



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PSYCHOLOGICAL SUPPORT FOR PARENTS RAISING CHILDREN WITH AUTISM SPECTRUM DISORDERS

Abstract. Parents caring for children with autism spectrum disorder (ASD) often report increased levels of stress, depression and anxiety. Unmet mental health needs of caregiving parents pose a significant risk to the psychological, physical and social well-being of the parents of a child suffering from ASD, and jeopardize the adaptive functioning of the family, as well as the potential of the child suffering from ASD.

This article presents the results of interventions that support the mental health of caregiving parents and offers recommendations for the support of practicing caregiving parents.

PubMed, Cochrane Database of Systematic Reviews and Scopus databases were searched to identify studies that met the following criteria: intervention was provided to parents caring for a child with ASD under the age of 18; the design of the study made it possible to compare the results by groups; and indicators of the mental health of the parents caring were used. The search was limited to the human population, research in English and Russian. Each included study was evaluated according to the control sheets of AMSTAR-2, CONSORT 2010.

We analyzed the results of three systematic reviews and meta-analyses, as well as seven randomized clinical trials (RCTs). Currently, there are no unified approaches to the application of programs for parents of children with ASD, contributing to the maintenance of psychological health and the development of coping skills with feelings of tension and stress.

The results show that an integrated educational program for parents developed for caregivers of children with ASD can have a positive impact on the quality of life of caregivers associated with mental health.

Key words: autism; autism spectrum disorder; parents and caregivers; stress support methods; coping strategies.

Introduction

Parents who care for a child suffering from autism spectrum disorder (ASD) often experience higher levels of stress and poorer physical health compared to parents of children with typical development [1-3], parents of children diagnosed with other disorders [4,5] or compared to the general population. [6-11]. Thus, parental stress experienced by the parents with ASD child seems to pose a greater risk to the psychological state of the parents and the quality of life associated with health.

ASD is a disorder of the nervous system development characterized by a lack of social interactions and communication skills, both verbal and nonverbal, limited interests and stereotypical behavior [12]. The manifestation of ASD symptoms can vary from mild to severe and vary from person to person. It is estimated that 1 out of 160 children worldwide (or 62.5 per 10,000) has ASD [13], while Japan is reported to have the highest prevalence – approximately 161 children per 10,000 [14], whereas in the United States (USA) the number of children diagnosed with

ASD increased from 66.7 to 147 per 10,000 between 2000 and 2016 [15].

A growing number of evidence suggests that parents of a child suffering from ASD experience higher rates of depression and anxiety [16-22], fatigue [23], increased physical health problems and body pain [24], as well as deterioration in general well-being [19] and quality of life [21,25]. Increased parental stress is explained by the need to provide constant supervision and assistance in the development of the child's daily life skills, ongoing sleep disorders, lack of available assistance during respite and lack of response from school staff and related services [26-29].

Satisfaction of unmet mental health needs of parents caring for a child suffering from ASD is necessary to improve the overall health and quality of life of parents, as well as other family members [30]. It has been reported that the effectiveness of behavioral treatment measures for a child decreases when the needs of parents in the field of mental health remain unsatisfied [31].

The health-related quality of life of parents caring for a child suffering from ASD can be improved

by directly reducing parental stress with caregivers involvement in effective mental health support strategies. Currently, there are no guidelines for mental health support for parents who have a child with ASD, but it would be important to define these guidelines in order to facilitate the provision of cost-effective services to parents in need of assistance[32].

The purpose of this work is to summarize the results of studies conducted among parents caring for a child with ASD in which the effectiveness of interventions in the field of mental health was studied.

Materials and Methods

According to Kitchenham, we used three stages: planning a review, developing a research question, conducting a review, selecting and evaluating the quality of the studies included in the analysis, and describing the results [33].

The research question included studying parents' perceptions of children with ASD and their coping strategies.

The literature was searched in the following bibliographic databases: PubMed, Cochrane Database of Systematic Reviews and Scopus. The search strategy included controlled vocabulary, such as the National Library of Medicine's MeSH (medical Subject Headings), and keywords: (((autism or autism spectrum disorder) and ((parents) or (caregivers)) and ((methods of) stress support) or (coping strategies))).

Methodological filters were applied to limit the search to systematic reviews, meta-analyses and RCTs. The search was limited to English and Russian languages published between January 2012 and December 2022. The search was limited to the human population.

At the first stage, two researchers evaluated the headings and abstracts, after which full articles were selected for in-depth study of the research issue. An assessment of the compliance of full articles with the criteria for inclusion in the review was carried out.

The studies included in this review met the following inclusion criteria: – intervention was provided directly to one or both parents caring for a child with ASD under the age of 18; – the study included a study design that allows you to compare the results of the intervention between groups; – the final assessment of the mental health of parents was used and – the study was published in English and Russian in a peer-reviewed journal with access to the full text. Outcome indicators (systematic reviews, meta-analyses, and RCTs) included any tool that assessed any aspect of mental health, including indicators of stress, anxiety, depression, quality of life (including health-related quality of life), and subjective well-being.

The exclusion criteria are cohort studies, non-randomized clinical trials and other types of research, animals, and ongoing studies.

Each included study was evaluated according to checklists: AMSTAR-2 (systematic review, meta-analysis), CONSORT 2010 (randomized clinical trials) [34].

After eliminating repeated works (duplicates), a total of 14 studies were identified. After evaluating the titles and annotations, 4 studies were excluded and 10 potentially relevant studies were extracted from the electronic search for a full-text review. Thus, the analysis includes 10 studies, including three systematic reviews-meta-analyses, 7 RCTs.

Results and Discussion

Denise Catalano et.al. in a systematic review divided studies with three main topics that were identified as central to improving the mental health of parents who have a child with ASD – these are access to social support with similar caring parents, receiving professional training in stress management and problem solving; and providing accurate information about ASD. One of the most effective factors identified in the generalization affecting the well-being of caregiving parents was interaction with other caregiving parents, for example, through a parent social support group. Establishing contacts with other guardians allowed parents to realize that they are not alone in the problems they face [35], and provided parents with an important confirmation of their own value and experience [35-37].

The authors found that caregivers involved in the parental social group also reported a decrease in anxiety [37] and social stress [38,39], increased group cohesion [40], as well as improved family health and functioning [39] and quality of life [41].

The results of interventions in the form of professionally organized seminars based on cognitive behavioral approaches that provided parents with various stress management strategies and problem-solving skills training were also analyzed. Interventions involving acceptance and commitment therapy have shown that this approach is associated with reduced depression and distress and increased psychological flexibility [42,43]. In some studies, [36,37,44,45,46] parents were trained in problem-solving or coping strategies. It was reported that these activities were particularly useful for parents when the training was structured and focused on providing practical knowledge and skills to solve their child's behavioral problems and day-to-day care. Eight studies [36-39, 47-49] examined the impact of providing caregivers with information about ASD and the types of re-

sources and services that were available to them as a strategy to reduce parental stress and anxiety. As parents' knowledge of ASD increased, stress, anxiety and distress decreased [37,48,49], self-confidence and health assessments increased [37,39], and the use of problem-solving skills increased [39].

The work of Isabel Yorke et.al. aimed to study the literature for evidence of a prognostic relationship between additional emotional and behavioral problems in children with autism and parental stress and mental health problems in their parents [50]

Children with ASD are highly likely to meet the criteria for additional mental health disorders [51-53]. They usually take the form of both internalizing (for example, anxiety or depressed mood) and externalizing (for example, behavior problems, oppositional behavior or hyperactivity) problems. They have been identified as a source of special difficulties and unmet needs for individuals and their families [54-55]. Some previous studies show that such emotional behavioral problems are more closely related to family functioning and parental well-being than to the severity of the main symptoms of ASD [56-58].

The use of coping mechanisms by parents was investigated in three studies with parental stress as a dependent variable [59-60]. Although coping mechanisms have shown a significant relationship with parental stress, children's emotional and behavioral problems have retained a significant association, suggesting that it has an independent effect. On the other hand, when parents' perception of their own upbringing was present in the models, the relationship of parental stress and mental health problems of parents with emotional and behavioral problems of the child became insignificant in three cases [61, 62] from four studies. Only the largest study showed that both the emotional and behavioral problems of the child and the parents' perception of their own upbringing seem to make a significant contribution to the parents' psychological health problems [63] Thus, parents' perception of their ability to effectively perform parental functions is a likely candidate for the role of mediator in establishing the relationship between the emotional and behavioral problems of the child and the variables of psychological stress of parents.

In a systematic review, *Alana Fairfax* and co-authors presented evidence that coping was associated with quality of life: in three studies, coping strategies considered adaptive were positively associated with psychological quality of life, while in one study, non-adaptive strategies were negatively associated with psychological quality of life. Only two studies considered coping as a potential mediating variable in the relationship between the complexity of care and the quality of life of parents, with conflicting

results and difficulties in interpreting intersectoral associations. No study considered coping as a constraining variable. The variety of tools used to measure key constructs, in particular coping strategies, made it difficult to generalize the results. The authors found that coping strategies may be associated with the psychological quality of life of parents of children with chronic diseases [64].

Caregivers and families of autistic people have experienced stress and increased demands due to the COVID-19 pandemic, which can have long-term negative consequences both for their own mental health and for the mental health of their children. Vivian Lee co-authors conducted a survey study to identify needs related to the pandemic faced by caregivers and families of children and youth with autism. Both quantitative and qualitative studies show that parents experienced increased stress and mental health-related symptoms during quarantine [65].

In a qualitative study conducted by Parentau et al., researchers asked parents to list the quarantine response measures introduced by the pandemic. In the report, parents listed physical exercise, attending virtual groups to communicate with their community, spending time taking care of themselves (for example, taking a bath, online shopping) and creatively using time away from their partners and children as ways to cope with the stress of isolation. In the same study, parents noted positive results due to self-isolation measures. Some parents reported that schools were closed, which meant that their child's school curriculum was reoriented from academic skills (i.e. reading, writing and mathematics) to daily life skills (i.e. self-help), which contributed to the well-being of both the child and his guardian (i.e. the child developed some independent adaptive skills) [66]. Similarly, Nis et al. (2020) noted that parents coped by implementing behavioral strategies, restoring daily routines, practicing meditation, giving family members space to relax and taking breaks from each other, and 92% of parents reported that they were able to cope with their circumstances related to the pandemic [67].

In a study by Jessica Bradshaw et.al., positive responses were received to a parent training program in RCT for parents of children with ASD and destructive behavior, in which children with ASD (N = 180) were randomized to participate in a parent training (PT) or parent training program (PEP) for 6 months. Parents who participated in PEP reported a significant decrease in the index of parental stress, the questionnaire on the stress of the educator and the questionnaire on the health of parents, as well as an increase in the scale of parental competence.[68]

The aim of the study by Christy Haakonsen Smith et.al. was to assess the feasibility of conducting a coping effectiveness training designed to increase self-efficacy of coping among caregivers with ASD. Caregivers were recruited and randomized into treatment (n=15) or control groups (n=13). Of these, 22 completed the study (retention: 78.6%). The intervention was highly feasible; most caregivers found coping effectiveness training useful, practical, and relatively easy to attend. The treatment group demonstrated significantly increased self-efficacy of coping after the intervention ($p=0.02$) [69].

A study conducted by Connie Kasari et.al. compared the impact of two parent-mediated interventions on the results of joint interaction as a supplement to the early intervention program for toddlers with ASD. Caregiver-child pairs were randomized to undergo a 10-week practical parenting training on naturalistic behavioral intervention for development (joint attention, symbolic play, involvement and regulation – JASPER) or psychoeducational intervention for parents only (PEI). It was found that PEI is effective in reducing parental stress associated with the characteristics of the child. These findings highlight the benefits of brief, targeted, parent-mediated intervention in outcomes for children. [70]

A quasi-experimental study by the team of Binbin Ji et.al. was aimed to determine the effectiveness of an interdisciplinary educational program for parents willing to improve the quality of life related to health (HRQOL) for those caring for children with ASD. This study included 42 participants (22 intervention, 20 control on the waiting list) who were the main caregivers for children with ASD. At the end of the parents' multidisciplinary training program, there were significant improvements in mental health, family functioning, self-efficacy and positive coping style. The results show that a multidisciplinary educational program for parents developed for caregivers of children with ASD can have a positive impact on the quality of life of caregivers associated with mental health, while at the same time having a negligible impact on the quality of life associated with physical health.[71].

The work of Leann E Smith et.al. presents the results of a longitudinal research program studying the bi-directional influence of the family environment on the behavioral phenotype of autism, and describes a recently developed family psychoeducation program called "Moving Together", designed to reduce family stress, solve behavior problems and improve the overall quality of life of adolescents with autism and their families. A case study illustrating how joint transition helps to reduce family stress and improve

the overall quality of the family environment is presented [72].

Suzannah Iadarola reports the results of a randomized clinical trial comparing the impact of parental learning with parents' psychoeducation by indicators such as the Parental Stress Index (PSI), parental sense of competence (PSOC) and the Caregiver Stress Questionnaire (CGSQ). Linear models with mixed effects evaluated the differences at the 12th and 24th weeks, controlling the baseline indicators. Parents in PT reported greater improvement than PEP in PSOC (ES = 0.34), CGSQ (ES = 0.50) and the subdomain of difficult children in PSI (ES = 0.44). This is the largest study evaluating the impact of educational interventions for parents with ASD on the outcomes of parents. Parental training reduces destructive behavior in children and increases parental competence, while reducing parental stress and parental tension [73].

In a study conducted in Malaysia under the leadership of Wan Natrah Wan Yaacob, coping strategies of parents with children suffering from ASD were studied using a qualitative approach. The analysis of interviews with parents in the framework of this study revealed dynamic mechanisms that make it possible to become stable in the Malay context. In this study, the authors found that most parents were grateful and positively assessed this condition, turning it from a crisis or stressor into a challenge, and began to accept their children's problems and condition. This is an important initial step towards adapting to the problems of caring for children with ASD. As a result, the results of our study are similar to numerous studies of coping strategies among parents who have children with ASD. Social support seems to be a coping strategy that relieves stress experienced by parents and improves their well-being and positive attitude towards their children with ASD.

This study demonstrated that a supportive environment and a high level of family cohesion can help parents cope with their children with ASD. The division of responsibilities contributed to a better adaptation in these families.

This study also confirms the conclusions of Ilias and Cornish [74], indicating that the support of society and government also plays a crucial role in increasing the resilience of parents. Parents found that gaining knowledge about autism is a fundamental aspect that would help them cope with these difficulties. In this study, parents adapted problem-oriented strategies to overcome the condition of their children [75].

The results of this study are limited by the number of participants representing each ethnic group, which was inadequate and lacked participation from

fathers. Another limitation is that a structured interview guide may influence the direction of responses overlooked any negative coping mechanisms on the part of parents.

This work includes a review of the literature on the study of mental health interventions and coping strategies of parents who have children with ASD. One of the most effective factors identified in the generalization that affect the well-being of caregiving parents is to access to social support with similar caregiving parents, receiving professional training in stress management and problem solving; and providing accurate information about ASD.

Although several studies emphasize the effectiveness of educational and training activities in ASD, no work classifies all types of educational and training activities available to parents of children with ASD, no work has been carried out to determine the needs of parents that must be met so that they can independently cope with changes in their daily lives, which require the acquisition of many self-management skills and psychosocial coping.

Important gaps in research related to the consistent and clear measurement of coping strategies and their supposed relationship to quality of life have also been identified. Understanding how coping strategies relate to quality of life is important for developing measures to support families of children with chronic conditions.

Thus, the development of a multidisciplinary parenting training program is effective and necessary to improve mental health, family functioning, and influence the quality of life of caregivers. In the fu-

ture, it is necessary to consider developing programs for PHC psychologists who have parents with ASD among the population of their catchment area or other organizations involved in the process of helping children with ASD. It is also important to study the readiness of psychologists who are able to conduct trainings for parents with ASD, which reduces destructive behavior in children and increases parental competence, while reducing parental stress and parental tension.

Conclusion

The analysis showed the needs of parents or guardians with ASD in psychological support. Worldwide, psychological counseling and correction practices are most often used instruments to assist families raising children with ASD, contributing to the development of favorable conditions for social interaction within families and external interaction of the family with social institutions (behavior analysis, systemic family therapy, integrative psychology). Studying the needs of parents and the competences of PHC psychologists to promote the integration of knowledge, various skills and social skills will provide timely psychological support to parents of children with ASD.

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