

REVIEW ARTICLE

The Effectiveness of Educational Programs on Parenting Stress and Coping Mechanism among Parents of Children with Autism Spectrum Disorder: A Systematic Review

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ABSTRACT

The aim of this systematic review was to evaluate the effectiveness of educational programs on parenting stress and coping mechanism among parents of children with Autism Spectrum Disorder. Our current review retrieved the articles from databases such as CINAHL, Springer, Ovid, PubMed, Google Scholar, and EBSCO host. Only articles published between the years of 2000 and 2018 in these databases were recruited using keywords such as Autism Spectrum Disorder, education program, parenting stress, coping mechanism, and coping strategies. The search generated 17 articles; 8 articles were relevant. This systematic review provides an important opportunity to advance our understanding of the effectiveness of the educational program for reducing parenting stress and improving coping mechanism among parents of children with Autism Spectrum Disorder. Nurses could also have a pivotal role in delivering the educational program for parents of children with ASD.

Keywords: Autism Spectrum Disorder, Education program, Parenting stress, Coping mechanism, Coping strategies

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INTRODUCTION

Health and well-being of children are inextricably linked to the physical, emotional, and psychological of their parents (1). As stated by Keen and colleagues (2) preserving parents' good health and well-being is crucial for achieving optimal care of their children with autism. Autism Spectrum Disorder (ASD) represents one of the neurological developmental disorders and is characterized by moderate to severe impairments in social interactions, language, and cognitive development, as well as repetitive behaviors, restricted interests, and emotional distress (3). There is no doubt that core ASD features especially behavioral problems, and socio-communication skill deficits could lead to significant stress in the families of ASD children (4-5).

Parents are usually the first to recognize the developmental differences in their children with ASD. Consequently, parents who have a child with ASD

are not only often upsetting, they also face unique stressors and demands over the provision of child care (6-7). Furthermore, parenting stress is a complex construct involving behavioral, cognitive, and affective components that are manifested into a tense of their relationship with a child (6, 8). Many studies have been published on examining differences in stress between parents with ASD children and parents with children of other developmental disabilities. These studies revealed that parents of children with ASD had a higher level of stress as compared with parents of children with typical development (9-12), parents of children with Down syndrome (13-14), and parents of children with intellectual disability and development delay (15-19).

Without proper support, parents of children with ASD may susceptible to distress. Moreover, previous studies have reported differences in how parents adapt to these stressors and demands (20-21). Therefore, parents who experience high levels of stress would require strategies to manage their own level of stress and to improve their coping skills. One way to support parents of children with ASD is through educational intervention programs (20, 21). In such programs, parents receive a comprehensive program within a treatment system with clear and

information about effective coping skills (20). According to Farmer and Reupert (23), educational program is a multi-stranded intervention designed to provide parents with information about ASD and concerning social, communication, thinking, and behavioral difficulties of ASD children. Parents can learn skills and strategies in the areas of managing child behavior and communication skills. In support of Farmer and Reupert (23), the present study reviewed educational programs aimed at improving parents' ability by helping them learn effective ways to cope and manage communication and social development of their ASD children through a series of educational, training, and support sessions (22).

In fact, educational intervention programs for parents of children with ASD have become an effective way for promoting successful behavioral strategies to manage child behaviors and to assist parents to improve child development (20). Multi-intervention strategies are often used. These strategies include lectures on specific topics such as understanding definitions, characteristics, causes, and diagnosis of ASD; learning communication and social difficulties in children with ASD; applying principles of behavioral management skills; providing mental health services and strategies to promote social communication skills; and managing parenting stress through relaxation techniques (2). Following these strategies, a host of educational programs have been developed for parents of children with ASD to provide knowledge and skills needed to improve parental well-being, reduce parental distress, and improve coping mechanism (2). It is evident that educational programs can promote parental coping skills leading to better stress management (2, 20).

The purpose of this systematic review was to evaluate the effectiveness of educational programs on parenting stress and coping mechanism among parents of children with ASD. This systematic review attempts to answer the following question: Are educational programs effective in reducing parenting stress and improving coping mechanism among parent of children with ASD?

MATERIALS AND METHODS

Literature Search Strategy

The literature search was conducted systematically based on a few strategies such as searching by a keyword, selecting databases, and applying a limit to the search results and the number of articles extracted. Our current review retrieved articles from databases such as CINAHL, Springer, Ovid, PubMed, Google Scholar, and EBSCO host. The search terms encompassed four steps: (1) recognizing the problem associated with the research questions, (2) conducting a systematic literature search, (3) reviewing the articles to identify a theme, and (4) analyzing the theme critically. The following search terms were used: Autism Spectrum Disorder, children with autism, effects of education program, educational

intervention, parenting stress, coping mechanism, and coping strategies. Also, the search terms entered were a combination of "Autism" OR "Autism spectrum disorder" AND "education program", "education programs" AND " parenting stress", "coping mechanism" OR "coping strategy" AND "education programs".

Inclusion and Exclusion Criteria

As for inclusion criteria, articles must fulfill the following: They must be published in the English from 2000 to August 2018, they examined parenting stress, coping mechanism or coping strategies as primary outcome variables (at least one or both).

Studies examining parents of children with other developmental disabilities were excluded in the present review.

Process of Selecting Relevant Studies

All studies retrieved from the search procedure were reviewed for study scope by examining the objectives of the studies closely. Authors from the present study independently reviewed the articles identified. They also analyzed and prepared extensive notes in an attempt to summarize the research purposes, methods, tools, main findings, and recommendations. They reached a final decision based on study criteria.

All articles were found in English language with full text/methodology section available. Seventeen studies were found. Nine studies were not taken into consideration because they recruited parents of children with other developmental disabilities.

As a result, the search strategy identified 8 articles in accordance to study criteria as stated in the present review. Figure 1 shows the process of selecting relevant articles using the PRISMA.

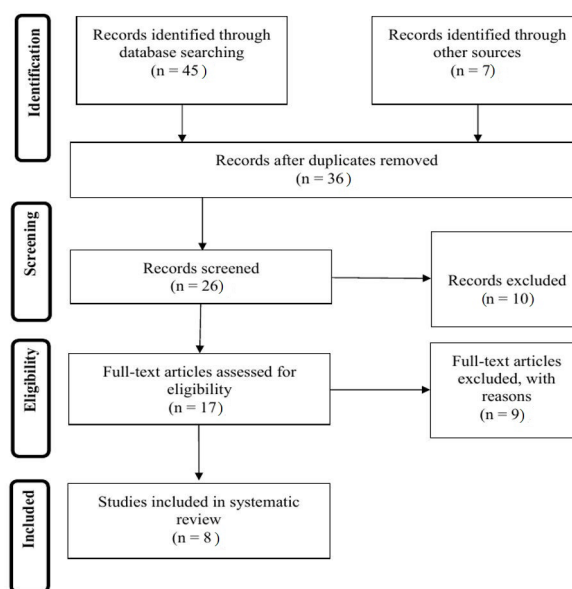


Figure 1: PRISMA flowchart for studies selection process

RESULTS

Effectiveness of educational programs on parenting stress and coping mechanism

Educational intervention programs are effective for improving and enhancing knowledge of parents (24). According to Schultz et al. (24), parental education is designed to provide parents with information and skills to reach family functioning. Chiang (25) also noted that educational intervention programs should not be only aimed at improving family functioning but also assisting parents in developing coping skills. As noted by Al-Khalaf and colleagues (20), improvements in managing coping styles among both parents are predictive of positive ASD children outcome.

Tellegen and Sanders (26) stated that parental education programs have a direct influence on both parents and children (in particular, social and communication skills). Multi-intervention strategies are often used. They include lecturing on specific topics (e.g., definition and etiology of ASD, on factors associated with parental stress, on principles of managing behaviors, on positive discipline to adapt with disorder, on coping strategies, and on strategies to promote social skills and communication and to manage parenting stress. Delivery methods include group discussions, problem-solving tasks, role-play session, homework, and small group activities to build social support among parent participants (25, 27).

This review was based on 8 studies. These studies were either randomized controlled trial or quasi-design studies (Table I).

The Use of Parenting Stress Index (PSI) as an Outcome Measure

Keen et al. (2), in their experimental study with a pre-post-test design, evaluated the effectiveness of an educational program among 39 parents of children with ASD (intervention group, n = 17; control group, n = 22). The intervention group received an educational program comprising a 2-day workshop and a 10-day consultation based-home visits. The workshop delivered information about autism, social, communication, and behavior problems, as well as strategies to encourage familial interactions and to improve social and behavior problems. Educational strategies include handling problems with attention, imitations, and turn-takings. Also included were augmentative and alternative communication approaches, environmental arrangements, and offering choices. All these educational strategies were delivered through the use of PowerPoint. In their study, the PSI was used to assess stress. Participants completed the scale at the beginning of the study and immediately after completing the workshop. Results of the study have indicated a statistically significant decrease in stress among parents after receiving the educational program.

Sarabi-Jamab and colleagues (29) reached a similar

conclusion in their pre-post study involving 21 mothers of preschool children who were diagnosed with an ASD. Participants were randomly allocated to an educational skill training intervention program or a control group without any intervention. Participants' stress scores at baseline, immediately after the program, and then a follow-up after 70 days. Stress scores were assessed by the PSI. Results of the study indicated that after post-test and follow-up mothers who received the educational program had a decrease in the PSI scores.

Home-based Educational Programs

Like Keen et al. (2), Bendixen et al. (28) conducted a quasi-experimental study to examine a educational program on stress reduction involving 38 parents (fathers n = 19, mothers n = 19) of children with ASD before and after a home-based educational program. The program consisted of 12 sessions. It focused on strategies to improve social and communication problems among ASD children. Data were obtained at the baseline study and immediately after the last session of the educational intervention program. As indicated by the Parenting Stress Index-Short Form (PSI-SF), parents reported lower mean scores of stress at the post-test compared to the pre-test.

Studies Involving Mothers and Fathers as Participants

In a randomized controlled education program for parents of children with ASD, Tellegen and Sanders (26) randomly assigned 64 participants into an educational program or usual care. In their study, parents' stress as assessed by the Parental Stress Scale (PSS) was administered at three time-points: pre-intervention, post-intervention, and six months follow-up. The educational program was effective in reducing stress level in participants from intervention group.

In Chiang's (25) study, participants received an educational program lasting 4 sessions. The first section included a lecture on understanding ASD. Participants learned effective ways to improve social and play skills, communication skills, and academic skills and to reduce undesirable behavior. The program was partly based on special education system teaching parents regarding functional skills, community resources, coping strategies, opportunities, and outcomes for children with ASD. The program also included group discussions and role-play sessions. The program was concluded with sharing personal experience of parenting a child with ASD. Results of the study revealed that participants reported a decrease in parenting stress after receiving the educational program.

Studies Involving Mothers as Participants

Hemdi and Daley (21) conducted an experimental study to evaluate the effects of an educational program in a sample of 62 mothers of children with ASD. Mothers from the intervention group received an educational program consisting of five sessions (each session

Table 1: The effectiveness of an educational program on parenting stress and coping mechanism among parents of children with ASD

Authors & Year	Study Design	Participants	Intervention & Duration	Dependent Variables	Follow-Up	Results
Ergöner-Tekinalp & Akkuk, (31) 2004	Experimental Study – Randomized controlled trial (RCT)	20 mothers of children with ASD were assigned to control group (n = 10) ; and intervention group (n = 10).	The educational program included four-sessions. It focused on understanding stress and its effects, problem-solving skills, positive thinking, social support, coping strategies, and relaxation training.	Parenting Stress & Coping Mechanism	No follow-up	No statistical differences in stress and coping scores between two groups. Only a significant difference in social support between two groups at post-test.
Keen et al.(2) 2010	Experimental Study- RCT	39 parents of children with ASD (intervention group = 17; control group = 22).	The educational program consisted of a workshop for 2 days followed by 10 days consultation based-home visits. Control group received DVD information about the strategies presented in the two-day workshop attended by the intervention group.	Parenting Stress	No follow-up	A decrease in stress among intervention group.
Bendixen et al (24) 2011	Quasi-Study.	38 parents of children with ASD (fathers, n = 19; mothers, n = 19).	The program consisted of 12 sessions. It focused on strategies to improve social and communication problem among children.	Parenting Stress	No follow-up	Parents reported lower mean scores of stress at post-test compared to pre-test.
Sarabi-Jamab et al. (30) 2012	Semi-Experimental/ pre-post test design.	21 mothers of preschool children who diagnosed an ASD were allocated randomly to 1 of the 2 groups: an intervention group and control group.	An educational training program was delivered to participants from intervention group. Mothers received eleven sessions of training. Participants from control group did not receive without any intervention.	Parenting Stress	Follow-up after 70 days	Intervention group reported lower stress scores after post-test and after follow-up.
Al-Khalaf et al.(22) 2014	Quasi-Study.	10 mothers of children with ASD.	The educational program consisted of four sessions. Each session lasted for 4 hours.	Parenting Stress & Coping Mechanism	No follow-up	A decrease in stress at post-test compared to pre-test. An increase in coping scores at post-test compared to pre-test study.
Chiang , (27) 2014	Quasi- Study.	9 families of children with ASD.	The educational program lasted 10 (each session lasted for an hour and twenty minutes). Each session consisted of four sections. A total of 10 topics were delivered during this program. The first section included lectures about understanding ASD, teaching social and play skills, learning communication skills, teaching academic skills, recognizing the challenging behavior, This section also included special education system teaching functional skills, community resources, coping strategies, opportunities, and outcomes for individuals with ASD. The second section included group discussions and role-play sessions associated with weekly topics were conducted. The third section included one or two parents sharing their own experience of parenting a child with ASD. The fourth section included one or two parents sharing information about what they felt with other families.	Parenting Stress	No follow-up	A decrease in stress after receiving the educational program.
Tellegen & Sanders, (28) 2014	Experimental Study- RCT	64 parents were assigned randomly to 1 of 2 groups: intervention group (n = 32) and control group(n = 32).	The educational program included four sessions to address one or two specific problems. Session durations ranged from 15 to 105 minute. Control group received usual care.	Parenting Stress	Follow-up after six months	A decrease in stress for participants from intervention group.
Hemdi & Daley, (23) 2017	Experimental Study- RCT	62 mothers were assigned to intervention group (n = 32) or control group (n = 30).	The educational program delivered through Whatsapp application consisting of five sessions (each session lasted for half an hour), handout of an educational program were distributed among participants from interventional group. Control group received only advice about behavioral problems pertaining to children.	Parenting Stress	Follow-up after two months	Participants from intervention group reported a lower level of stress compared with those from control group.

Abbreviation : ASD = Autism Spectrum Disorder ; RCT= Randomized Controlled Trial

lasted for half an hour) through the use of WhatsApp application. Mothers in the control group received only advice about behavioral problems pertaining to children from their organization. Hemdi and Daley (21) showed that mothers who received educational program via Whatsapp reported a lower level of stress compared with those from the control group.

Parenting Stress and Coping Mechanism as Study Outcomes

There is a paucity of studies examining the effectiveness of an educational program on parenting stress and coping among parents of children with ASD. In Ergöner-Tekinalp and Akkuk’s study (30) involving 20 mothers of children with ASD. Participants were randomly

assigned to intervention group (n = 10) or control group (n = 10). The educational program included a 4-session educational program focusing on understanding stress and its effects, problem-solving skills, positive thinking, social support, coping strategies, and relaxation training. Participants’ scores on the Questionnaire on Resources and Stress (QRS) and the Coping Strategy Indicator (CSI) were collected at the baseline and immediately after the educational program. Only a statistically significant difference in social support subscale, one domain of coping mechanism, was reported between the two groups at post-test.

Al-Khalaf et al. (20) evaluate the effectiveness of a 4-session educational program on reducing stress and

on improving coping among 10 mothers of preschool children with ASD. Participants' scores on the Parenting Stress Index-Short Form (PSI-SF) and the Coping Strategy Indicator (CSI) were collected at the pre and post-programs. There were significant changes in stress and coping strategy among participants before and after the programs.

DISCUSSION

There are effective ways to cope with stressful situations deriving from internal and external demands (31). According to Lazarus and Folkman (32), individuals employ their behavioral and cognitive abilities to manage and deal with stressful situations. Coping methods can be divided into two types: problem-based coping—strategies applied to solve the problem or to change the source of stress, and emotion-based coping—strategies applied to reduce or manage feelings associated with the main stressor (32). Hence, effective coping mechanism could play a vital role in mastering, reducing, or tolerating stress, leading an adaptive or maladaptive process (1).

Here, we reported a systematic review to evaluate the effectiveness of educational programs on parenting stress and coping mechanism among parents of children with ASD. The effectiveness of the educational programs on parenting stress and coping mechanism among parents of children with ASD was reported, but there is no agreement on their duration and frequency. The findings by this systematic review provide support for the effectiveness of educational programs to reduce parenting stress and improve coping mechanism in parents of children with ASD. Eight studies met the inclusion criteria. Seven of the eight studies reported that educational intervention programs were effective in reducing parenting stress and improving coping mechanism among parents of children with ASD. However, only one study indicated that there was no difference in parenting stress and coping mechanism among parents who received an educational program. This systematic review has provided preliminary findings for the effectiveness of educational programs to reduce parenting stress and improving coping mechanism among parents of children with ASD. The role of nurses is unique. As they play multiple role as an educator, counselor, and researcher, nurses could help in promoting health, health education, physical, intellectual, and emotional well-being within the context of communities. They can also directly involve in providing care for parents and children with disabilities by delivering educational program.

Evidence for the effectiveness of educational programs to reducing parenting stress and improving coping mechanism among parents of children with ASD was at a preliminary level. Past studies did not use a standardized tool for assessing parent stress, hinting

at the presence of method variance and measurement bias. Various tools were used in the reviewed studies including the Parenting Stress Index-Short Form, the Questionnaire on Resources and Stress, and the Parental Stress Scale. The present review is also limited to several methodological issues. Only databases such as CINAHL, Springer, Ovid, PubMed, Google Scholar, and EBSCO host were included. It is plausible that both parents may be stressful placing them both at a risk for negative psychological health outcomes. Previous studies have recruited mothers as sole study informant. Father's involvement is still lacking, leading to the loss of information to identify paternal stress. Only a small body of research focused on both parenting stress and coping mechanism as primary outcomes. Most studies often used a quasi-experimental design. Their sample sizes were relatively small and had no follow-up assessment. Taken together, what we concluded in the present review should be regarded as preliminary in part due to (1) the limited articles concerning the effectiveness of educational programs and (2) the publication bias where only studies with significant findings were published.

We offered a few directions for future research endeavour. Firstly, it is recommended to include articles published in Scopus and Cochrane. Secondly, future researchers can adopt a wider review by investigating the effectiveness of educational programs with the incorporation of other existing interventions such as cognitive behavior therapy and mindfulness-based interventions. Thirdly, as randomized controlled trial (RCT) represents the gold standard for examining the effectiveness of an intervention, future researchers are recommended to perform RCT whenever possible. We know from the literature that quasi-experimental design has no random assignment thus compromising internal validity. Fourthly, future research should examine the effectiveness of educational programs by using fathers and mothers of children with ASD as informants. Fifthly, the quality of the studies included in the present study was not investigated. Future studies are suggested to evaluate the quality of the eligible studies as per NHMRC level of evidence (NHMRC 2009). Finally, future research needs to assess the effectiveness of educational programs by implementing follow-up assessments. It is suggested that at least a six-month follow-up could provide information about the sustainability and maintenance of effectiveness of educational programs.

CONCLUSION

Studies have documented that educational program could play a key role in reducing parenting stress among parents of children with ASD. This systematic review provides an important opportunity to advance our understanding of the effectiveness of educational programs for reducing parent stress and improving coping mechanism among parents of children with ASD. We offered a few suggestions for future researchers to

advance our knowekdge regarding the effectiveness of educational programs in an attempt to promote parental functioning.

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