

Counseling Intervention for Parents of Children with Down Syndrome on their Needs, Stress and Coping Strategies

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Abstract

Background: Having child with disability is a major difficult that negatively affects parents . Down syndrome is one of the most common disabilities that have a negative impact on parents' health and well-being and may force them to evaluate their plans, goals, and relationships in light of restrictions and limitations associated with their children's disability. Parents may experience a need for a counselling intervention for utilize available support resources, or look for alternative ones, as an attempt to adopt strategies to regain their equilibrium between resources and disability needs to cope effectively with stresses associated with their children's down syndrome to alleviate their stress, developing appropriate and effective coping strategies .**The aim of this study** was to investigate the effect of counseling intervention for parents of children with down syndrome on their needs, stress and coping strategies. **Design:** A quasi-experimental design was used to conduct the study. Setting: This study was conducted at the Genes Clinics of Down syndrome in the specialized clinics of the university pediatric hospital affiliated to Ain Shams University Hospitals. **Subjects:** A purposive sample was obtained from fifty parents who accompanying their children with down syndrome in the previously mentioned settings. **Tools of data collection :** Data were collected using the following tools; An interviewing questionnaire to assess parents' socio demographic data and health assessment of children with down syndrome , Family Need Questionnaire to examine the needs of parents of children with down syndrome., Parent Stress Index Scale to measure stress associated with parenting of children with down syndrome , and the Ways of Coping (Revised) Questionnaire to describes a number of thoughts and acts (coping strategies) which used by parents to cope with a threatening situation. **Results:** The study results revealed that there was a highly statistically significant difference between pre and post counseling intervention regarding total level of needs, stress level and coping of parents having children with down syndrome, also there was a positive correlations between studied parents' needs, stress and their coping in pre and post counseling intervention. **Conclusion:** It was concluded that the application of counseling intervention had a positive effect on the improvement of the level of parents' needs, alleviating stress and promote coping strategies among parents of children with down syndrome. **Recommendations:** Conducting psycho-educational training program focused on reducing parental stress and training parent how to deal effectively with their disabled children under stress.

Key words: Down syndrome- Parenting needs -Parenting stress- coping.

Introduction

Down Syndrome (DS) is one of the most common chromosomal disorders in the world, it the most common cause of mental, developmental, and learning disabilities in children. It

describes the condition of genetic disorders that not only discuss the child's physical but also mental/psychological such as moderate retardation, and other medical complications. This condition makes DS children increase difficulties in processing information, the ability to

combine and use language, and increase emotional development (Nurmalita, 2019).

Family is the core in caring for and raising children with mental and physical disabilities. The birth of a child with DS is likely to affect the family system in many ways. Generally, raising a child with DS is associated with higher levels of parental stress, sources of caregiver strain change during the child's lifespan, especially during transitions, more symptoms of depression and anxiety, and poorer health-related quality of life than in family caregivers of typically developing children. Furthermore, children with DS may have greater disease burden, face greater unmet needs, and their families are more likely to report family impacts (e.g. financial problems and loss of employment (Kiami, 2017 and (Gashmard et al., 2020)

The existence of DS children can trigger internal and social problems for parents. Generally, parents of children with DS are having plenty of problems in their life in physical, psychological and social compared to the parents of normal children. Parents of children with intellectual and developmental disabilities as DS are facing lots of fear about their future and their child's future which will have adverse effect on the wellbeing due to inability to cope with this situation. In spite of that some parents accept the reality and tend to lead a positive life it developing their coping skills and self-esteem (Parameswari & Eljo, 2016; Cless, 2017).

Coping strategies can be positive (i.e., leading to less distress) or negative (i.e., leading to more distress) and can be executed behaviorally, such as seeking emotional support, or cognitively, such as attaching positive thoughts to a stressful situation. Coping with a physically or

intellectually disabled child is a highly individual process, and there is evidence to suggest that some families may never adjust fully to this event (Ganjiwale et al., 2016). It requires a cognitive reappraisal of the situation to manage it properly. Positive coping can occur in the form of changed world views concerning life and disability, gaining sense of coherence, and an appreciation of the positive contribution made by children to family members and society as a whole (Choi, 2015). Utilization of effective coping strategies has been identified as an important mechanism of managing parental stress and promoting well-being (Ludlow et al., 2012; & Seymour et al., 2013).

Psychiatric nurses play a crucial role in helping parents to adapt. Successful parents' adaptation occurs when the parents are able to balance the needs of the family, the child with down syndrome, and other family members. Nurses can aid in this balance by providing a safe environment for parents to verbalize their frustrations or conflicting emotions. Having a safe environment to do so means that parents will not be judged for their feelings. Nurses can help parents identify stressors, community resources, coping strategies, and effective means of communication for the entire family (Coren et al, 2018).

Significance of the study:

Down syndrome (DS) is a common numerical chromosome disorder that has burdens on both family and community, it is considered one of the commonest causes of mild to moderate mental retardation in children. The worldwide prevalence of DS is estimated to be 1 in 650 to 1,000 live births (El-attar, 2019). DS not only impedes the development of the child, but also threatens the psychological well-being of

all other family members, especially the parents. Raising a child with DS is a particular challenge for parents (Alexander & Walendzik, 2016). It is one of the most common chromosome abnormalities in humans, the incidence of DS is 1 in every 1000 to 1100 births worldwide (WHO, 2017). In Egypt is 1 in 700 (Eldars, et al. 2013) and this incidence of DS increased in Egypt and became 1:555 (Abou-Youssef et al., 2014). Various descriptions of the problems of parents who have DS children, especially those related to psychological conditions require a solution so that parents can go through a period of difficulty adapting to the condition of their DS child. One strategy to overcome problems faced by parents with DS children is a coping strategy (Duranovic, 2017).

The demand of the parents of children with DS is significantly higher because they must actively participate in the care of the child due to the delay in development, the limitations in activities of daily living related to self-care such as dressing, personal hygiene, walking, and talking, and aspects related to health, education, psychological, leisure and how to cope. So this study aimed to investigate the effect of counseling intervention for parents of children with down syndrome on their needs, stress and coping strategies.

Aim of the study

This study aimed to investigate the effect of counseling intervention for parents of children with down syndrome on their needs, stress and coping strategies.

Hypothesis:

Counseling intervention may have a positive effect on the improvement of the level of parents' needs, alleviating

stress and promote coping strategies among parents of children with down syndrome.

Material and Methods

1-Technical design:

Research design: A quasi-experimental design was used to conduct this study.

Setting: This study was conducted at the Genes Clinics of DS in the specialized clinics of the university pediatric hospital affiliated to Ain Shams University Hospitals.

Subjects: A purposive sample was obtained from (50) parents who accompanying their children with down syndrome in the previously mentioned study settings. The sample size was calculated based on the following formula available at <http://www.ifad.org/gender/tools/hfs/anthropometry>).

$$n = \frac{4p(1-p)}{m^2}$$

Description:

n = required sample size.
4= confidence level at 95%.
p = estimated total number of proportion of the population which has the attribute in question (0.5).
m = margin of error at 10% (standard value of 0.01).

$$n = \frac{4 \times (0.5 \times 0.5)(1-60)}{(0.01)^2} = 50$$

So the sample size would be

50. The subjects met the following criteria:

Inclusion criteria for children with DS:

- Intelligence Quotient (IQ) from (25-70).
- Age :(6-12) years.
- Sex: both sexes.
- Free from another disability

Inclusion criteria for parents of children with DS:

- Have only one disabled child.
- Free from any physical disability or psychiatric illness.

Tools of data collection: -

The tools used in the study for data collection were:

I-An interviewing questionnaire:

it was designed by the researchers, based on the literature review, to assess parents' socio demographic data and demographic data and health assessment of DS child as the following:

a. Demographic data of parents:

It includes data such as; age, sex, residence, level of education, occupation, consanguinity and family size.

b. Demographic data and health assessment of DS child: It includes data related to demographic characteristics of DS child such as; age, sex, education, order of birth and data related to child's category of mental retardation ,physical complains and disabilities and previous hospitalization.

II-Family Need Questionnaire (FNQ): it was originally done by (Waaland, et al., 1993) and modified by (Siklos and Kerns, 2006) to examine the needs of parents having children with Down syndrome. This questionnaire was adapted by the researchers from the original questionnaire which consisted of 23 statements by added 17 new statements concerning with the psychosocial needs of children with Down syndrome from their parent's point of view. So, the overall 40 statements of the questionnaire became included into two parts as the following:

a. The first part includes (23) statements focused on parent's needs.

b. The second part includes physical, psychological, and social needs of children with Down syndrome from their parents' point of view.

Scoring System

The modified (40) FNQ utilizes a 2 -point to indicate the degree that the need is important to the parent or the child from parents view: (1) not important, (2) important. In addition, for each one, the respondent chooses "met" or "unmet". We calculated the sums of participants identifying each statement as important or not important and as met or unmet. Percentages of important needs were calculated by dividing the sum of needs identified as important by the total number of need statements (important needs percentage = number of need statements identified as important/total number of need statements). In addition, need statements identified as both important and unmet were summed, and percentages were calculated by dividing the sum of important unmet needs by the sum of all important needs (important unmet needs

percentage = number of important needs identified as unmet / total number of important needs, the percentage below 60% considered unsatisfactory needs, but more than 60% considered satisfactory needs.

III-Parent Stress Index (PSI)

scale: It was created by (Abidin,1990).The PSI is a 36-item self-reported questionnaire designed to measure stress associated with parenting of children having Down syndrome from 6 to 12 years of age. The scale has three subscales (parental distress, parent-child dysfunctional interaction, and difficult child).Each of the three subscale consisting of 12 items and its aim described as the following, parental distress sub-scale measures parents 'perceptions of their own behavior including perceived competence, marital conflict, views of social support, and life restrictions because of the parenting demands. The parent-child dysfunctional interaction sub-scale measures the parents 'view of expectations and interactions with their child. The difficult child sub-scale measures the parents 'perceptions of their child's temperament, demandingness, and compliance. The items of the scale range from 1(strongly disagree) to 5 (strongly agree).

Scoring System

The overall score of the total parental stress scale was if it below 90 it indicates a low level of stress. But if it was above 90 it indicates significant high level of stress. Meanwhile, total score for parental stress subscale, and difficult child subscale if it was above 33 it indicates high level of stress, meanwhile only for parent child dysfunctional interaction subscale if it was above 27 it indicates a high level of stress. 4) **The Ways of Coping**

(Revised) Questionnaire (WC-R): the ways of coping was originally by (Folkman and Lazarus, 1985) consisted of a (68 items) to describes a number of thoughts and acts (coping strategies) which a person may use to cope with a threatening situation, then it modified by (Knussen et al, 1992) with several changes on the items' content and on the rating form. More specifically, some inconsistent items were omitted and new items were added, and the rating scale changed in a 4-point Likert frequency scale (instead of Yes /No answers). After modification of the questionnaire, it became (66 items) focused on the ways in which parents coped with problems concerning their children with Down's syndrome representing their thoughts and actions which can be used to deal with the demands of a stressful encounter. It divided into five dimensions of coping: Practical Coping, Wishful Thinking, Stoicism, Seeking Emotional Social Support, and Passive Acceptance. Responses of parents rate each item on a four-point, from 1 = ' not used ' to 4 = ' used a great deal '.

Scoring System

Scores on the WC-R were originally obtained by summing the scores of each item in a subscale to produce the score. The percentage below 60% considered negative coping. But more than 60% considered positive coping.

Operational Design:

The operational design included preparatory phase, content validity and reliability, pilot study and field work.

A- Preparatory phase:

It included reviewing current,

past, local and international related literature and theoretical knowledge of various aspects of the study using books, articles, internet, periodicals and magazines to develop tools for data collection.

Validity of the Tools

To achieve the criteria of trustworthiness of the family needs questionnaire in this study, the tools were tested and evaluated for its face and content validity by jury group consisting of (5) experts from different specialties in the field of nursing, (3) professor of psychiatric nursing, faculty of nursing, Ain Shams University, (2) professor of pediatric nursing, faculty of nursing, Mansoura University. The items on which most of the experts have agreed were included in the questionnaire. And the required corrections and modifications were done for some statements as the following; removal of unnecessary or repetitive statement, rephrasing and paraphrasing as exchange from the sentence (To be reassured that it isn't uncommon to have negative feelings about my child's strategies) into (to be able to reassure myself when negative feelings about my child's syndrome comes) ,also, there was exchange from (Help remaining hopeful about my child's future) into (To be easily get information that gives me hope for my child's future), and exchange from (To have professional working with my child to speak to me in terms I can understand) into (To have the skills that enables me to speak and to understand my child). To ascertain relevance and clarity such as use of the sentence and added some statements to cover all aspects of parent needs (physical, psychological and social) regarding their children with Down

syndrome needs as to have the ability to support my child's physical, mental and psychological health throughout his or her life span and to have awareness about the places that providing the suitable services for children with down syndrome , to have aware about the appropriate job for children with down syndrome when they reach to adulthood stage, to know how to deal with my child's psychological problems resulting from his illness as anxiety, Stubbornness and tension. In this procedure, the researcher also translated the instruments from English formats into Arabic language, rendered the same English formats into bilingual experts for more verification of translation of the Arabic formats, the resulting versions were translated back into the original language by other bilingual experts, and minor discrepancies in the content were found and necessary modifications were done.

Reliability of the tools

The measure of the reliability was done on the whole 40 statements of the questionnaire and found that there was a high (Cronbach alpha=.91) which providing evidence of acceptable reliability.

Pilot Study:

The Pilot study was carried out for 10% of the sample (5) parents of children with DS to test the clarity of questions and applicability, of the tools, and the time needed to answer them then the tools were modified according to the findings of the pilot study. Subjects who shared in the pilot study were excluded from the main study sample. The time needed to fill out the tools was about 20 to 25 minutes.

Administrative design:

Official permissions were obtained from the administrators of the Genes Clinics of DS in the specialized clinics of the university pediatric hospital affiliated to Ain Shams University Hospitals. The researchers met the directors in the specialized Clinics, explained the study aim and procedures, and asked for their cooperation.

Ethical consideration:

Ethical approval obtained from the Scientific and Ethical Committee of Nursing Faculty of Ain Shams University. The researcher clarified the aim of the study to the parents included in the study, and anonymity and confidentiality of the data were assured and maintained. The researchers emphasized to parents of children with DS that the study was voluntary and anonymous. They had the full right to refuse to participate in the study or to withdraw at any time without giving any reason. The researchers clarified that all information would be used for scientific research and for the benefits of the parents.

Field Work:

Data collection was carried out through three months, from the beginning of June 2020 to end of August 2020. The interview methods were used for data collection; subjects were interviewed by the researchers, after explaining the aim of the study that was conducted through four phases:

1. Pre-assessment phase. It was done before the implementation of the counseling intervention to identify the parents' and their children needs regarding to Down syndrome.

2. Development of the therapeutic intervention phase.

According to the identified parents' needs; the researchers developed counseling sessions, aimed to support needs of parent having children with DS and improve their coping strategies. Sessions include accurate knowledge about DS, appropriate caring practices toward patient's behaviors.

3. Implementation of counseling sessions' phase:

The researchers interviewed with the parents of children with DS in The Specialized Clinics in the university pediatric hospital affiliated to Ain Shams University Hospitals after the researchers explained the aim and objectives of the counseling sessions to the parents, The intervention program was implemented by classifying the parents of children with DS into 5 groups, each group consisted of 10 parents.

The intervention program was introduced for each group separately due to the small size of the clinics that leads to difficulties in gathering all studied parents at the same time and also due to the implementation of the preventive measures against COVID 19 in the hospital, the selected parents attended to the Genes Clinics daily except on Friday the data was collected during morning and afternoon at the working time of the Genes Clinics of DS from (8.00 Am to 2.00 Pm) after coordination with clinics nurses and security throughout only two days (Monday and Thursday) for the data collection in one of The Genes clinics of DS. The duration of each session lasted from 45 - 60 minutes. Each clinic contains 2 beds and 6 chairs; also it has good ventilation and many light sources. The researchers took the

patients' telephone number at the first interview to determine the next appointments.

The tools of data collection were filled in by the parents or by the researchers when they were not educated. Filling in the tools lasted from 20-25 minutes for each participant. The period of implementation of the counseling sessions was achieved within 10-12 weeks; each session consisted of the following activities: participant's acquaintance, expressing feelings, exchange experiences, interaction with others, training to listen attentively and arrange what the subject wants to say.

At the end of each session, the researchers make conclusion, take feedback from every participant. Also at the beginning of each next session the researchers review and discuss their knowledge about the previous session.

Approach of the researchers during the sessions:

Leaving them expressing inner feelings freely, listening attentively to every subject, control the session, encouragement and involvement, constructive criticism and appraisal of achievement, encouraging speaking or stopping speaking to listen without interruption.

Contents of counseling program:

The content of the booklet covers the following parts:

a- The first was the theoretical part that concerning with the needs of the parents of children with DS for knowledge about (DS) as definition, problems of children with DS, definite criteria of children with (DS), and

important needs of children with (DS), and the available services. In addition to the knowledge about the role of parents in modifying the behaviors of their children with (DS) including the methods of dealing with (DS) child problems, how to encourage the children in participation of a specific routine and occupational therapy, also how to improve the communication of those children with others, the importance of engaging them in community, and the appropriate methods for learning them, and the steps that they should be used for improving their positive behaviors and how to enhance self-responsibility of those children, which in turn support the parent's needs.

b- The second was the practical part that concerning on how to relieve stress and improve the coping strategies of parents having children with down syndrome as: definition of coping, types of coping methods, difference between problem-focused and emotion-focused coping methods, examples for both problem-focused and emotion-focused coping methods, the ways of application for positive thinking skills, the ways of expressing emotions, time management and performing different relaxation techniques.

4. Evaluation phase: The pre-assessment tools were repeated again at the end of counseling sessions (post-test).

Statistical analysis:

Data entry and statistical analysis were done using the Statistical Package for Social Science (SPSS) version 23.0. For statistical analysis, data were tabulated, coded, and revised, Description of quantitative variables analyzed using number and percentage distribution arithmetic mean (\bar{x}) and

standard deviation (SD). The validity and reliability tests were confirmed by using the Cronbach Alpha Coefficient test. In order to determine whether there were significant differences or not and comparisons between pre and post tests were done using T- test, chi square (X^2) and by Pearson correlation (r- test) to test relations. Statistical significance was considered at p-value <0.05, and P <0.001 highly significant.

Results:

It's evident from **table (1)** that, the majority (88%) of parents accompanying their children with down syndrome are mothers, (68%) ranged from 30 to less than 45 years old and more than half of them (54%) have a moderate level of education. Concerning mothers' occupation, it was found that (62 %) of them are not working. In relation to their residence, there were (86%) of them lived in urban area and (48%) have insufficient monthly income. Meanwhile (68 %) of them had no consanguinity and (78%) are live in family consisted of 3 to 4 persons.

Table (2) shows that, (68%) of children understudy are from 6-< 9 years old and in a moderate rate of mental retardation, and more than three fifth (62%) of them are boys. In relation to their birth order; it was found that more than half (52%) of them are the first child and the majority (88%) of them are illiterate. Concerning their physical complain, it was noticed that GIT disorders, heart disease and urinary incontinence are the most common physical complains among children understudy which constitute (34%), (30%) and (16%) respectively, in addition to more than three quarter (76%) of them are previously hospitalized.

Figure (1) denotes that, there

was a highly statistically significant difference ($X^2 = 30.38$ at $p < 0.001$) between pre and post counseling interventions regarding total level of parents' needs of having children with down syndrome, where (39%) of studied parents had satisfied needs pre counseling intervention compared with (65%) post counseling implementation.

Table (3) displays the comparison of parents needs pre - post counseling interventions, It indicates that, more than two thirds (70%) of mothers understudy have satisfaction of their needs in comparison with (42%) in pre intervention and more than one third (35%) of them who are at age of 45 and more years old and working are became have a satisfied needs in post counseling interventions. Also more than two fifth of them who lived in rural area and have sufficient money, their needs are satisfied which constitute (40%) and (43%) respectively. There was a highly statistically significant difference between parents needs and their demographic characteristics pre-post counseling interventions with ($p < 0.001$).

Table (4) illustrates the comparison of parental stress scale scores pre - post- counseling intervention, it indicates that, more than half (58%) of parents understudy, experienced a high level of stress before intervention, meanwhile in post-intervention there were more than three quarters (78%) of them experienced a low level of stress. There was a highly statistically significant difference between parents stress scores pre - post-counseling, implementation with ($X^2=50.05$ at $P < 0.01$).

Table (5) clarifies the comparison between parents' coping strategy pre and post counseling

intervention and found that, there are (30%) of parents of children with down syndrome experienced a positive coping in pre counseling intervention and their percentage improved to (78%) post counseling intervention. Meanwhile, more than two third (70%) of them who experienced a negative coping in pre counseling intervention become improvement through decreasing their negative coping into (22%) in post counseling intervention. There was a

highly statistically significant difference between parent's positive coping pre - post counseling intervention with ($X^2=32.45$ at $P< 0.01$).

Table (6) indicated that, there is a positive correlations between studied parents' needs and stress and their coping in pre and post counseling intervention as evidence by ($p = < 0.001$).

Table (1): Number and percentage distribution of parents having children with Down syndrome regarding their demographic characteristics.

Items	No. (50)	%
Gender of accompanying parent		
▪ Mother	44	88
▪ Father	6	12
Age of accompanying parent		
▪ 20 -< 30 y	5	10
▪ 30 -< 45 y	34	68
▪ 45 and more	11	22
Mean \pm S D	32 \pm 5.1	
Educational level of accompanying parent		
▪ Illiterate	9	18
▪ Read and write	7	14
▪ Moderate education	27	54
▪ High education	7	14
Parent's occupation		
▪ Working	19	38
▪ Not working	31	62
Residence		
▪ Urban	43	86
▪ Rural	7	14
Monthly income		
▪ Sufficient	18	36
▪ Barley sufficient	8	16
▪ Insufficient	24	48
Presence of consanguinity		
▪ Yes	16	32
▪ No	34	68
Family Size		
▪ 3-4	39	78
▪ 5-6	11	22
▪ >6	0	0

Table (2): Number and percentage of children with Down syndrome according to their demographic characteristics and health status.

Items	No.	%
Child's age (years)		
▪ 6 - < 9	34	68
▪ 9 - < 12	16	32
Mean ± SD	8.5 ± 0.87	
Sex		
▪ Males	31	62
▪ Females	19	38
Birth order		
▪ First	26	52
▪ Second	8	16
▪ Third	6	12
▪ Fourth and more	10	20
Level of education		
▪ illiterate	44	88
▪ School of special needs	0	0
▪ Normal school	6	12
Category of mental retardation		
▪ Mild (IQ: 50–69)	8	16
▪ Moderate (IQ: 35–50)	34	68
▪ Severe (IQ: 20–35)	5	10
▪ Profound (IQ <20).	3	6
Physical complains and Disabilities associated with DS		
• Heart Disease	15	30
• Gastro Intestinal Tract Disorders (GIT)	17	34
• Other Chronic Diseases “renal or hepatic or bone diseases”	3	6
• Urinary Incontinence	8	16
• Inability to Control Defecation	2	4
• Visual Disability	0	0
• Motor Disability	0	0
• Hearing Disability	5	10
History of Previous Hospitalization for the Child		
• Yes	38	76
• No	12	24

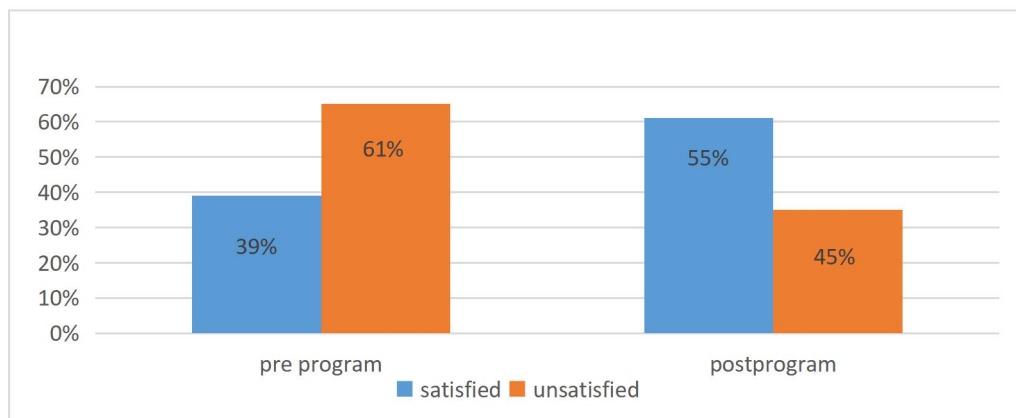


Figure (1): Level of needs of parents having children with Down syndrome pre and post counseling intervention.

$$X^2=30.38 \quad p=0.00$$

Table (3): Relationship between parents' total level of needs and their demographic characteristics pre and post counseling intervention

Items	Total level of needs				X ²	P value
	Pre program		Post program			
	Satisfied %	Unsatisfied %	Satisfied %	Unsatisfied %		
Gender of parents accompanying child						
▪ Mother	42	46	70	18	25.200	<0.001
▪ Father	4	8	8	4		
Age of parents accompanying child						
▪ 20 -< 30	12	18	17	10	14.600	<0.001
▪ 30 -< 45	11	22	27	6		
▪ 45+	25	12	35	5		
Educational level of parents accompanying child						
▪ Illiterate	17	15	19	10	19.800	<0.001
▪ Read and write	10	17	13	12		
▪ Moderate education	13	12	15	8		
▪ Highly education	7	9	19	4		
Occupation of parents accompanying child						
▪ Working	16	40	35	23	11.300	<0.001
▪ Not working	19	25	32	10		
Residence						
▪ Urban	14	24	36	12	19.700	<0.001
▪ Rural	12	50	40	12		
Monthly income						
▪ Sufficient	12	11	43	12	13.900	<0.001
▪ Barley sufficient	8	19	17	8		
▪ Insufficient	17	33	8	12		

Table (4): Comparison between level of parental stress index pre and post counseling intervention

Items	Pre intervention		Post intervention		T-test	P-value
	No.	%	No.	%		
▪ low	21	42	39	78	50.05	<0.001
▪ High	29	58	11	22		

Table (5): comparison between parents' coping strategy pre and post counseling intervention (n=50).

Items	Pre intervention		Post intervention		X ²	P-value
	No.	%	No.	%		
parents' coping strategy						
▪ Positive coping	15	30	39	78	32.45	<0.001
▪ Negative coping	35	70	11	22		

Table (6): Correlation between studied total parents ' needs, total stress and their coping regarding their children with Down syndrome pre-post counseling intervention.

Items		Total parents 'coping			
		Pre intervention		Post intervention	
		r	P-value	r	P-value
▪ Total parents' needs	0.213	<0.001	0.345	<0.001	
▪ Total parents' stress	0.201	<0.001	0.323	<0.001	

Discussion

Parents caring their children with Down syndrome tend to be anxious, disappointed, angry, and show other negative emotions towards their children. This condition shows the pattern of coping strategies with a negative attitude. Coping strategies with negative attitudes increasingly make parents with DS children feel stressed and depressed. Conversely, coping strategies with positive attitudes that parents adopt are considered effective in increasing well-being of parents and children with disabilities (Nurmalita, 2019).

Parents of disabled children are affected badly due to this problem as they have to face stressful events in their lives.

The demand of the family of children with DS is significantly higher because the family must actively participate in the care of the child due to the delay in development, the limitations in activities of daily living related to self-care such as dressing, personal hygiene, walking, and talking, and aspects related to health, education, and leisure. Generally, parents of children with DS are having plenty of problems in their life in physical, psychological and social compared to the parents of normal children. Parents of children with intellectual and developmental disabilities as DS are facing lots of negative emotions like stress, anxiety, depression and they also have more fear about their future and their child's future which will have adverse effect on the wellbeing due to inability to cope with this situation. In

spite of that some parents accept the reality and tend to lead a positive life it developing their coping skills and self-esteem (**Parameswari & Eljo, 2016**).

This study aimed to investigate the effect of counseling intervention on supporting needs, alleviating stress and promoting coping strategies among parents of children with Down syndrome.

Concerning demographic data related to parents' children with down syndrome, the finding of the present study showed that more than three quarter of parents who accompanying their children with down syndrome understudy are mothers and reside in urban area and more than three fifth of them are unemployed. This results may be due to the mothers traditionally take more responsibility of care, spend more time with their children and the strong emotional ties between mother and child which often gives up her job or career to stay home and because of the caregiver demands for children with lower mental, motor, and adaptive functioning or chronic medical concerns and of children who require adaptive equipment. So they frequently provide support and affection to their children. These results agree with **Said, (2018)** who studied the relationship between psychological well-being and coping strategies among family caregivers of children with DS and found that the highest proportion of family caregivers is mother and unemployed.

Results of the present study reveals that, near half of parents under this study have insufficient monthly income, this could be due to parents of children with chronic disability which require continuous health care needs had more lost workdays than parents of children with fewer health care issues which negatively affect their income. This result is in agreement with **Laufer,**

(2017) who studied coping mechanisms and support needs for children with disability and clarified that care givers roles and responsibilities can affect paid work time, which results in increased absenteeism, distractions, and an overall negative effect on productivity at work for the parents.

Concerning sex and categories of children with DS, the results of the present study shows that the majority of children with DS under this study are with a moderate level of mental retardation and illiterate and more than three fifth of them are boys. These results are supported with **Choi, (2015)** who found that, children with DS have moderate to severe mental retardation which affects both general intelligence and adaptive behavior of the child.

Regarding level of parents needs having children with down syndrome, the results of the present study clarifies that the majority of parents of children with down syndrome have increase their level of unsatisfied needs before counseling intervention. Meanwhile, after counseling intervention, the level of unsatisfied needs improved and transferred to upgraded level of satisfied needs with a highly statistically significant difference between pre and post program implementation. These results could be due to before counseling intervention, parents of children with DS were suffering from lack of practical knowledge about their children needs and about the rehabilitation centers for DS children in case of exposed to unexpected problems such as physical and behavior problems. Unlike, in post intervention they acquired the necessary knowledge about their children needs, problems and how to deal with it after attending the sessions and workshops of the counseling intervention so, they became more aware about the available resources in Egypt

that may help their children with DS.

This study result is consistent with **Parameswari and Eljo (2016)** in their study about "A Study on Psychological Well Being among the Family caregivers of Children with Intellectual and Developmental Disabilities", as they reported that there were highly statistically significant differences between pre and post intervention regarding autonomy, as post intervention, more than half of the parents of children with DS had high percentage of autonomy. Also, that this may be that the majority of parents of the children with DS included in the study were better educated, old aged and able to benefit from knowledge and skills acquired during the intervention program. As that made them had enough experience to deal with child disability, child behavior problems and uncertainty of child condition.

Concerning the relationship between parents' total level of needs and their demographic characteristics, the results of the present study clarifies that near half of mothers understudy are unmet their needs before counseling intervention. Meanwhile after intervention about one third of them are met their needs.

Also, a forty five years parents founded increase their level of needs satisfaction in post counseling intervention comparing with pre-program intervention. These results could be due to the strong desires of those parents to overcome their confusion and guilty feeling toward their children with Down syndrome and their trail to be good caregivers who offer praise, consequence feedback to care their children without obstacles depending on a scientific basis.

Concerning parental stress index, the results of the present study denotes that, more than half of parents understudy experienced a high level of stress before intervention. This may be due to parents being close to their children with Down syndrome which consequently lead to high level of stress. Meanwhile in post-intervention there are improvement in more than three quarter of them experienced a low level of stress. This result reflected the positive effects of the counseling intervention on parents of children with DS in caregivers who experienced high level of stress used the positive coping strategy so their stress level decreased enormously. Improvement that have occurred after the counseling intervention could be referred to its content which was developed based on the parent's needs, as well as to its clarity, simplicity, illustrated with pictures, using simple language, frequent repetition and discussion which fix the knowledge and most of parents were interested in caring of their patients. This finding supported by **Zaki, (2015)** whose study on the effect of psycho-educational training program on practice, stress and coping strategies of parents having children with ADHD and revealed that there is a statistically significant improvement post counseling intervention compared to pre counseling in all items of stress scale.

Regarding coping strategy among parents of children with Down syndrome, the results of the present study shows that, there was a highly statistically significant difference between parent's positive and negative coping in pre - post counseling intervention. This finding could be due to that the parents of children with down syndrome in post intervention became aware of the types of coping strategies, examples of coping strategies, methods of application and advantages as well as disadvantages of different coping

strategies that helped them to benefit from coping strategies in overcoming their stresses and their tendency to be positively play a more active role with their children and help them to face the condition that who are less than perfect. These results are consistent with **Choi & Van Riper, (2020)** in their study about “Health family adaptation intervention for families of young children with Down syndrome” who indicated that improvements were noticed between pre-test and post-test scores regarding active coping and clarified that this may be due to increasing awareness of the parents after a program discuss the coping strategies that are effective to cope with their child disability. In addition, these findings are agrees with **Burton, etal. (2018)**, in their study about “The nurturing program: An intervention for parents of children with special needs” who clarified that teaching parenting coping strategies enabled parents to use multiple coping strategies that helped them to build strength family relation and alleviate the challenges associated with raising children with medical and developmental disorders or disabilities.

Regarding the relationship between studied parents' coping and their needs, the results of the present study clarifies that, there is a positive correlations between studied parents' coping and their needs in pre and post counseling intervention .This may be due to that the positive impact of the intervention program on increase the reassurance of parents about how to accomplish their needs which provides a solutions for their children problem and enhance their use of coping and alleviating their stress resulting from their children illness.

Regarding the relationship between studied parents' coping and their stress, the results of the present study

clarifies that, there is a positive correlations between studied parents' coping and stress in pre and post counseling intervention .This result may be due to that the parents of children with DS are also likely to acquire the benefit of counseling intervention and modify their roles and responsibilities to relieve the added stress experienced by the primary caregiver. This result is consistent with **Susanty, et al. (2020)**, in their study about “Benefits and cultural adaptations of psychosocial interventions for parents and their children with intellectual disabilities in low-and middle-income countries: A systematic review” in which they described the findings which which suggested that interventions reduced the risk of depression, stress and motivated the parents to use a coping strategies resulting in positive perceptions of family functioning. This finding also supported by **Hsiao (2018)** who stated that, family appraisal was positively associated with family functioning and parents' well-being and mediated the relationship between family demands and the family' and parent's adaptation .

Conclusion

Based on the findings of this study, it was concluded that the application of counseling intervention for parents having children with down syndrome had a positive effect on the improvement of the level of parents' needs, alleviating their stress levels and promote coping strategies among those parents of children with down syndrome.

Recommendations

In the light of the findings of the present study the following recommendations are suggested:

- The importance of increase awareness about illness by health care professionals through counseling, family therapy, free workshops for parents who are really in need to reduce their stress and promote their effective coping .

- More education for healthcare professionals in particular is needed to enable appropriate guidance for parents about the best available treatment for this disorder so that outcomes for children with Down syndrome may be enhanced.

- Furthermore, raising the awareness of nurses and healthcare professionals about parents' experiences of parenting a child with Down syndrome that has the appropriate guide support for these parents, and minimizing the possible negative impact on their family life.

- Conducting psycho-educational training program focused on reducing parental stress and training parent to deal effectively with their disabled children under stress.

- Elevating social awareness of the challenges encountered by DS children and their families to promote their social support.

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