


ORIGINAL ARTICLE

The impact of health counseling education program among Sudanese mothers on coping with autistic children

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ABSTRACT

Autism spectrum disorder is a collection of developmental abnormalities that can lead to significant social, communicative and behavioural challenges. A nurse is critical in establishing a parent's level of autism awareness and coping skills. Our purpose was to evaluate how a parenting program for mothers influenced their ability to manage with autistic children. Quasi-interventional research, before and after the program was done. A total of 70 mothers of autistic children were enrolled in Khartoum State's five autism centres. The Short Form Parenting Stress Index was used to measure the level of stress and burden experienced by mothers caring for children with autism. The study showed that 31.4% of mothers had a good score in physical care skills before the intervention and 50.0% after the intervention. The mean scores of stresses pre-training 134.48 decreased to 64.1 post

training program. In the pre-training program 42.90% of the mothers used problem focus coping strategy and the post-training program represented 92.85%. The educational health and counselling program played an important role in improving mothers' ability to cope with their autistic children.

KEYWORDS

Health counselling; Health education; Autistic children; Autism; Sudan.

INTRODUCTION

Autism spectrum disorder (ASD) is a group of developmental disorders that may result in significant social, communication and behavioural challenges [1-3]. ASD is currently defined as 'a single disorder that involves disturbances that were previously thought segregated autism, Asperger's syndrome, childhood disintegrative disorder, and developmental disorder not

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Received: 03 July 2021 | Accepted: 19 February 2022

How to cite this article:

Sidig EA, Aljohani KA, Fadlalmola HA, Hamed RA. The impact of health counseling education program among Sudanese mothers on coping with autistic children. Sudan J Paediatr. 2022;22(1):19–26. <https://doi.org/10.24911/SJP.106-1625340484>

otherwise specified' by the American Psychiatric Association's Diagnosis and Statistical Manual of Mental Disorders (DSM-5) [4]. Although the name 'Asperger syndrome' is no longer in the DSM, the term 'spectrum' in ASD alludes to the range of symptoms and severity [5].

ASD is estimated to affect between 500,000 and 1 million children between 6 and 17 years in the United States and 10's of millions around the world [6]. Furthermore, according to official figures, autism prevalence rates have risen from 10% to 17% every year in recent years [7].

Whether it is career counselling or coping with emotional tragedy, counselling is a scientific procedure that many individuals embrace. Counselling makes it much easier to seek expert help [8,9].

It is recommended that nurses have further educational preparation in order to care for patients with intellectual disabilities and/or autism [10]. Counsellors are educated to listen with empathy and can help people in dealing with unpleasant thoughts and feelings [8]. In the lack of qualified health specialists, many families turn to dealing with the disease with the support of friends and neighbours who have comparable situations [11]. A nurse plays a crucial role in evaluating parents' and families' awareness of autism, coping capacities, access to support groups or resources, and desire to use these services [12].

The implications and difficulties associated with having an autistic kid, impact family connections and social life [13]. Programs were implemented to improve parents' understanding of the early symptoms of ASD (red flags) and the effect of having a child with ASD [14].

The purpose of the study was to evaluate the effects of the counselling program for mothers on coping with their autistic children after the implementation of the health education program.

MATERIALS AND METHODS

Study design and participants

This is quasi-interventional one-group research conducted before and after the test to evaluate the

impact of counselling for mothers dealing with autistic children at autism centres in Khartoum City, Sudan. This research covered all five autistic centres. The purposive-sampling strategy was used to choose a total of 70 mothers on coping autistic children dealing with autistics for this cross-sectional research. The autistic children involved in the study range in age from 3 to 12 years.

Questionnaire

The instrument used to collect data from the sample population for this study was a set of interview questions approved by the Research Review Board of the Faculty of Nursing Sciences of the University of Khartoum for the protection of human subjects. Parenting stress index (PSI) was used to assess the stress of mothers in caring of their autistic children, The PSI within the family system, detects dysfunctional parenting and predicts the likelihood of parental behaviour issues and kid adjustment challenges. The PSI may be utilized with parents whose children are 12 years old or younger, despite its major concentration on pre-schoolers [15].

Concerned with assessment of children dependency in the activities of daily life we used Assessment of Activities of Daily Living, Self-Care, and Independence [16]. Also, we used Family Impact of Childhood Disability Scale according to their adjustment. Its goal was to examine mothers' subjective interpretations or first impressions of children with developmental impairments in family systems, as well as their influence on the family as a whole [17].

Data analysis

SPSS software version 25.0 was used to statistically analyse the data. The distribution of demographic characteristics was determined using descriptive statistics. Means and standard deviations were used to report continuous variables. Absolute numbers and percentages were used to express categorical variables.

RESULTS

A quasi-interventional pre- and post-test was undertaken in Khartoum City to study the effects

of counselling for mothers coping with their autistic children. Complete data were obtained from 70 mothers from intervention group in pre and post phases. Demographic characteristics for the autistic children sample, as presented in Table 1, revealed that 67.10% of the children with autism were boys, age for 57.1% ranged from 3 to 5 years, and 52.90% of children were ranked as first child.

The demographic characteristics for the mothers presented in Table 2 denote that 60% was first degree marital relation, 28.6% of mothers' age ranged from 35 to 39 years, and 60.0% were working mothers. Most of them (67.1%) had 1-3 rooms, 62.9% were nucleus families, and the family size ranged from 5 to 7 persons in 30.0%.

The study looked at whether mothers' abilities in physical, social, motor, and emotional care of their autistic children altered between pre- and post-counselling and training programs, as shown in Table 3. To determine the satisfaction of mothers' relationships with their autistic children, the findings revealed that 42.9% of mothers were content with their autistic children's pre-intervention, whereas all moms were satisfied with autism.

Table 4 demonstrates that the children were completely reliant on their mothers in all elements of daily life, including eating, mobility, walking, clothing, bathing, elimination and communication

skills. Before the program, they had a score of 1 (1.4%) for cooperating, communicating, and participating effectively, while after the program, they improved to 6 (8.6%), followed by clothing and walking [before 22 (31%) and 40 (57%) vs. after 34 (48.6%) and 45 (64.3%), respectively]. There were also statistical disparities between the before and post program in addition to pre- and post-testing.

DISCUSSION

According to the pre-assessment (base line data) which was carried out at the beginning of the first counselling program workshops, it was found that the mothers have poor knowledge about autism. Most of them mentioned some types of autism, but they were not aware about signs and symptoms, nature of the disease, and different types of treatment including the importance of treating their children. Also, they did not define correctly certain types of autism and did not know the importance of counselling and coping with autism.

The first hypothesis stated that after the intervention there will be a significant difference among the coping strategies on pre-intervention and post-intervention tests. The data were analysed using the percentage of cases that lie on the low, normal and high range. Significant ranges of coping on both pre-training and post-training tests were observed in study population.

In the present study, demands placed on mothers for a child with autism contribute to a higher overall incidence of mother's stress, and anxiety, and adversely affects family quality of life. This is consistent with previous literature conducted in Arab countries, one in Saudi Arabia and the other in Kuwait [18,19].

Moreover, most mothers of autistic children felt they have failed as wives and some others were threatened with divorce or violence. These results were supported by previous studies which stated that women who have children with exceptional needs experience more stress than mothers who do not have special needs children [20].

Table 1. Characteristics of 70 autistic children.

Child age/years	Number	%
3 - <5	40	57.1
5 - <7	12	17.1
7 - <9	7	10.0
9 - 12	11	15.7
Child gender		
Male	47	67.1
Female	23	32.9
Child order		
First	37	52.9
Second	18	25.7
Third	6	8.6
Fourth	5	7.1
Others	4	5.7

Table 2. Characteristics of 70 mothers.

	Number	%
Parents relationship		
First degree	42	60.0
Second degree	19	27.1
No relation	9	12.9
Mothers' age when they delivered their autistic children		
20-24	4	5.7
25-29	19	27.1
30-34	19	27.1
35-39	20	28.6
40-45	6	8.6
> 45	2	2.9
Mother work		
Working	42	60.0
Not working	28	40.0
Number of rooms		
1 - 2	47	67.1
3 - 4	21	30.0
> 5	2	2.9
Family types		
Nucleus	44	62.9
Extended	26	37.1
Family size		
1 - 2	15	21.4
3 - 4	25	35.7
5 - 7	21	30.0
>7	9	12.9

Table 3. Distribution of the 70 studied mothers about physical, social, motor, and emotional care of their children suffering from autism pre-and-post counselling and training programs.

Mothers' care	Good >75%		Average 50%-75%		Poor <50%	
	Pre %	post %	Pre %	post %	Pre %	post %
Physical care skills	31.4	50.0	34.3	21.7	46.2	23.3
Social skills	15.1	48.9	25	41.1	49.9	20
Motor skills	58.6	61.0	22.2	27.6	41.1	37.6
Attention and concentration skills	23.2	35.8	41.3	46.5	35.5	17.7
Communication skills	42.8	48.6	34	34	25.2	20



Table 4. Distribution of 70 mothers according to coping patterns of care for their children with autism to daily living activities.

Items	Pre						Post						Follow up					
	Totally dependent		Semi-dependent		Independent		Totally dependent		Semi-dependent		Independent		Totally dependent		Semi dependent		Independent	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
1. Arranging his/her bed when he wakes up	60	85.7	6	8.6	4	5.7	60	85.7	5	7.1	5	7.1	54	77.1	11	15.7	5	7.1
2. Doing household tasks, including the organization all around	58	82.9	10	14.3	2	2.9	55	78.6	12	17.1	3	4.3	52	74.3	14	20.0	4	5.7
3. Reforming glitches at home including minor repairs around	61	87.1	6	8.6	3	4.3	59	84.3	8	11.4	3	4.3	55	78.6	12	17.1	3	4.3
4. Washing and drying clothes	61	87.1	8	11.4	1	1.4	55	78.6	11	15.7	4	5.7	51	72.9	16	22.9	3	4.3
5. Going to the bathroom and personal hygiene after defecating	31	44.3	18	25.7	21	30.0	18	25.7	19	27.10	33	47.10	18	25.7	21	30.0	31	44.3
6. Cleaning, tooth brushing and oral care, clean nose, bathing	19	27.1	29	41.4	22	31.4	13	18.6	22	31.4	35	50.0	12	17.1	27	38.6	31	44.3
7. Dressing and rearranging or putting things in place after use	19	27.10	29	41.4	22	31.4	12	17.10	24	34.3	34	48.6	11	15.7	28	40.0	31	44.3
8. Walking upstairs	16	22.9	14	20.0	40	57.1	9	12.9	16	22.9	45	64.3	8	11.4	21	30.0	41	58.6
9. Holding the pencil correctly	18	25.7	11	15.7	41	58.6	10	14.3	17	24.3	43	61.4	8	11.4	21	30.0	41	58.6
10. Preparing foods that do not require mixing or cook	61	87.1	6	8.6	3	4.3	55	78.6	9	12.9	6	8.6	54	77.1	12	17.1	4	5.7
11. Mixing and cooking simple foods	63	90.0	7	10.0	0	0.0	61	87.1	9	12.9	0	0.0	57	81.4	13	18.6	0	0.0

Items	Pre						Post						Follow up					
	Totally dependent		Semi-dependent		Independent		Totally dependent		Semi-dependent		Independent		Totally dependent		Semi dependent		Independent	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
12. Preparing a complete meal	64	91.4	6	8.6	0	0.0	63	90.0	7	10.0	0	0.0	58	82.9	12	17.10	0	0.0
13. Processing and organizing the dining table before and after	61	87.10	6	8.6	3	4.3	58	82.9	8	11.4	4	5.7	55	78.6	12	17.10	3	4.3
14. Drinking water or juice from the cup	13	18.6	16	22.9	41	58.6	4	5.7	13	18.6	53	75.7	2	2.9	17	24.3	51	72.9
15. Eating from plates or dishes	11	15.7	18	25.7	41	58.6	5	7.1	12	17.1	53	75.7	2	2.9	17	24.3	51	72.9
16. Washing dishes	64	91.4	5	7.1	1	1.4	58	82.9	8	11.4	4	5.7	53	75.7	13	18.6	4	5.7
17. Cooperating, communicating, and participating effectively	59	84.3	10	14.3	1	1.4	56	80.0	8	11.4	6	8.6	40	57.1	24	34.3	6	8.6

The autistic child has an impact on the family's lifestyle and financial position, but no study to date has looked at the cultural aspects of having a child with intellectual disabilities in the way that we did in this study.

The level of stress in mothers of children with ASD is heightened due to various reasons. It is necessary to be able to cope with worries about the future, grief, and also to be able to find and acquire proper services.

Considering factors related to autism in child and its impact on his/her mother mental health, age of child, age of appearance of first symptom and time lag between appearance of first symptom and diagnosis of autism, the only significant factor was the mean age of autism child, which is consistent with other reports [21].

As regards children's age, more than one half of children's age ranged between 3 and 5 years. This finding is in accordance with other studies which mentioned that the autism typically appears in the first 3 years of life [22], and is to some extent supported by other reports [23].

The results of the present study showed that more than two-thirds of children with autism are boys, similar to other reports which mentioned that autism is four times more likely to appear in boys than in girls [24].

The results of the present study indicate that two-fifths of children with autism were ranked the first child in their families. This result is in agreement with other reports which found that more than two-thirds of children with autism are boys and two-fifths were ranked as the first child [25]. Similarly, as well, when the birth order of the autistic child was examined, it was ascertained that 43.3% were the first-born child, compared to another study which reported that 76.4% were the first-born child [26].

The present study provided evidence that the age of the mothers, number of children, socio economic status and educational level of the mothers significantly affected the kind of coping mechanisms employed by them. This finding is consistent with others' who mentioned that the mothers should be in suitable age to be able to

assume appropriate responsibility toward children because young mothers are usually unprepared psychologically for parenthood [27].

CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

FUNDING

None.

ETHICAL APPROVAL

The mothers of autistic children were reminded by the researchers that the study was completely voluntary and anonymous. To participate in the study, all mothers had to give their informed verbal and written consent. The information obtained was kept in strict confidence. Their freedom to refuse to participate in the study was respected and refusal or withdrawal had no penalties. The Research Review Board of Khartoum University Faculty of Nursing Sciences granted ethical approval, and the administrative committee of the Data Gathering Center gave formal authorization.

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