND "parents" or "caregivers" or "mother" or "father" or "parent" or "family" or "families" AND "children with autism" or "children with ASD". This search found 4883 sources. After that, we refined the search using the following filters to identify articles that were published in peer-reviewed journals written in English. That yielded 3441 articles published between 1989 and 2022. Then, we narrowed down the search to databases found in the following repositories: academic search complete, education research complete, education full text, Eric, family studies abstracts and educational administration abstracts. After removing duplicates, 697 remained to which we applied inclusion criteria.

The inclusion criteria of this review are caregivers' stress of children with autism who are between 7-12 years old. The exclusion criteria are children's stress, children with other genetic

disabilities such as Down syndrome, other types of autism spectrum disorder such as Asperger's syndrome, caregivers of children with autism who are above 12 years old and less than 7 years old, not about parental stress, targeting siblings, literature reviews, not providing the kids' age, and studies related to Covid-19 parents stress.

After applying the inclusion and exclusion criteria, 12 articles were retained and included in this review.

5. Results

5.1. Stressors (A)

There are a lot of stressors among caregivers of children with autism during their care time for their children [23]. Also, there is a positive relationship between parents' stress and the intensity of challenging behaviors [2], material reward and punishment [5] in addition to a relationship between parental stress and the self-reported behaviors of caregivers of children with autism [5]. For example, repetitive behaviors are one of the most common behaviors of children with autism which has a strong relationship with the child's sleep problems, behavior problems, low adaptive and cognitive acts. These clinical characteristics have been linked highly to parents' stress when they rated their stress level [11]. However, when the repetitive behaviors had been controlled, children sleep's problems and adaptive behaviors disappeared.

In addition, Argumedes et al. indicated that the increase of parents stress level leads to an increase the intensity of challenging behaviors of their children with autism. And the opposite is the same, the decrease in the challenging behaviors of children with autism leads to a decrease the parental stress [2].

Moreover, the long distance between home and the care providers is another stressor for those who don't have transportation [23]. Also, living circumstances, social and financial status, not having necessary resources, and late arrival to the health providers are other parental stressors which cause to loss and delay the child intervention program and then lead to unimproved in the child's social and cognitive system [23].

Caregivers of children with autism show stress related to autism symptoms or work [5]. Autism symptoms are responsible to change in heart rate variability of mothers of children with autism [10]. A child with high autism symptoms lead to the highest heart rate variability although self-reported results indicated that there was not a big link between stress and heart rate variability [10]. Caregivers of children with autism who have a high level of difficulty regulating their emotions are more to have higher

parental stress, parental care, parental protection and parental best behaviors [13].

5.2. Resources (B)

Family navigation services used by some families of children with autism which showed improvement in parents' strain, activation and decrease of parental stress [9]. The experiences of parents were different based on what they felt about earning skills and their perspectives were effective based on their family and environmental elements [9]. More activated parents were looking for family navigation services [9]. Families of children with autism preferred to receive FN services after diagnosis and provided to them when it's needed [9].

Written Emotional Disclosure is another resource for caregivers of children with autism [17]. It can be implemented as a home intervention of caregiver providers, and it was clear that the scores of anxiety were less likely to be in the clinical mood disorder range [17].

5.3. Perceptions (C)

Most parents' beliefs about autism causes are genetic factors, the child's brain construction, accidents or injuries, nourishment, parents' decisions, poisons in the vaccine, the will of God, stress in general and environmental stimulations [12]. 25% of parents of children with autism hesitate for vaccines because of their negative feeling about autism especially when they have a higher understanding of autism and they are not able to predict it [12].

Parents' negative perceptions about autism that deterioration of a child's immune system as a reason of having autism, and what vaccines could cause [12]. As a result, some parents believe vaccines cause language deficit and developmental plateau [12]. Vaccine-hesitant parents reported less control about autism, and they hope to have more control if there is expect of autism treatment [12]. Identifying unknowledgeable families about the vaccine and enriching them about its benefits is very important for children's health [12].

Parenting support is very important to emphasize caregivers' perceived ability, and they are more likely to scope their experiences in an adaptive way that allow them to use it later as an assistance response to emphasize their perceived ability [8]. The most effective resources in mothers of children with autism are their different past experiences that they went through with their children [8].

5.4. Crisis or Strain (X)

Improving the ability of parents to control their children behavior could lead to decrease parents'

stress although this intervention of didn't target parents' stress directly [2]. Some feelings could transform to emotional adaptive cases that stored with other experiences to control their children's problem behaviors because some caregivers of children with autism are optimistic and ready to face difficulties across their believes [8]. Caregivers of children with autism tend to frame their negative experiences in an adaptive way and focus more on the skills that they need to overcome their difficulties because they do not control autism factors [8]. It allows them also to find multiple ways of building and emphasizing their kids' abilities and indulge repeated failure [8].

The characteristics of the child with autism may affect caregivers' behavior to not act sensitivity toward their children behaviors [5]. They may learned through the past years how to reduce using sensitive behaviors when they react although they show higher stress than mothers of typical development children [5].

In addition, using cognitive appraisal which considered as a coping strategy may be a responsible for self-reported results of having higher stress or not based on the child with autism symptoms [10]. Using the engagement coping strategy [3] and social support [3], [8] also reduce parental stress, improve children with autism's communication skills with their families [3] and have meaning of their struggles.

Moreover, the relaxing strategy is the most positive thinking training interesting method [4]. However, parents of children indicated that the most hard part was to remember including this strategy in their daily routine schedule [4]. Also, providing emotional support for caregivers of children with autism is very important in addition to provide them with systematic emotion regulation training, especially when it provided by a governmental agency which would help parents to reduce their stressors [13].

In addition, some parents of children with autism use religious methods to adapt, accept, and cheerfulness although the provided services are limited [23]. As a result, institutions should decrease the factors that are expected to raise the perceived stress on caregivers of children with autism [23]. They also try to adapt to the environment based on their children's needs through preventing distracted stimulations and adjusting their communication relationship with the child [5].

Caregivers of children with autism can develop their efficacy from self-knowing and personal beliefs which can enrich them of different explanations that emphasize their confidence in raising a child with autism [8]. Studies showed that there is an inverse relationship between depressive cognitions and positive thinking between people of autism which has an effect on their caregivers' well-being [4].

However, there is a need for positive thinking training between parents of children with autism to help reducing stress and depression symptoms [4].

Caregivers of children with autism set fewer rules and support their kids' independency [5]. However, in Chong and Kua's study, they did not mention a lot of accidents that they went through which means that their experiences were convincing to evaluate and explicate parental experiences [8].

6. Discussion and Conclusion

The previous results showed that 9 out of 12 studies that had been found addressed coping strategies or how families could adapt with the situation. For example, they suggest improving the ability of parents to control their children's behavior [2], using the engagement coping strategy [3] and social support [3], [8], [23], positive thinking training including relaxing strategy [4], not show sensitive reaction by caregivers of children with autism toward their kids' behaviors, adapt with the environment based on their children's need, set fewer rolls and support their kids' independency [5], developing caregivers efficacy from self-knowing and personal believes, feeling transformation, optimism [8], cognitive appraisal [10], emotional support, emotion regulation training [13], decrease health institutions factors, religion methods to adapt, accept, and cheerfulness, and engagement coping strategy [23].

Two of 12 studies addressed resources and perceptions. Crossman et al. [9] discussed family navigation services, and how family could have benefits to reduce their parental stressors. Lovell et al. [17] also provided written emotional disclosure which was very helpful for caregivers to express their feelings and reduce their stress and depression. While Chong and Kua [8] discussed caregivers of children with autism's perceived ability and experiences, and Goin-Kochel et al. [12] pointed out to multiple perceptions of caregivers of children with autism, such as genetic factors, child's brain construction, accidents or injuries, nourishment, parents decisions, poisons in the vaccine, will of God, stress in general, environmental stimulations, deterioration of child's immune system.

In addition, 6 out of 12 studies investigated different stressors that could prevent caregivers of children with autism to have a regular day as planned. These stressors include challenging behaviors of children with autism [2], work, material rewards, child's punishment, caregivers' behaviors [5], heart rate variability of caregivers of children with autism, high autism symptoms [10], difficulties to regulate caregivers emotions [13], repetitive behaviors, child's sleeping problems, behavior problems, low adaptive and cognitive acts [11], long distance between home and the care providers, living

circumstances, social and financial status, and late arriving to the health providers which cause delay of receiving the child's intervention [23].

The double ABCX model fits well unless there are not enough studies that target the indicated age area. For further research, there are a lot of parental stressors that have not been investigated yet especially for this age group such as parents sleeping problems, using pets as a stress relief for families of children with autism, and we would like to know more about different families perceptions toward autism and their stressors.

7. References

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