

Effect of Child Family Care Pathway Intervention on Managing Autism Spectrum Disorder Behaviors among Children

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Abstract: Background: Children with autism spectrum disorders may experience medical or neurologic, gastrointestinal symptoms, sleep difficulties, behavioral or mental health symptoms that occurs in the most of them. The aim of the study was to examine the effect of child family care pathway intervention on managing autism spectrum disorder (mothers' knowledge, stress, confidence, coping level and children behavior outcome). Method: Design: A quasi-experimental research design was utilized. Setting: The study was conducted in pediatric psychiatric out-patient clinic at Mansoura University Hospital, Egypt. Sample: It composed of 63 autistic children and their mothers. Tools of data collection: -I: Mothers constructed interviewing questionnaire, II: Child behavior checklist, III: The Coping Health Inventory for mothers-Parents, IV: The Confidence Degree Questionnaire for Families/ mothers, and V: Parenting Stress Instrument Index Results; Minority 7.9% of studied mothers have highly coping level during dealing with autistic children pre intervention, which increased to be three quarter 74.6% & 79.4% respectively have high coping level immediately after and 3 months' post pathway intervention. Mothers reported that their autistic child's behavior had slightly improved after pathway intervention related to anxious, depressed, withdrawal, social problems, somatic complaints, thought problems, attention problems, aggressive and rule-breaking behavior. Also it was found that the one third of studied autistic children were ranged in borderline behavior range pre child family pathway intervention, which slightly improved to 42.9% and 41.3% respectively) were ranged in borderline behavior range immediately after and 3 months' post pathway intervention with statistical significant differences. Conclusion: All mothers participated in the current study, seeing behavioral changes in themselves and their children. Implications for Practice: Development of free to access supportive services to autistic children and their families in Egypt, for example early diagnosis and counseling parents.

Keywords: Autism Spectrum Disorder- Child/Family Care Pathway- Intervention.

1. INTRODUCTION

Autism is defined as severe disorder of childhood marked by impaired communication, impaired social functioning and repetitive behaviors and delay in language (Lauritsen, 2013; Grzadzinski et al., 2013; American Psychiatric Association, 2013). The parent having a new child with disability is considered a stressful situation, the whole family's life, needing a wide range of coping strategies. Parents of children with autism spectrum disorder(ASD) reported more stress compared to parents of normally developed children and nearly 3 times more liable to psychological ill health and distress (DePape and Lindsay, 2015; Gau et al., 2012). Increased parenting stress is attributed to the need of providing persistent supervision and assisting for the daily living skills of the child, constant sleep disruption, deficiency of available respite care and lack of responsiveness by school staffs (Kuhaneck et al., 2015).

An epidemiological study revealed that the incidence of ASD all-over the world was increased and reported 1 in 150 children(Posar& Visconti, 2017);while in the United Kingdom was one in 100 children (McConkey, 2020). Whereas in the United States the prevalence of ASD is approximately 1 in 54 children. This prevalence is more than 1% (11.3 per 1000 or 1 per 88 children) and that male/female ratio is about 4/1 (ASD is more seen among boys, 18.4 per 1000, that is 1 in 54 boys while in girls the prevalence was 4.0 per 1000, that is 1 per 252 girls), That means boys are four times more likely to be diagnosed with autism than girls (CDC, 2020). The increase in ASD in the United States is necessitate slowdown that increase by finding more therapeutics to manage ASD more efficiently (CDC, 2020).

Tell now, there is no accurate prevalence of autism in the Middle East and nationally documented. The number of people with autism in Egypt is estimated at 800,000, according to the Social Solidarity Ministry. one in every 160 children shows signs of ASD and the rate among men is times that recorded in women. (Al-Masry Al-Youm, 2017).

There are no such guidelines for children with ASD. Previous research has shown that parent-training programs based on the individual-difference relationship can improve the developmental abilities, communicative development, adaptive functioning, and parents' parenting skills of children with ASD (Meng-Hsin Ho and Ling-Yi Lin, 2020).

Call for action urgently for a clinical pathways (CPs) for medical, nursing psychologist and clinicians, specifically for management of children who have ASD. The clinical pathways provide clinicians with critical steps in guidance on the choice of appropriate management. These clinical pathways are adapted for each specific patient (Kinsman, Rotter, James, et al., (2010).

The concept of a pathway means the right people, doing the right things, in the right order at the right time to achieve the desired outcomes for the child focus on the key tasks that require their level of expertise. The effects of an personalized intervention for children with (ASD) which encourages caregivers to follow their child's interests ,emotions and interaction with them in a normal social environment which encourage the child to develop social communication skills(Helena, Reis, Ana, Pereira & Leandro, Almeida, 2018). The study outcomes for patients who receive the ASD education demonstrated enhancements in care during their stay, improves patient transitions to less limiting care environments after discharge, continue to work to increase accessibility to evidence-based family supports and keep them integrated in the community (Paige Cervantes, 2021).

Pediatric and community health nurse are playing many roles for caring ASD ,one of those roles is health education. The parents and siblings of those children need to be educated on different aspects of autism so nurses should be experts in finding the excellent strategies that an autistic children and their families are benefited in addition to their supportive role in relieving stress and keeping appointments for regular follow up visits which assists in improvement of the autistic child behaviors (Ooi et al., 2016).

Significance of the Study

Autism is a lifelong disorder that most of the children's mothers have to live and care for their children on their own continually. Decreasing mothers' stress, includes being mindfully aware about the disease and how to deal with their autistic children (Ruparelia et al., 2016). In Egypt, caring for autistic child can be overwhelming for mothers, due to the services are minimal. Autistic children and their families face the possibility of poor health, mental health service, social care, lack of special education, rehabilitation and access to equal opportunities. A key problem among the mothers of autistic children to identifying and diagnosing ASD is insufficient knowledge and awareness(Gobrial et al., 2018).

To receive a proper diagnosis and management of ASD, a child must have an integrated multi-disciplinary assessment and integrated family care intervention "child family care pathway" as designed and implemented by the researchers , see Figure (1).

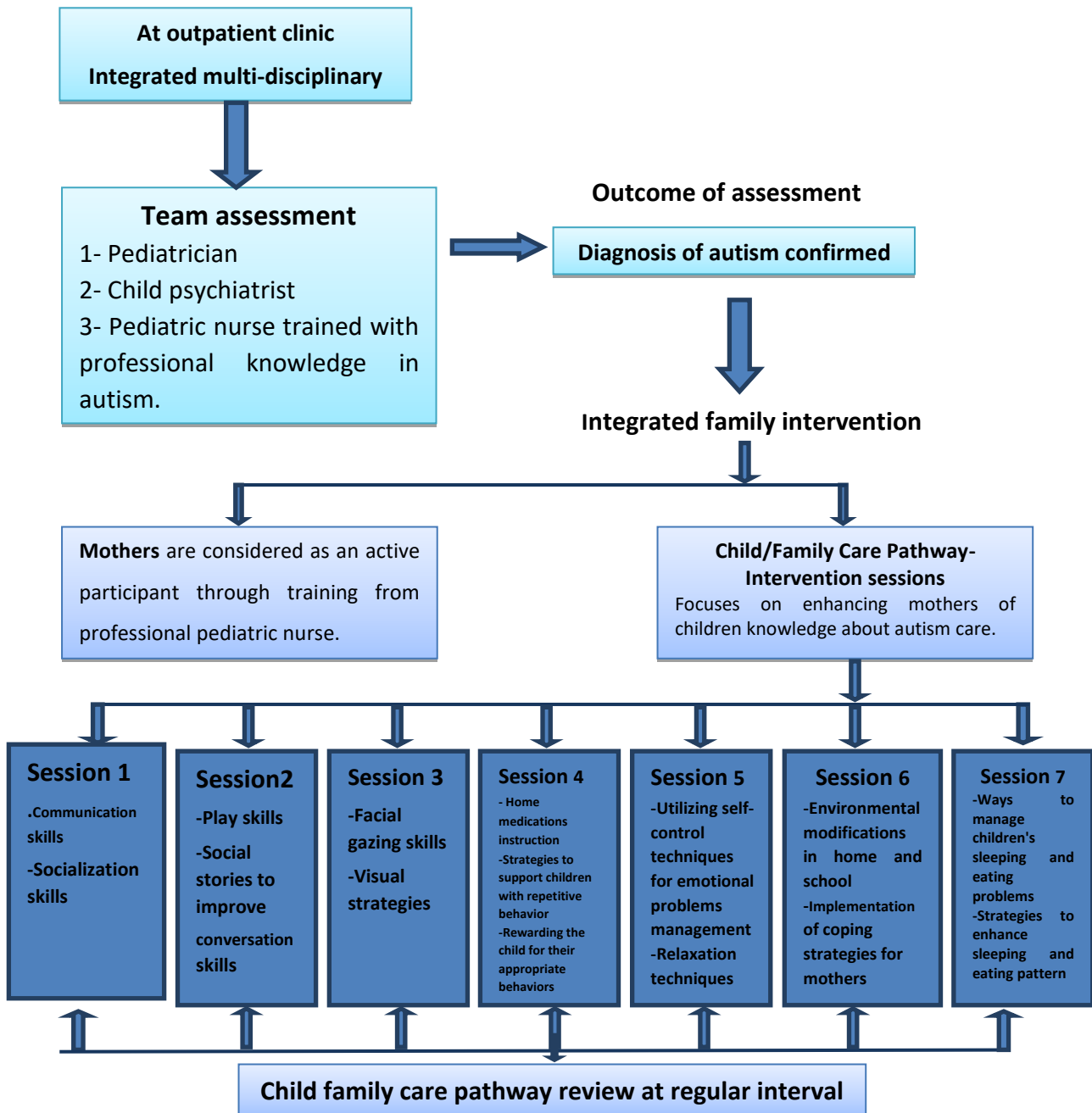


Figure I: Theoretical Framework for Child Family Care Pathway Intervention for Autistic Children

Aim of the study

The aim of the study was to examine the effect of child family care pathway intervention on managing autism spectrum disorder (Mothers' knowledge, stress, confidence, coping level and children behavior outcomes).

Research hypotheses:

1. Mothers, who participated in the child family care pathway intervention, will have a significant improvement in their knowledge than before child family pathway intervention.
2. Mothers, who participated in the child family care pathway intervention, will have lower feeling of stress, high level of confidence and coping than before child family pathway intervention.

3. A significant decreasing in undesirable child behaviors through increasing participation in activities and interaction with people after child family care pathway intervention.
4. There is a significant improvement in children' behavior range outcomes after child family care pathway intervention.

2. SUBJECTS AND METHOD

Design

A quasi-experimental research design was used in this study "one group pre and post-test".

Setting: The study was conducted in pediatric psychiatric out-patient clinic at Mansoura University Hospital. The pediatric psychiatric out-patient clinic was received pediatric patients with psychiatric and mental disorders.

Subjects

A controlled randomized trial suggests was used to assess the effectiveness of intervention about autism on children behavior outcomes and their mothers'/ parent knowledge, stress, confidence and coping level. Based on findings of previous study (**Miranda et al., 2019**), considering the level of significance of [5%] and power of the study of [80%], with a two-tailed study design, the following formula can be used for the sample size calculation:

$$n = [(Z_{\alpha/2} + Z_{\beta})^2 \times \{2(SD)^2\}] / [\text{mean difference between the two groups}]^2$$

where

SD = Standard deviation

$Z_{\alpha/2}$: This depends on level of significance, for 5% this is 1.96

Z_{β} : This depends on power, for 80% this is 0.84

Therefore,

$$n = [(1.96 + 0.84)^2 \times \{2(7.01)^2\}] / (3.5)^2 = 62.9$$

Based on the previous formula, the required sample size is 63 and it composed of 63 autistic children and their mothers whom were selected after fulfilling the inclusion criteria:

Inclusion criteria:

- Both gender
- Children aged from six to sixteen years.
- Children had confirmed diagnosis for autism

Exclusion criteria:

- Children with speech delay or with cognitive deficit.
- Children suffer from hearing loss.
- Child with mental retardation or with chronic diseases.
- Mothers and their children were attained previous educational program about autism care.

Tools of data collection: - to collect the data in this research there are five tools were used.

Tool I: Mothers constructed interviewing questionnaire: -

The tool was developed by the researchers after reviewing literatures regarding evidence-based practice care for children with autism and their parents, (**Norfolk Country Council, 2016: American Psychiatric Association, 2013**), it was included three parts:

Part 1: Demographic characteristics and clinical data of children include; age, gender, age of child at diagnosis, child order in family, school grads, type of education center/school, types of treatment (medications, speech, behavioral & others), family history for autism and sibling with developmental disorders.

Part 2: Socio-demographic characteristics of mothers include; age, residence, educational level, employment, marital status, number of children and types of family system (nuclear or joint).

Part 3: The Parental Knowledge Index (PKI) questionnaires was designed by researchers based upon the review of the literatures and the proposed guidelines, (Matthewsetal., 2018; Leadbitter et al ., 2018) to assess mothers' different knowledge aspects about autistic children and their care, it was consisted of five areas of knowledge and each area had 10 questions regarding (nature of autism; appropriate intervention approaches to autism; nature of the child's diagnosis and understanding of the child's behaviors; Knowledge about the interventions that the mother considered it effective with her child, including types of treatment (medicine, behavioral& speech therapy) and knowledge about the services provided to the autistic children and also, sleeping and eating problems.

Scoring system:

The PKI was developed with four categories, each of the five categories was consisted of 10 true or false, multiple choice & open-ended questions, correct answer scored (1) and incorrect answer scored (zero), the total score 50 marks, the mothers' level of knowledge was classified [poor if the score percent was less than (60 %), fair knowledge from (60 % to less than 75%) and good knowledge if the percent score was $\geq 75\%$ Matthews et al., (2018).

Tool II: Children' Behaviors Checklist (CBCL)

This checklist was developed and validated by Achenbach & Edelbrock, (1983). It is a caregiver-report measure of the child's perceived competencies, which designed for the evaluation of children aged 6 – 18 years and used to determine behavioral and emotional problems in autistic children and adolescents. It was consisted of 2 subscale "internalizing and externalizing behaviors ", which including a 113 item that measured (internalizing and externalizing behaviors). Internalizing behaviors reveal mood disturbances, including (anxious, withdrawn, depressed, and somatic complaints). Externalizing behaviors reveal violation of social norms and conflict with others, including (the aggressive behavior and rule-breaking). The CBCL was categorized into 8 syndrome scales, comprising (anxious or depressed, withdrawal, depressed, social problems, somatic complaints, thought problems, attention problems, aggressive behavior and rule-breaking behaviors).

Scoring system:

Each item was scored 1-2 on a three-point Likert scale (Zero= absent, 1= sometimes occurs, 2= often occurs). The total score 226 equal 100%, total problems score including (summarizing all internalizing and externalizing problems scores), higher scores point to greater degrees of behavioral and emotional problems. The total scores can be explained as [*normal, borderline, or clinical behavior*]. Any score that falls below the 93% was considered normal range, scores between the 93-97% was considered borderline range, and score above the 97% considered the clinical range Achenbach & Edelbrock, (1983).

Tool III: The Coping Health Inventory for mothers - Parents (CHIP)

It was developed by McCubbin et al., (1983), to assess coping patterns of parents have a child who is chronically and/or seriously ill. It includes 45-item divided into 3 subscales and measuring 3 different coping patterns as ; coping pattern (1) which assessed (maintaining family integration, cooperation, and an optimistic definition of the situation) and comprised from 19 items that focused on family life strengthening, relationships and the parents' view on life with a chronically ill child as the mothers said 'trusting husbands support to help mothers and their children . Coping pattern (2) which assessed and measuring (maintaining social support, self-esteem, and psychological stability) and consists of 18 items that focuses on parents' efforts to establish relationships with others, participate in activities that promote feelings of individual identity, self-worth and strategies to deal with psychological tension and pressure as 'participating in relationships and friendships which assist mothers feel important and appreciated'. Coping pattern (3) which assessed (understanding the healthcare situation through communication with other parents and consultation with the healthcare team) and was comprised from 8 items which focused on the parents' relationships with healthcare professionals and other parents of chronically ill children as the mothers said 'talking with the medical and nursing staff when mothers visit the medical clinic'. Higher subscale scores indicate greater help of coping patterns.

Scoring system:

Every item of CHIP has 4 response categories on a Likert scale of (zero–3), with zero indicating {not helpful}, 1 indicating {minimally helpful}, 2 indicating {moderately helpful} and 3 indicating {extremely helpful}. The higher the

coping score indicates the increased use of coping. Total score of CHIP 135, the mothers' coping levels were classified into 3 grades: (Mild coping: 0-45, Moderate coping: 46- 90 and high coping: 91-135) McCubbin et al., (1983).

Tool IV: The Confidence Degree Questionnaire (CDQ) for Families/ mothers

It was adopted from Iwasaka et al., (2002). It was comprising 18 statements to assess the confidence degree for parents of children with ASD to provide appropriate care for their children. Each CDQ statement was answered on 5-point Likert scale from [1 to 5], as indicated 1: Not confident, 2: Slightly confident, 3: Neutral, 4: Somewhat confident, 5: Confident. The total score was 90, the mothers' confidence levels were categorized into 3 levels, score 0-30 means poorly confident, indifferent confident if score 31-60, while highly confident state if score 61-90. When the CDQ score was increased, it was indicated that the parent's confidence in relating to care of their children was considered to be increased.

Tool V: Parenting Stress Instrument Index (PSI)

It was adopted from Abidin (1995), it was aimed to measure stress associated with parenting ; identify the sources and different types of stress among parents of autistic children. It had 3 subscales including [Parental Distress (PD); Parent-Child Dysfunctional Interaction (PCDI); and Difficult Child (DC)]; each one of them contain 12 items where the total items were 36-item of self-reported questionnaires. The PD assess parents' perceptions of their behavior including perceived competence, outlooks of social support, marital conflict and life limitations because of the parenting demands, as 'I feel trapped by my responsibilities as a parent'. The PCDI assess the parents' outlook of expectations and relations with their child, as 'My child rarely does things for me that make me feel good'. The DC assess the parents' perceptions of their child's demandingness, temperament, compliance and how a parent perceives their child to be, whether the child is easy or difficult to take care, as 'My child makes more loads on me than most children'. The items of the PSI scale were answered on 5-point Likert scale from 1-5 "1= Strongly disagree, 2= Disagree, 3= Neutral, 4= Agree, 5= Strongly agree". The total score 180 equal 100%, it was classified into three level (typical stress if the score 15 – 80%, high stress scores range from 81 – 89% and clinically significant levels of stress above 90-100%) that suggests a need for professional intervention.

Procedures for Data Collection

Data collection was conducted over a duration of 7th months from beginning of March till the end of September 2021.

- **Validity of tools;** Tools of the current study were reviewed by a panel of 3 expertise in the pediatric and psychiatric nursing before introducing it to the participants to confirm its validity and their notes were considered.
- **The reliability of tools** was tested through Cronbach's alpha test; Knowledge was calculated as 0.79. PSI Test-retest reliability coefficients of the total stress score have been reported to be 0.91, for PD 0.87, for PCDI 0.80 and for the DC sub-scale 0.85. CHIP, each of the three subscales has been (Cronbach alpha = 0.79, 0.79, and 0.71 respectively). CBCL Cronbach's alpha, internalizing 0.90, Externalizing 0.94 & Total Problems Score = 0.97. The Confidence Degree Questionnaire (CDQ) for Families/ mothers, Cronbach alpha = 0.78.
- **Pilot study;** It was done on 10% of the studied mothers and their children (n=7 mothers and 7 children) to measure the clarity, applicability and feasibility of the tools and some changes were done. The pilot sample weren't involved in the study.
- **Ethical considerations;** it was gained from Research Ethics Committee at the Faculty of Nursing, Mansoura University. Also, an official approval was gained from the director of hospital and the head of the psychiatric department after an explanation the study aims, tools, period and the advantages. Additionally, oral approval was gained from the mothers of autistic children after explanation of the study aims and advantages. They were confident about the privacy of the collected data. The mothers were informed about their rights to be accepted or refuse participation of their children without interference with the care given to their children.
- Mothers were interviewed individually to complete the socio-demographic data and their children characteristics, as well as, pre- assessment was done using the previous tools for data collection, in order to obtain the essential data about their children's behaviors, mothers' knowledge, stress level, mothers' confidence about care of their children and coping

level among the mothers of autistic children to carry out this study. The interviewing questionnaire was filled in about 30 minutes.

- **The child family care pathway intervention *Figure (1)*** was designed by researchers to help increasing the mother's knowledge about the ASD characteristics and by training them about practical skills and coping strategies, the intervention was designed to rise the mothers' knowledge, and confidence level, also, improve coping ways and reduce mothers' stress. Different teaching materials and methods were used comprising small lectures, power point presentations, group discussion, video, handout with pictures and role playing.
- **The child family care pathway intervention *Figure (1)*** was concentrated on the 3 major areas of impairment linked to ASD [behavior, communication and social relations,]. The contents aimed at assisting mothers create strategies to deal with usual daily occasions and to develop ways to decrease daily stressful situations when they dealing with their autistic children.
- The researchers were presented in the previously mentioned study setting three days / week from 9 A.m. to 1 P.m. to collect data. The researcher interviewed the mother and their child individually and/or in groups from 2-5 mothers based on the availability of them.
- **The child family care pathway intervention for the mothers;** it consisted of 11 sessions over 11 weeks, 2 sessions for theoretical part includes (knowledge about autism nature, its intervention approaches, sleeping and eating problems) and 9 sessions for practical part includes (verbal & nonverbal communication, conversation skills, facial gazing, play skills and strategies to manage children's eating, sleeping and toilet problems).
- Each session has learning objectives and was taken from 45- 60 minutes, including a brief review about last meeting, a 10 minutes video for mothers and their children playing and practicing skills they have learned, a brief discussion of the new skill and going over notes explaining the skill; a 15-20 minutes session role play the skills through using three strategies, including the *table time* with the researcher modeling and coaching, the children were played specific games based on the target skill following the role-play with the researchers, *a floor play time* for 15 minutes following the child's lead in play and *routine*, try & do all 3 strategies every day. A five minutes' discussion of how to put table time & floor play time into the routines of daily life activities as; meals, dressing, bathing...etc. Also, group discussion led by the researchers to allow mothers / participations expressing their experiences and ways they utilized to reduce their stress.
- **The child family care pathway intervention sessions for mothers & their autistic children: -**

The researchers trained the mothers of autistic child through those sessions to accommodate to the situation and modify the autistic child behaviors: -

Session 1: Greeting and orientation

Welcome, introduction to the intervention, information about ASD and building relationship among the researchers and mothers and between mothers themselves.

Session 2: Focused on understanding the greeting methods and social skills.

Session 3: Focused on understanding communication difficulties in autistic children and social difficulties.

Session 4: Focused on understanding how to extend play invitation.

Session 5: Focused on understanding how to increase the autistic child's facial gazing.

Session 6: Focused on understanding repetitive behavior, sensory processing, helping the children adapt to their home and school environments.

Session 7: Focused on understanding how to ask for help.

Session 8: Focused on how increase the child's ability to follow a hand point, eye point and vocalization.

Session 9: Focused on understanding conversation skills.

Session 10: Focused on understanding emotional problems of ASD children and relaxation techniques.

Session 11: Focused on understanding the autistic children's sleeping and eating problems and its appropriate management.

- **Evaluation of child family pathway intervention:**

Child family care pathway intervention was evaluated before, immediately, and after three months from starting of the pathway intervention using previously mentioned tools of data collection for mothers and their autistic children.

Statistical analysis:

All statistical analyses were performed using SPSS for windows version 20.0 (SPSS, Chicago, IL). All variables with continuous data showed normal distribution and were expressed in mean \pm standard deviation (SD). Categorical data were expressed in number and percentage. The comparisons were determined using one-way analysis of variance (ANOVA) test was used for comparison among more than two variables with continuous data. Chi-square test was used for comparison of variables with categorical data. Statistical significance was set at $p < 0.05$.

3. RESULTS

Table (1). Shows demographic characteristics and clinical data of autistic children who their mean age was 8.4 ± 2.7 years, more than half of the autistic children (54.0%) were male, Mean age of child at diagnosis 5.8 ± 2.3 years, more than half (55.6%) were learned in autism specific school. Regarding types of treatment, it was clear that less than half (42.9%) of autistic children were treated by Behavioral therapy. Concerning family history for autism, it was evident that more than one quarter (27.0%) of them have positive family history for autism.

Table (2). Presents socio-demographic characteristics of studied mothers, the mean age 29.2 ± 5.2 years. Regarding Number of children in family, it was clear that less than two third (61.9%) of the studied mothers have 2- <4 children.

Table (3). Illustrates total mothers' knowledge score about the nature of autism; appropriate child family care pathway intervention approaches to autism; it was found that total mothers' knowledge score level about autism nature and autistic children care was generally improved in immediately and three months post child family care pathway intervention with highly statistical significant differences $P < 0.001$.

Figure (2). Shows the effect of child family care pathway intervention on the mean score of the subscale of mothers' stress index (PD, P-CDI and DC) pre, immediately after and 3 months after child family pathway intervention, it was observed that there are decreases in the mean score of stress subscale immediately after and 3 months after child family pathway intervention among the studied mothers with highly statistically significant difference than pre intervention mean score where $p > 0.001$.

Figure (3). Illustrates effect of child family care pathway intervention on the mean score for mothers' total stress index pre, immediately after and 3 months after child family care pathway intervention. It was clear that their significant decrease in mean score for mother's total stress index immediately after and 3 months after child family care pathway intervention among the studied mothers with highly statistically significant difference than pre intervention mean score $p > 0.001$.

Figure (4). Illustrates total score of mothers' stress levels, it was clear that two third 65.1% of studied mothers have high stress level pre-child family care pathway intervention, which decreased to less than one quarter (19.0 & 17.4 respectively) immediately after and 3 months' post child family care pathway intervention with highly statistical significant differences $P < 0.001$.

Table (4) Presents total score of mothers' confidence levels, it was found that about one quarter (30.2%) of studied mothers have highly confident level to provide care for their autistic children pre-child family care pathway intervention, which increased to be (68.3% & 79.4% respectively) of them immediately after and 3 months' post child family pathway intervention with high statistically significant differences ($P < 0.001$).

Table (5). Show effect of child family care pathway intervention on the mean score of coping subscale types among studied mothers pre, immediately after and 3 months after child family pathway intervention. It was observed that there are increases in the mean score of coping subscale types and in the total mean score of coping immediately after and 3 months after child family pathway intervention among the studied mothers with highly statistically significant difference than pre intervention mean score $p > 0.001$.

Table (6). Illustrates effect of child family care pathway Intervention on studied mothers' level of coping pre, immediately after and 3 months after child family pathway intervention. It was clear that minority 7.9% of studied mothers have highly coping level during dealing with autistic children pre-child family pathway intervention, which

increased to about three quarter and majority (74.6% & 79.4% respectively) of them have high coping level immediately after and 3 months' post child family pathway intervention with highly statistical significant differences $P < 0.001$.

Table (7). Presents effect of intervention on the mean score of eight subscale of children behavioral and emotional problems pre, immediately after and 3 months after child family care pathway intervention as reported by mothers. It was observed that, mothers reported that their autistic children's behavior had slightly improved after the child family pathway intervention related to anxious, depressed, withdrawal, somatic complaints, thought problems, social problems, attention problems, aggressive behavior and rule-breaking behavior with statistically significant differences ($p < 0.05$).

Figure (5). Illustrates effect of child family care pathway intervention on total score level of children behavioral and emotional problems pre, immediately after and 3 months after child family pathway intervention as reported by mothers. it was found that only one third (34.9%) of studied autistic children were ranged in borderline behavior range pre- child family pathway intervention, which slightly improved to (42.9% and 41.3% respectively) of them were ranged in borderline behavior range immediately after and 3 months' post child family pathway intervention with statistically significant differences ($P < 0.05$).

Table (1). Demographic Characteristics and Clinical Data of Studied Autistic Children (n=63)

Demographic characteristics of autistic children	N = 63	
	No.	%
Age in years		
6 - < 8 years	30	47.6
8 - < 12 years	26	41.3
12 - ≤ 16 years	7	11.1
Mean ± SD	8.4 ± 2.7	
Gender		
Female	29	46.0
Male	34	54.0
Age of child at diagnosis		
< 6 years	38	60.3
6 - < 12 years	25	39.7
Mean ± SD	5.8 ± 2.3	
Child order in family		
First	6	9.5
Second	17	27.0
Third	22	34.9
Fourth or more	18	28.6
School grads		
Primary school	36	57.1
Preparatory school	20	31.8
Secondary school	7	11.1
Type of education center/school		
Ordinary school	10	15.9
Special education school	35	55.6
Autism specific school	18	28.6
Types of treatment		
Medications	21	33.3
Speech therapy	15	23.8
Behavioral	27	42.9
Family history for autism	17	27.0
Sibling with developmental disorders (sibling n= 57)	14	24.6

Table 2. Socio-Demographic Characteristics of Studied Mothers (n= 63)

Socio-demographic characteristics of studied mothers	No = 63	
	No	%
Age in years		
< 20	9	14.3
20 - < 30	23	36.5
30 - < 40	22	34.9
≥ 40	9	14.3
Mean ± SD	29.2 ±5.2	
Residence		
Urban	40	63.5
Rural	23	36.5
Educational level		
Primary	2	3.2
Preparatory	7	11.1
Secondary	12	19.1
Technical institute	23	36.5
Higher education	19	30.2
Mothers' employment		
Housewife	44	69.8
Employee	19	30.2
Marital status		
Married	49	77.8
Widowed	4	6.4
Divorced	10	15.9
Number of children in family		
<2	6	9.5
2- <4	39	61.9
≥ 4	18	28.6
Types of family system		
Nuclear	46	73.0
Joint	17	27.0

Answer the first hypothesis

Mothers, who participated in the child family care pathway intervention, will have a significant improvement in their knowledge than before child family pathway intervention.

Table3. Total Mothers' Knowledge Score about the Nature of Autism and Appropriate Intervention Approaches for Autistic Children Pre, Immediately after and 3 Months after Child Family Care Pathway Intervention (n=63)

Variables	Pre-pathway		Immediately after pathway		3 months after pathway		Chi square test	
	No.	%	No.	%	No.	%	X ²	p
Mothers' knowledge about the nature of autism								
Poor (<60 %)	38	60.3	3	4.8	4	6.3		
Average (60- <75%)	16	25.4	10	15.9	8	12.7		
Good (≥ 75%)	9	14.3	50	79.4	51	81.0	87.319	<0.001**

Mothers' knowledge about appropriate intervention approaches to autism

Poor (<60 %)	44	69.8	6	9.5	5	7.9		
Average (60- <75%)	11	17.5	8	12.7	8	12.7		
Good (≥ 75%)	8	12.7	49	77.8	50	79.4	86.800	<0.001**

Mothers' knowledge about nature of their child's diagnosis and understanding of their child's behaviors

Poor (<60 %)	45	71.4	5	7.9	4	6.3		
Average (60- <75%)	10	15.9	12	19.1	12	19.1		
Good (≥ 75%)	8	12.7	46	73.0	47	74.6	90.379	<0.001**

Mothers' knowledge about effective intervention for their children

Poor (<60 %)	47	74.6	4	6.3	4	6.3		
Average (60- <75%)	11	17.5	10	15.9	11	17.5	104.41	
Good (≥ 75%)	5	7.9	49	77.8	48	76.2	7	<0.001**

Mothers' knowledge about services provided to the autistic children & sleep & eating problems

Poor (< 60 %)	42	66.7	4	6.3	4	6.3		
Average (60- <75%)	15	23.8	9	14.3	8	12.7		
Good (≥ 75%)	6	9.5	50	79.4	51	81.0	97.476	<0.001**

Total knowledge

Poor (< 60 %)	44	69.8	5	7.9	6	9.5		
Average (60- <75%)	13	20.6	10	15.9	10	15.9		
Good (≥ 75%)	6	9.5	48	76.2	47	74.6	88.592	<0.001**

**Highly statistically significant $P < 0.001$

Answer the second hypothesis:

Mothers, who participate in the child family care pathway intervention, will have lower feeling of stress, high level of confidence and coping than before child family pathway intervention.

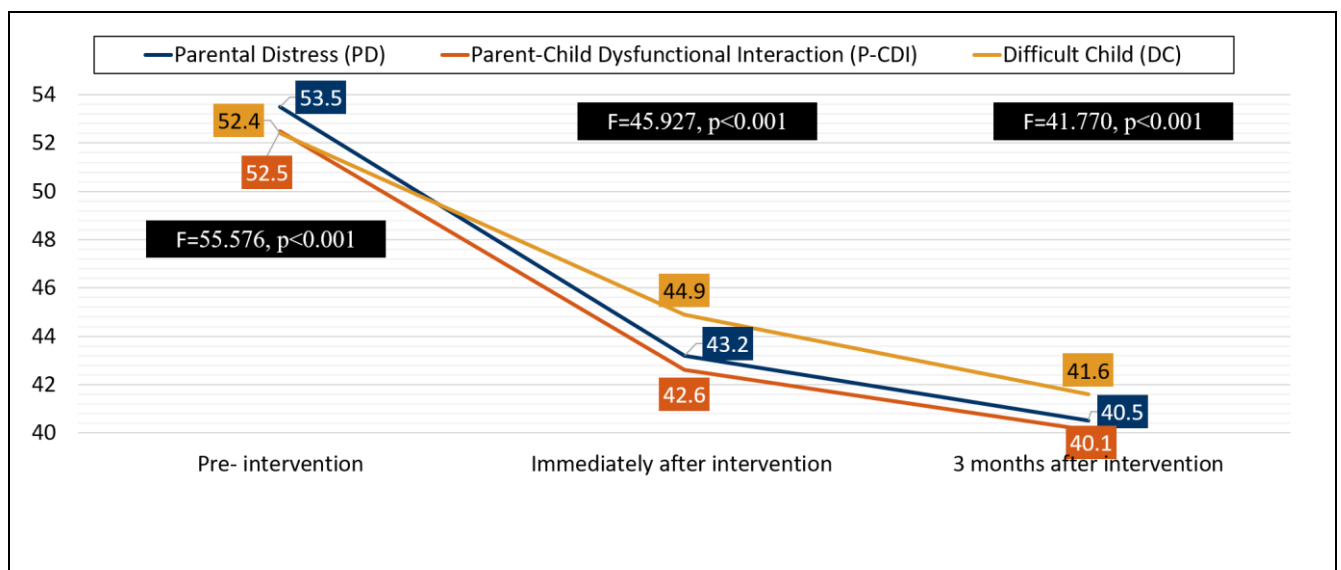


Figure 2. Effect of Child Family Care Pathway Intervention on Mean Score the Subscale of Mothers' Stress Index Pre, Immediately after and 3 Months after Pathway Intervention (n= 63)

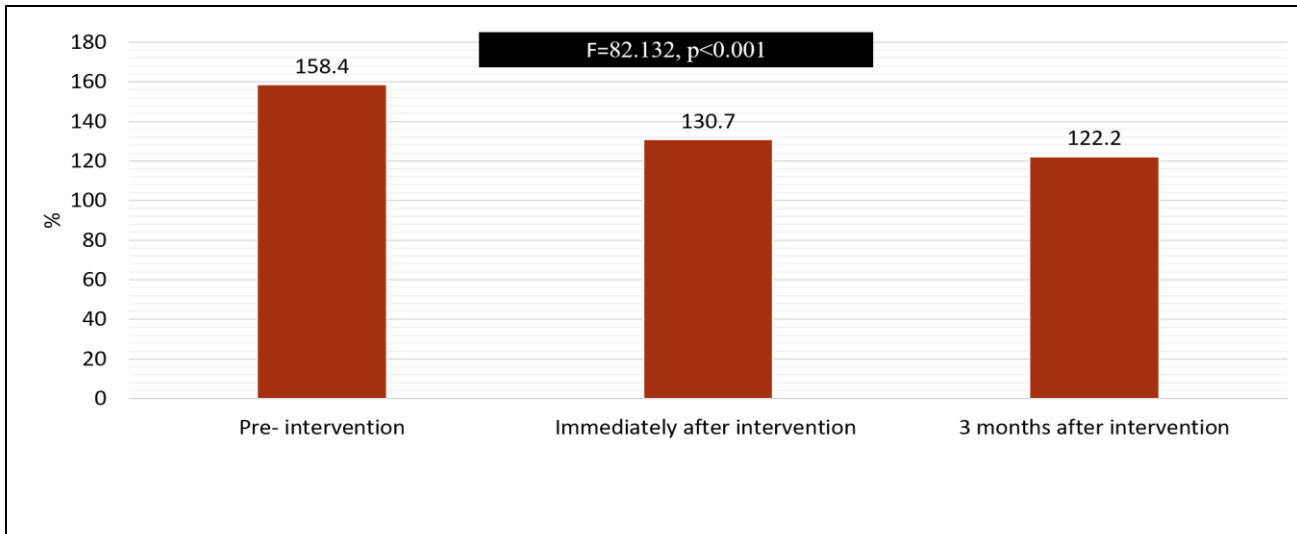


Figure 3. Effect of Child Family Care Pathway Intervention on the Mothers' Total Stress Index Pre, Immediately after and 3 Months after Pathway Intervention (n= 63)

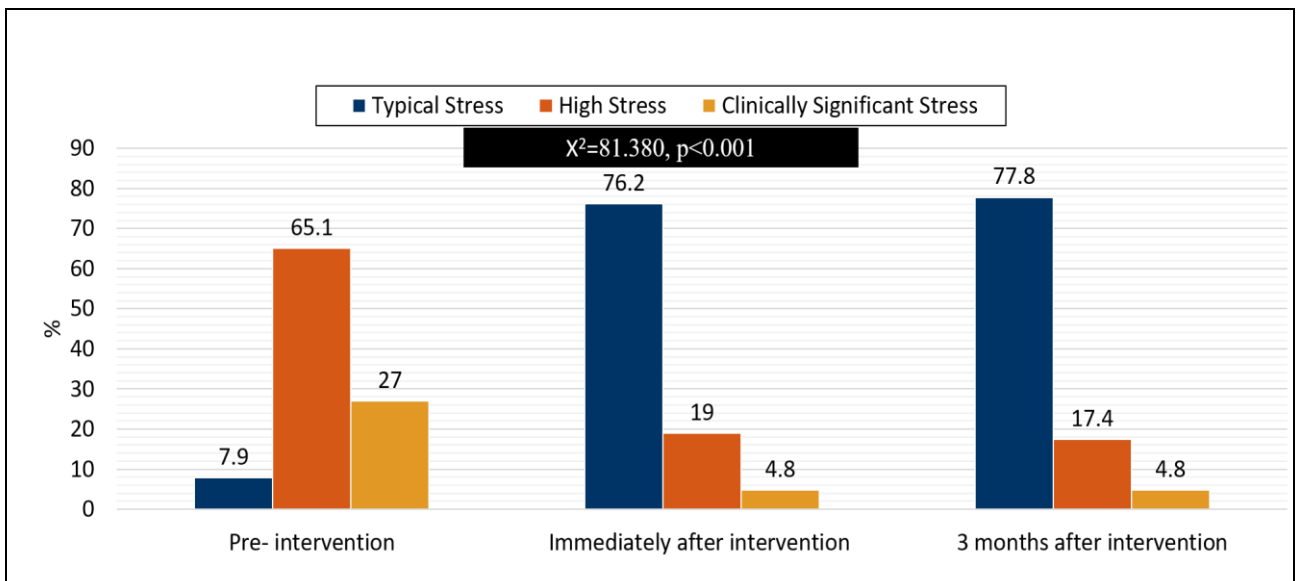


Figure 4. Effect of Child Family Care Pathway Intervention on the Total Score of Mothers'/Parent Stress Levels Pre, Immediately after and 3 Months after Pathway Intervention (n= 63)

Table 4. Effect of Child Family Care Pathway Intervention on the Total Score of Mothers' Confidence Levels Pre, Immediately after and 3 Months after Pathway Intervention (n= 63)

Variables	Pre- pathway		Immediately after pathway		3 months after pathway		Test of significance	
	No.	%	No.	%	No.	%	X ²	p
-Poorly confident state (0 – 30)	38	60.3	14	22.2	5	7.9		
-Indifferent confident state (31 – 60)	6	9.5	6	9.5	8	12.7		
-Highly confident state (61 – 90)	19	30.2	43	68.3	50	79.4	45.192	<0.001**

**Highly statistically significant P <0.001

Table 5. Effect of Child Family Care Pathway Intervention on the Mean Score of Coping Subscale Types among Studied Mothers Pre, Immediately after and 3 Months after Pathway Intervention (n= 63)

Variables	Pre- pathway	Immediate after	3 months after	ANOVA test	
	(n= 63)	pathway (n= 63)	pathway (n= 63)	F	p
	Mean ±SD	Mean ±SD	Mean ±SD		
-Maintaining family integration, co-operation, and an optimistic definition of the situation	18.5 ±8.9	38.5 ±10.8	44.1 ±12.6	96.533	<0.001**
-Maintaining social support, self-esteem, and psychological stability	17.9 ±8.6	36.4 ±9.1	41.6 ±11.4	102.277	<0.001**
-Understanding the healthcare situation through communication with other parents and consultation with the healthcare team	7.4 ±3.6	14.1 ±5.2	18.6 ±6.6	71.844	<0.001**
Total score of coping	43.8 ±19.1	88.9 ±14.3	104.3 ±18.1	208.315	<0.001**

**Highly statistically significant P <0.001

Table 6. Effect of Child Family Care Pathway Intervention on Mothers' Level of Coping among Studied Mothers Pre, Immediately after and 3 Months after Pathway Intervention (n= 63)

Variables	Pre- pathway		Immediately after pathway		3 months after pathway		Test of significance	
	n	%	n	%	n	%	X ²	p
- Mild coping (0 – 45)	48	76.2	5	7.9	4	6.3		
- Moderate coping (46 – 90)	10	15.9	11	17.5	9	14.3		
- High coping (91 – 135)	5	7.9	47	74.6	50	79.4	103.856	<0.001**

**Highly statistically significant P <0.001

Answer the third hypothesis

A significant decreasing undesirable child behaviors through increasing participation in activities and interaction with people after child family care pathway intervention.

Table 7. Effect of Child Family Care Pathway Intervention on the Mean Score of Eight Subscale of Children Behavioral and Emotional Problems Pre, Immediately after and 3 Months after Pathway Intervention as Reported by Mothers (n= 63)

Variables	Pre- pathway	Immediately	3 months after	Test of significance	
	intervention	after pathway	pathway	X ²	p
	Mean ±SD	Mean ±SD	Mean ±SD		
Anxious/depressed	53.6 ±12.9	48.9 ±10.8	47.2 ±10.3	5.338	0.006*
Depressed (withdrawal)	56.2 ±12.2	53.2 ±12.8	49.8 ±10.3	4.628	0.011*
Somatic complaints	57.6 ±12.6	53.2 ±10.5	51.2 ±11.7	4.992	0.008*
Social problems	53.7 ±14.1	49.5 ±11.3	47.5 ±9.8	4.479	0.013*
Thought problems	55.5 ±13.8	53.3 ±11.7	49.0 ±10.7	4.676	0.010*
Attention problems	55.7 ±11.8	52.9 ±12.6	50.1 ±11.3	3.481	0.033*
Rule-breaking behavior	53.8 ±13.8	51.0 ±9.8	48.1 ±8.5	4.280	0.015*
Aggressive behavior	52.1 ±10.4	49.9 ±9.6	47.6 ±9.2	3.358	0.037*
Total score	438.2 ±74.2	411.9 ±76.0	390.5 ±73.4	6.427	0.002*

* Statistically significant p ≤ 0.05

Answer the fourth hypothesis

A significant improvement in children' behavior range outcomes after child family care pathway intervention.

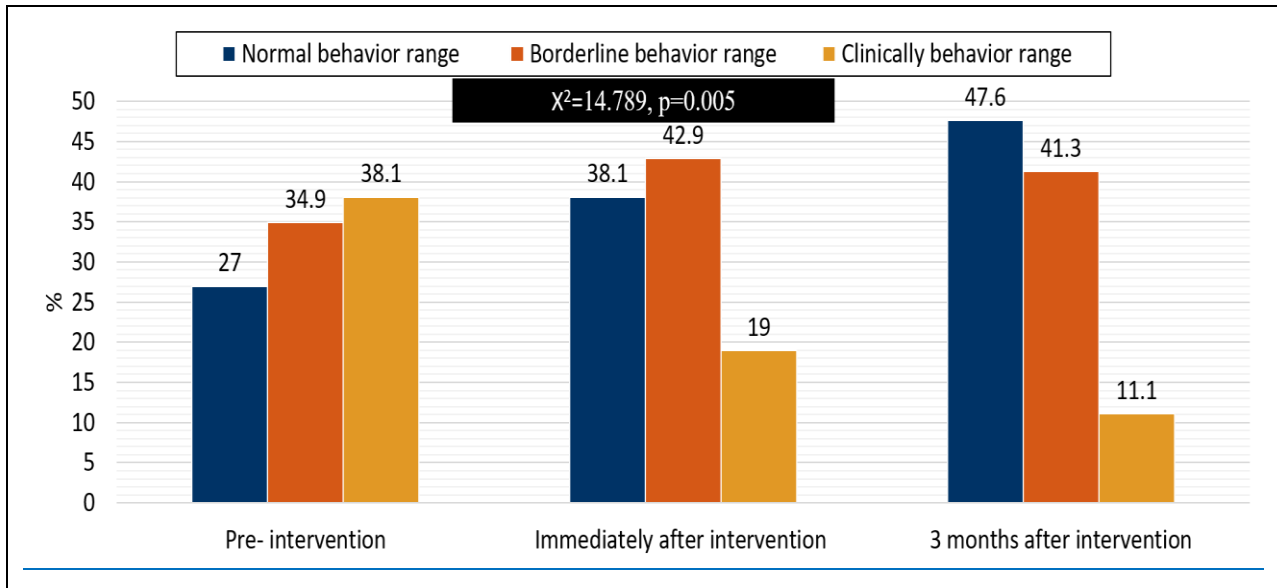


Figure (5). Effect of Child Family Care Pathway Intervention on Total Score Level of Children Behavioral and Emotional Problems Pre, Immediately after and 3 Months after Pathway Intervention as Reported by Mothers (n= 63)

4. DISCUSSION

The psychological impact of caring for autistic child is described to be massive for parents. Parents of autistic child have more stress than parents of typically developing children (TD) and were about 3 times as vulnerable to psychological ill and distress (Gau et al., 2012). Increased parenting stress is refer to the need to supply steady supervision and assist in the routine daily skills of the child, persistent sleep disruption, insufficiency of available respite care and deficiency of responsiveness by school staff and regarding services (Kuhaneck et al., 2015). The aim of this study was to examine the effect of child family pathway intervention on managing autism spectrum disorder (Mothers' knowledge, stress, confidence, coping level and children behavior outcomes).

The results of current study were revealed that more than half of the studied autistic children were males (Table1), indicating a higher prevalence of ASD in males than females. This result was in the same direction with Baba, (2015) who stated that the boys are four times more likely to have ASD than girls. Additionally, Centers for Disease Control and Prevention, (2012) mentioned that diagnosis of ASD across all ethnicities and races, occurs five times more often among males than females. Also, Ratto et al, (2018) who stated that the correct ASD ratio was 3:1 male to females' ratio, and suggested that there perhaps a higher genetic factor for ASD in females relative to males. Also, hormonal effects have been hypothesized to play a role in the ASD etiology and in the observed sex differences in occurrence. high levels of fetal testosterone have been implicated in the ASD development, and there have been certain results of higher levels of testosterone in autistic female as compared to typically developing female (Bargiela et al., 2012). This could be attributed to males are genetically predisposed to having ASD compared to females.

Regarding to age of child at diagnosis, it was found that about two third of children were diagnosed with autism less than six year of age, this could be attributed to early childhood period characterized by early social interaction with others, so that, the child behaviors are easily observed by mothers, this lead to early diagnosis in early age years, this result supported by Simsek and Koroglu, (2012) who concluded that half of autistic children were diagnosed from 1-5 years.

The finding of the current study found that the mothers' mean age was 29.2 ±5.2 years. Concerning studied mothers' educational level, it was found that more than one third of them were technical institute. Regarding mothers' employment more than two third of them were housewife (Table2). This might be concerning the challenges of autistic children care,

meanwhile they may need persistent educational intervention and health caregivers' supervision. Mother with low educational experience about care of autistic children may be not able to perform the proper care and the facilities of health care. This result was congruent with (Amr et al., 2012) who concluded that most of families with autistic children have low socio-economic standards with insufficient income, this study stated that housewives tend to more repeatedly reports that their children exhibited further autistic symptoms and problems contrast to the working mothers. It has been revealed that autistic children whose mothers were working may have better understanding about autism, more financial resources and arrival to therapeutic care and registration in regular or special education schools in Egypt.

Answer hypothesis number one regarding to mothers' knowledge, this study illustrated that the level of mothers' knowledge about autism nature and autistic children care were generally improved in immediately and three months after the child family pathway intervention, compared to majority of studied mothers were poor knowledge pre-intervention. There was a highly statistically significant differences in total scores of mother's knowledge immediate and 3 months after than pre-intervention (Table3). This result was supported by Al-Khalaf, et al., (2014) who mentioned that, their study program focused on help mothers create strategies to deal with typical daily occasions and to promote ways to decrease stress in daily situations. through enhancing the mothers' knowledge about autism characteristics and through supply them with practical skills, knowledge and strategies, the educational program was intended to improve the mothers' knowledge, perceived control and confidence. Also, this result was supported by Preece & Trajkovski., (2017) they were concluded that a positive educational intervention resulting in improved parents' knowledge about ASD, reductions in stress and anxiety and improved coping post health education intervention compared to pre- health education intervention implementation. The differences between the later results may be attributed to lack of knowledge and lack of attending specific program about care of autism, the mothers' knowledge was improved after intervention, this due to good and clear communication with the studied mothers during the intervention and outcome of the different teaching materials and methods which used in the intervention. As well as, the majority of mothers were housewife, who have lack chance for interaction with their coworkers who shorten the exchange of perceptions and knowledge about autistic children care.

Answer the second hypothesis as regards have lower feeling of stress, high level of confidence and coping than before intervention, (Figures 2,3 &4) showed that there are decreases in the mean score of stress subscale and in the total mean score of stress immediately after and 3 months after intervention compared with pre intervention. This result was in the same line of Tint, & Weiss, (2016) they were documented that there raised level of stress, depression, fatigue and anxiety in parents of autistic children. Also, this result was agreement with Al-Khalaf, et al., (2014) who found that parents of autistic children are possible to have more stress than parent of child with other developmental disabilities, this stress can be clinically levels. As well as the current finding was supported by Lilly & Tungol., (2015) who concluded that the post-intervention test for parent stress shows the mean scores and standard deviation values of parent stress in experimental group was reduced than parent in control group. Those variations in the results could be attributed to mother's stress is a result of alterations between anticipations mothers have for themselves and for their children, compared with what is really experienced due to child diagnosis with autism, which decreased after the researchers' explanation for autistic children behaviors criteria and how to deal with their children behaviors, as well as educate the mothers about coping strategies to deal with stress.

Regarding mothers' confidence, the current study illustrated that minority of studied mothers have highly confident level to provide care for their autistic children pre the child family pathway intervention, which increased to majority of them immediately after and 3 months' post intervention with high statistical significant difference $P < 0.001$ (Table4). This result in the same direction with Shimabukuro et al., (2020) who stated that multiple sessions group-based program for families of ADHD lead to increase mothers understanding of ADHD, lead to enhance confidence in their ability to implement care and improve their psychological well-being. Also, this result was congruent with Okuno et al., (2016) who stated that greatest of the mothers and their autistic children stated discomfort when educated to force their children's social skills at the start of the simultaneous training with a focus on social skills improvement course; however, the mothers' confidence score in relating to their children care was increased after intervention course compared with before intervention. This might be attributed to lack of mothers' knowledge about appropriate care for their autistic

children that improved after intervention and thereby improved their confidence to provide care for their autistic children accordingly, concerning the mean score of coping subscale types and mothers' level of coping among studied mothers pre, immediately after and 3 months after intervention (**Tables 5&6**), the current study presented that there are increases in the mean score of coping subscale types and in the total mean score of coping, also, increase in mothers' level of coping immediately after and 3 months after intervention among the studied mothers with highly statistically significant difference than pre intervention mean score $p > 0.001$. This result was supported by **Amireh, (2019)** who revealed that the most commonly used coping strategies among parents of children with autism and Down syndrome in Jordan after intervention. Inadequate research has been conducted in Jordan on this topic but identify the parent's stress stages and coping strategies aids specialists to helps parents to recognize these matters more deeply and better dealing with parents. Also, this result was confirmed by the results of **Vernhet, (2019)** who stated that parents of autistic children use coping strategies that help overcome the challenging circumstances of raising their child, and he was observed that communication with other parents with autistic children and seeking of social support are an effective coping strategy for parents of autistic children. Matching of Those results may be due to the intervention improve mothers' attention, enhance their tolerance of unpleasant feeling, and encourage communication with other parents and thereby effective coping.

Answer third hypothesis about decreasing in undesirable child behavior, the mean score of eight subscale of children behavioral and emotional problems pre, immediately after and 3 months after child family pathway intervention; mothers reported that their autistic child's behavior had slightly improved after the implementation of the intervention related to anxious, depressed, withdrawal, social problems, somatic complaints, thought problems, attention problems, aggressive behavior and rule-breaking behavior with statistically significant differences ($p < 0.05$) (**Table7**). This finding was confirmed with **Bearss et al., (2015)** who concluded that a 24-week parents training program was superior to parent education for reducing autistic children disruptive behaviors on parent-reported outcomes. Also, the current finding was supported by **Peterson et al., (2019)** who mentioned that analysis of the autistic children with post-intervention data showed that the CBCL aggressive behaviors scale decreased to non-clinically significant levels by post-intervention and statistically significant improvement in all CBCL scales. Also, this result was agreed with **George and Sakeer, (2013)** who reported that there is statistical significant enhancement in the autistic children's behavior after application of the awareness program for parents. On the other hand, the result of the present study was incongruent with **Okuno et al., (2016)** who concluded that their no progress in the child's behavior was observed in high-functioning children with ASD during the follow-up period; however, enhancements were seen in peer relationships and social skills. This could be due to the current study intervention focused on training the mothers to appropriate strategies to dealing with their autistic children and the written handout of the care items which comprise a pictures which serves as constant reference, as well as training for autistic children to modify disruptive behavior and encourage them to build social relationship with others.

Answer hypothesis number four; an improvement in children' behavior range outcomes after child family pathway intervention whereas the total score level of children behavioral and emotional problems pre, immediately after and 3 months after intervention ; one third of studied autistic children were ranged in borderline behavior range pre child family pathway intervention, which slightly improved, but still in borderline range immediately after and 3 months' post intervention with statistical significant differences (**Figure 5**). This finding was supported by **Danial et al., (2013)** they stated that cognitive behavior therapy has been demonstrated to be effective for a group of problems including anxiety disorders, depression, eating disorders, drug use problems, and reduce their anxieties, fears and develop impulse control, which lead to improves their behavior and improvements in social relationship. Also those results was in line with **Meng-Hsin Ho and Ling-Yi Lin (2020)** who reported that, children and their parents in the group of parent-training programs about autistic children showed significant greater enhancements in child's emotional development and parenting skills more than those in the control group after the 14-week period. This improvement of the current study results might be attributed to the comprehensive content of the clinical pathway intervention, which contain a pictures which assists as constant reference, encouragement of ask questions, mother's attentiveness and willingness to know. Also, the mothers were gratified with the content of the intervention and they attempt to implement intervention steps to improve their autistic children's behaviors. Also, the mothers were educated and skilled in the intervention with numerous techniques to arouse the desired behavior of the autistic children. Also, **Donnelly, Cervantes, Okparaek, Stein,**

Filton, Kuriakose, Havens, & Horwitz (2021) who studied “staff perceptions and implementation fidelity of an autism spectrum disorder care pathway on a child/adolescent general psychiatric inpatient service. They found that staff identified visual communication aids and reward care pathway on a child/adolescent strategies as most helpful.

5. CONCLUSION

Child family pathway intervention affect positively in improving mothers' knowledge, confidence, stress and coping abilities for provide high confident care that improve autistic children behavior outcome.

6. IMPLICATIONS FOR PRACTICE

Development of supportive free access services through availability of web sites / different social media tools to autistic children and their families in Egypt that facilitates early diagnosis, counseling parents, education of school aged children in free suitable schools, community living arrangements for children, social and leisure time activities that aids in maintaining for ASD children quality of life.

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