

## Illness Cognition and Family Adjustment among Parents of Children with Disabilities Attending Speech Clinics and Rehabilitation Centers

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### Abstract

**Background:** Developmental disabilities in children alter the children's life and that of the family. Parents of children with disabilities may experience positive or negative beliefs and thoughts regarding disabilities of their children that adversely impact parenting practices, children's adjustment, and families' adjustment. **Aim of the study was to** assess illness cognition and family adjustment among parents of children with disabilities attending speech clinics and rehabilitation centers. **Subjects and Methods:** A descriptive cross-sectional study was conducted including 80 parents of children with disabilities attending Speech Therapy Clinics affiliated to Zagazig University Hospitals and El-Ahrar Hospital. In addition to The Center of Rehabilitation affiliated to Faculty of Disability Science and Rehabilitation, Zagazig University, Egypt. **Tools:** Four tools were used to collect data. Tool I: An Interview sheet for demographic data of the studied parents and their children, as well as medical diagnosis of children. Tool II: The Illness Cognition Questionnaire Parent-version. Tool III: The Child Adjustment and Parent Efficacy Scale-Developmental Disability. Tool IV: The Parenting and Family Adjustment Scale. **Results:** The results showed that 52.5% of parents had low level of illness cognition and poor efficacy to adjust their children's problems, and 73.8% of parents practiced low level of parenting and family adjustment. However, 65.0% of parents practiced low parental consistency and 63.7% practiced high coercive. **Conclusion:** Parents showed low level of illness cognition regarding their children's disability with less acceptance, less perceived benefits, and more helplessness. Children with disabilities have emotional, behavioral and prosocial problems with low adjustment and low parental efficacy. Parents practiced low level of parenting and family adjustment with low consistency and high coercive. **Recommendations:** The present study recommended that family-based interventions should be introduced by medical, psychological, and educational professionals as an urgent need for parents and all family members to help empower raising a child with a disability.

**Keywords:** Illness Cognition, Family Adjustment, Children with Disabilities

### Introduction

Illness cognition is an important mediator between disease and psychological adjustment (Sint Nicolaas et al., 2016). Illness cognition among parents of children with an illness refers to persistent positive or negative thoughts that parents have towards their children illness (Bilani et al., 2019). Illness cognitions among parents of disabled children can enhance positive perception, interpretation, and understanding of the disability and its

challenges adjustment in both parents and children.

Illness cognition was defined as the beliefs of the patients and their parents/caregivers about a disease and its treatment that determine the ways in which they manage and adapt to the new situation created by the diagnosis. Patients and their caregivers modify their beliefs, feelings and behaviors in ways that may affect the illness outcome (Siafaka et al., 2020).

The number of 240 million children with disabilities is globally estimated according to UNICEF's latest reports. Children with disabilities have long-term physical, mental, intellectual or sensory impairments which hinder their full and effective participation in society. (Olusanya et al., 2022). According to the Centers for Disease Control and Prevention, about 1 in 6 children is born with a developmental disability (Zablotsky, 2019).

Children with disabilities included those who were born with a genetic condition that affects their physical, mental or social development. In addition, children with disabilities include those who sustained a serious injury, nutritional deficiency or infection that resulted in long-term functional consequences. Exposure of children to environmental toxins may be a cause of their developmental delays or learning disabilities. Moreover, children who developed anxiety or depression as a result of stressful life events also are included and categorized as possessing disabilities (Szmukler et al., 2014).

There 12 million persons with disabilities in Egypt. Due to a dramatic decrease in infant mortality, chronic disabling conditions in infants and young children become a challenge facing modern medicine (Sawahel, 2018). Special needs in Egypt constituted 10.64% of the total population, according to the Central Agency for Public Mobilization and Statistics (State Information Service of Egypt, 2019).

Family adjustment refers to family response to stressful events such as an illness, disability, or injury that occurs within the family system (Kreutzer et al., 2011). Raising a child with a disability can be an overwhelming experience and may cause many emotional implications for the parents and for the entire family unit that certainly affect the child. The long-term care of a child with a chronic disability frequently affects various areas in parents' life domains (e.g., marriage, career, relationships), which can lead to stress and affect the functioning of the family as a whole. Moreover, parents of children with disabilities may experience higher levels of stress and may be at a higher risk for mental

health issues and affected well-being than those with typically developing children (Trute et al., 2007; Benson, 2011).

### **Significance of the study:**

Children with disabilities are a diverse group of individuals, exhibiting many difficulties in different areas. Having a child with disability is a significant challenge that burden parents and their roles toward their disabled children. Parents tend to experience increased demands and greater challenges associated with the physical, emotional, and behavioral needs of their children than do parents of typically developing children. Therefore, assessment of illness cognition, parenting practices, and family adjustment among parents is important not only to understand the parental beliefs and perceptions of an illness of their children, but also to understand positive and negative thoughts that parents have toward their children's disability and their efficacy to adjust their children and their families as a whole.

### **Aim of this study was to:**

Assess illness cognition and family adjustment among parents of children with disabilities attending speech clinics and rehabilitation centers.

**This aim of the study was fulfilled through the following objectives:**

- 1- Assessment of illness cognition and its domains (helplessness, acceptance and perceived benefits) that parents have towards their children's disabilities.
- 2- Assessment of emotional, behavioral and prosocial problems among children with disabilities aged from 2 to 16 years, as well as parental efficacy in managing and handling these problems
- 3- Assessment of parenting practices and family adjustment.

### **Research questions:**

The research questions that guided this study were as follows:

1- What are the levels of illness cognition and its dimensions (acceptance, helplessness and perceived benefits) that parents have regarding the disability of their children?

2- What are the levels of behavioral, emotional and prosocial problems that children have and levels of parents' efficacy to adjust these problems?

3- What are the levels of parenting practices and family adjustment?

### Subjects and Methods

#### Research design

A descriptive cross-sectional study was utilized in this study.

#### Setting:

This study was conducted at the Speech Therapy Clinics affiliated to Zagazig University Hospitals and El-Ahrar Hospital, in addition to The Center of Rehabilitation affiliated to the Faculty of Disability Science and Rehabilitation, Zagazig University, Egypt, from the beginning of September, 2021 to the end of February, 2022.

**Subjects:** A convenience sample composed of 80 parents of children with special needs

attending the previous mentioned settings and accepted to participate in the current study were recruited for this study.

#### Tools of data collection:

Four tools were used to collect the necessary data for reaching the research objectives. Tools written in simple Arabic language, were as follows:

**Tool I:** An Interview sheet for demographic data of studied parents and those of their children, as well as medical history. The interview sheet includes demographic data of studied parents as age, residence, educational level, and occupation, as well as consanguinity. In addition to, medical history as family history of similar disability, and family history of chronic illness. Demographic characteristics of children includes age of the children, gender.

**Tool II:** The Chronic Illness Questionnaire Parent-version (ICQ-P). Parental illness cognition about the disease of their child was assessed with the ICQ-P. The ICQ measures illness cognitions that reflect different ways of evaluating the aversive character of a chronic condition of a child, namely, helplessness, acceptance and benefits.

#### Scoring

The scale consisted of 18 items which are scored on a 4-point Likert scale (1 = not at all, 2 = somewhat, 3 = to a large extent, 4 = completely). The scale is divided in three subscales namely helplessness, acceptance and disease benefits, and each subscale consists of 6 items. Scale scores are calculated by summing the item scores, resulting in a subscale score ranging from 6 to 24 and a total score ranging from 18 to 72.

#### Validity and reliability

The Chronic Illness Questionnaire Parent-version (ICQ-P) has good validity and reliability with internal consistency of the three subscales of the original ICQ ranged from  $\alpha = .65$  to  $\alpha = .90$ .

**Tool III:** The Child Adjustment and Parent Efficacy Scale-Developmental Disability (CAPES-DD). It is a brief inventory for assessing emotional and behavioral problems of children with developmental disabilities aged 2- to 16-years, as well as parents' self-efficacy in managing and handling these problems. The CAPES is 21-item, three-factor model of CAPES-DD child adjustment with 13 items describing behavioral (10 items) and emotional (3 items) problems and 8 items describing prosocial behavior. Three additional items were included due to their clinical usefulness and contributed to a total problem score. The instrument is in the public domain and free for practitioners and researchers to use (CAPES; Morawska & Sanders, 2010).

#### Scoring

The CAPES-DD, provides a recommended clinical cutoff of 9 for the total problem score, although this cutoff score is

based on preliminary analysis and should be interpreted with caution. For the remaining subscales of the CAPES-DD, there are no clinical cutoffs provided but higher scores indicate greater levels of child behavior problems (range = 0-30), emotional problems (range = 0-9), prosocial behavior (range = 0-24), and self-efficacy (range = 16-160).

To obtain a Behavioural Problems subscale score, sum "how true" ratings for items 1, 3, 4, 5, 6, 7, 8, 9, 10 and 12, with a possible range from 0-30. To obtain an Emotional Problems subscale score, sum "how true" ratings for items 2, 11, and 13 with a possible range from 0-9. To obtain a Total Problems scale score, sum the Behavioural Problems subscale score, the Emotional Problems subscale score and the "how true" ratings for the three additional items (14, 15, 16), with a possible total range from 0-48. Higher scores indicate greater levels of child emotional or behavioural problems. To obtain a Prosocial Behaviour scale score, sum "how true" ratings for items 17, 18, 19, 20, 21, 22, 23 and 24, with a possible range from 0-24.

**Self-Efficacy Scale:** sum all parent confidence ratings for the emotional or behavioural problems (rating scale 1- 10). Note that there are no parent confidence ratings for the prosocial behavior scale. Possible range for the total score is 16-160 with higher scores indicating higher levels of parent self-efficacy.

#### Validity and reliability

Psychometric evaluation of the CAPES-DD revealed that the scales had satisfactory to very good internal consistency, as well as very good convergent and predictive validity with internal consistency of the subscales. Cronbach's alpha ranged from  $\alpha = .90$  to  $\alpha = .95$ .

**Tool IV:** The Parenting and Family Adjustment Scale (PAFAS). The PAFAS is a brief outcome measure for assessing changes in parenting practices and parental adjustment. It consists of two parts. The first part is the Parenting scale which measures parenting practices and quality of parent-child

relationship. The second part is the Family Adjustment scale which measures parental emotional adjustment as well as, partner and family support in parenting.

The PAFAS is a 30-item which provides a scored evaluation on seven different aspects of parenting.

#### Scoring

1. Parental Consistency scores are calculated by adding scores for questions 1, 4, and 12, with the reverse-score for questions 3 and 11 (reverse-scoring means that a selection of 0 = a score of 3, 1 = 2, 2 = 1, and 3 = 0).

2. Coercive parenting scores are calculated by adding scores for questions 5, 7, 9, 10, and 13.

3. Positive Encouragement scores are calculated by reverse-scoring questions 2, 6, and 8.

4. Parent-Child relationship scores are calculated by reverse-scoring questions 14, 15, 16, 17, and 18.

5. Parental Adjustment scores are calculated by adding scores for questions 19 and 21 with the reverse-scores for 20, 22, and 23.

6. Family Relationships scores are calculated by adding scores for 26 and 27 with the reverse-scores for 24 and 25.

7. Parental Teamwork scores are calculated by adding the score for 29 with the reverse-scores for 28 and 30.

#### Validity and reliability

Psychometric evaluation of the PAFAS revealed that the scales had good internal consistency, as well as satisfactory construct and predictive validity with internal consistency of the subscales. Cronbach's alpha ranged from  $\alpha = .78$  to  $\alpha = .90$ .

#### Pilot study

A Pilot study was carried out on 10% of the studied parents at the previously mentioned settings in order to test the applicability of the constructed tools and the clarity of the included questions related to the tools for data collection. The pilot study had also served to estimate the time needed for each parent to fill in the

questionnaire and answer the study related questions. According to the results of the pilot, no modifications were required. The studied parents of the pilot study were included in the main study sample.

#### Field work:

Data collection extended over a period of 6 months, started from beginning of September, 2021 to the end of February, 2022. The researchers were available in the study setting during working hours all days of the week from 9.00 a.m. to 12.00 afternoon except Fridays to assess the studied parents for parental illness cognition about the disability of their children and parental adjustment and efficacy to emotional and behavioral problems of their disabled children.

#### Ethical considerations

An oral approval was taken from each parent before collecting data and after explanation of the purpose and nature of the study. The researchers assured maintaining anonymity and confidentiality of the collected data throughout the study phases. They were informed about their right to withdraw from the study at any time without giving any reason and without any responsibility.

#### Statistical design:

All data were collected, tabulated and statistically analyzed using IBM Corp. Released 2015. IBM SPSS Statistics for Windows, Version 23.0. Armonk, NY: IBM Corp. Quantitative data were expressed as the mean  $\pm$  SD and qualitative data were expressed as number and percentage. Pearson's correlation coefficient was calculated to assess relationship between various study variables, (+) sign indicates direct correlation, and (-) sign indicates inverse correlation, also values near to 1 indicate strong correlation and values near 0 indicate weak correlation. Multiple linear regression which is a predictive analysis, is used to describe data and to explain the relationship between one dependent

continuous variable and one or more independent variables. All tests were two sided. P-value  $<$  0.05 was considered statistically significant, p-value  $\geq$  0.05 was considered statistically insignificant.

#### Results

**Table (1)** shows frequency distribution of the studied parents according to their demographic characteristics. The table reveals that 61.3% of mothers were within age group of 35 years or more with a mean of age  $35.1\pm 5.6$  years and 55.0% of fathers were within age group of more than 40 years with a mean of age  $40.83\pm 6.58$  years. Concerning residence 65.0% of studied parents come from rural areas. Only 20.0% of fathers versus 17.5% of mothers had university education. Concerning parent's occupation, 75.0% of fathers were free workers and 88.8% of mothers were housewives. Regarding consanguinity, 68.8% of parents had no consanguinity.

**Table (2)** demonstrates frequency distribution of disabled children of the studied parents according to their demographic characteristics and medical diagnosis. The table clarifies that 50.0% of children were in age less or and 50.0% were in age more than 8 years with a mean of age  $8.39\pm 3.56$ . Regarding age of diagnosis, 60.0% of children were diagnosed at age of two or more years with a mean age of diagnoses  $2.21\pm 1.78$  years. Regarding diagnosis of children's disabilities, 33.75%, 31.25%, 20%, and 15%, constituted respectively sensory and speech impairment, cognitive and intellectual disorder, motor disabilities, and behavior and communication disorders.

**Figure (1)** illustrates diagnosis of children as reported by parents Regarding sensory and speech impairment, 15% of the children diagnosed with delay in speech. Concerning motor disabilities, 12.5% of children were diagnosed with epilepsy. Concerning children with intellectual disorders, 13.75% of them diagnosed with learning difficulties. As well as, autism was reported by 12.5% of parents as the most common diagnosis as behavior disorder.

**Table (3)** demonstrates frequency distribution of the studied parents regarding illness cognition and its dimensions (helplessness, acceptance, and perceived benefits). The table shows that 41.3% of the studied parents reported high level of helplessness regarding their children's disabilities with mean and standard deviation of  $15.34 \pm 3.68$  for the total score, while 43.8% reported low level of acceptance with mean and standard deviation of  $14.96 \pm 3.09$  for the total score as well as, 45.0% reported low level of perceived benefits with mean and standard deviation of  $15 \pm 2.99$  for the total score. Regarding total score of illness cognition, 52.5% of parents reported low to moderate level with mean and standard deviation of  $45.3 \pm 7.63$  for total score.

**Table (4)** clarifies frequency distribution of children's emotional, behavioral, prosocial problems and parent efficacy level. The table demonstrates that 35.0% of children had severe level of emotional problems, while 30.0% had moderate level and 17.5% had profound level, with mean and standard deviation of  $4.59 \pm 2.14$  for the total score. Regarding behavioral problems, 43.8% of children had severe problem level, while 32.5% had moderate level, and 20.0% had profound level with mean and standard deviation of  $16.84 \pm 6.17$  for the total score. Concerning total score of both behavioral and emotional problem, 51.2% of children had severe problem level with mean and standard deviation of  $26.23 \pm 9.11$  for the total score. Prosocial problems represented severe problem level among 38.8% of children and profound level among 27.5% of children.

**Figure (2)** illustrates levels of parental efficacy to manage and deal with their child's behavioral and emotional problems. Regarding parental efficacy, 52.5% of parents had poor level of efficacy to manage and deal with the emotional and behavioral problems of their disabled children, while 43.8% had very poor level of efficacy.

**Table (5)** shows frequency distribution of the studied parents regarding parenting practices and family adjustment. The table demonstrates that 65.0% of parents practiced low level of consistency with mean and standard deviation of  $8.38 \pm 2.37$ , versus 63.7% of parents who practiced high level of coercive parenting with mean and standard deviation of  $8.49 \pm 2.63$  for the total score. Regarding parental positive encouragement, an equal percentage of 37.5% of parents practiced low and high level with mean and standard deviation of  $4.14 \pm 1.85$  for the total score. Concerning Parent-child relationship, 70.0% of parents reported low level with a mean and standard deviation of  $9.98 \pm 2.52$  for the total score. Regarding total score of parenting, 77.5% of the studied parents practiced low parenting level with a mean and standard deviation of  $30.98 \pm 6.23$  for the total score.

Regarding family adjustment, 66.3% reported low level with mean and standard deviation of  $9.65 \pm 2.16$  for the total score. Concerning family relationship, 47.5% had high level with a mean and standard deviation of  $5.51 \pm 1.99$  for the total score. Concerning family team work, 46.3% reported low level with mean and standard deviation  $4.73 \pm 1.83$  for the total score. Regarding total score of family adjustment, 67.5% of parents reported low level with mean and standard deviation of  $20.26 \pm 5.54$  for the total score. Concerning total score of both parenting and family adjustment, 73.8% of the studied parents had low level with mean and standard deviation of  $51.24 \pm 9.99$  for the total score.

**Table (6)** shows highly statistically significant correlations between parental efficacy and both of illness cognition and total problems score. In addition, there were statistically significant correlations between prosocial problem score and both age of children, and total parenting and family adjustment.



**Table (1): Frequency and Percentage Distribution of The Studied Parents According To Their Demographic Characteristics (N=80)**

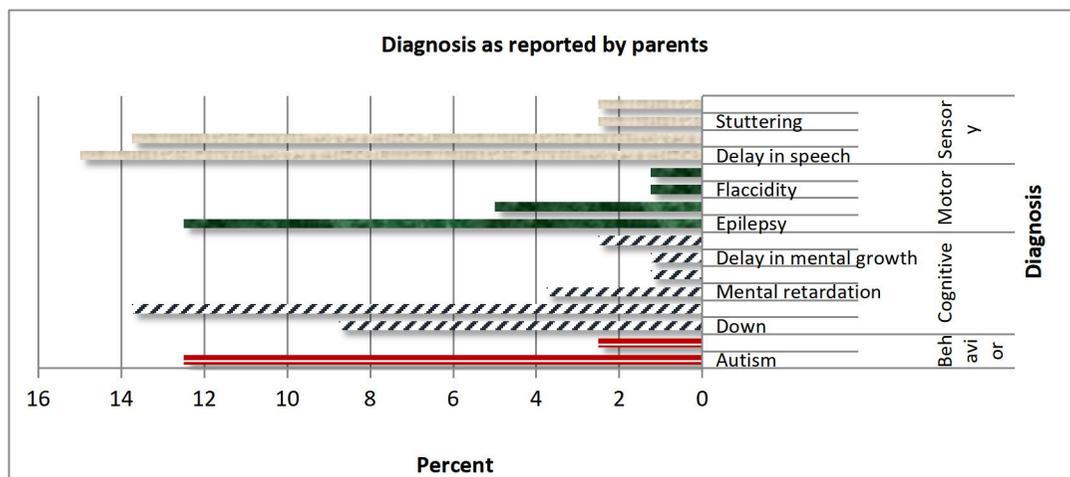
<b>Parents' characteristics</b>	<b>No</b>	<b>Percent</b>	
Participants	Father	6	7.5
	Mother	67	83.8
	Others	7	8.8
Mother age (in years)	<35	31	38.8
	≥35	49	61.3
	Mean ±SD	35.1±5.6	
Father age (in years)	≤40	36	45.0
	> 40	44	55.0
	Mean ±SD	40.83±6.58	
Residence	Rural	52	65.0
	Urban	28	35.0
Educational level of father	Primary	22	27.5
	Secondary	39	48.8
	University	16	20.0
	Other	3	3.8
Educational level of mother	Primary	21	26.3
	Technical Secondary	39	48.8
	University	14	17.5
	Other	6	7.5
Occupation of father	Government Employee	12	15.0
	Free Worker	60	75.0
	Don't Work	4	5.0
	Other	4	5.0
Occupation of mother	Housewife	71	88.8
	Work	9	11.3
Consanguinity	Yes	25	31.3
	No	55	68.8

**Table (2): Frequency Distribution and Percentage of Disabled Children of the Studied Parents According to their Demographic Characteristics and Medical Diagnosis (N=80)**

Child characteristics		N	Percent
Age of the studied children (in years)	≤8	40	50.0
	>8	40	50.0
	Mean ±SD	8.39±3.56	
Gender	Males	46	57.5
	Females	34	42.5
Age of diagnosis (in years)	<2	32	40.0
	≥2	48	60.0
	Mean ±SD	2.21±1.78	
<b>Diagnostic categories</b>			
Behavior and communication disorder	Autism	10	12.50
	ADHD	2	2.50
	Total	12	15
Cognitive and intellectual disorder	Down	7	8.75
	Learning difficulties	11	13.75
	Mental retardation	3	3.75
	Red syndrome	1	1.25
	Delay in mental growth	1	1.25
	Angelman syndrome	2	2.50
Total	25	31.25	
Motor disabilities	Epilepsy	10	12.50
	Cerebral palsy	4	5.00
	Flaccidity	1	1.25
	Weakness in nerve	1	1.25
	Total	16	20
Sensory and speech impairment	Delay in speech	12	15.00
	Cochlear implant	11	13.75
	Stuttering	2	2.50
	Hearing impairment	2	2.5
	Total	27	33.75

The table clarifies that 50.0% of children were less than eight years of age and 50.0% were in age more than 8 years with a mean of age 8.39±3.56. Regarding age of diagnosis, 60.0% of children were diagnosed at age of two or more years with a mean age of diagnoses 2.21±1.78 years. Regarding diagnosis of children’s disabilities, 33.75%, 31.25%, 20%, and 15%, constituted respectively sensory and speech impairment, cognitive and intellectual disorder, motor disabilities, and behavior and communication disorders.

**Figure (1): Diagnosis of Children as Reported by Parents**

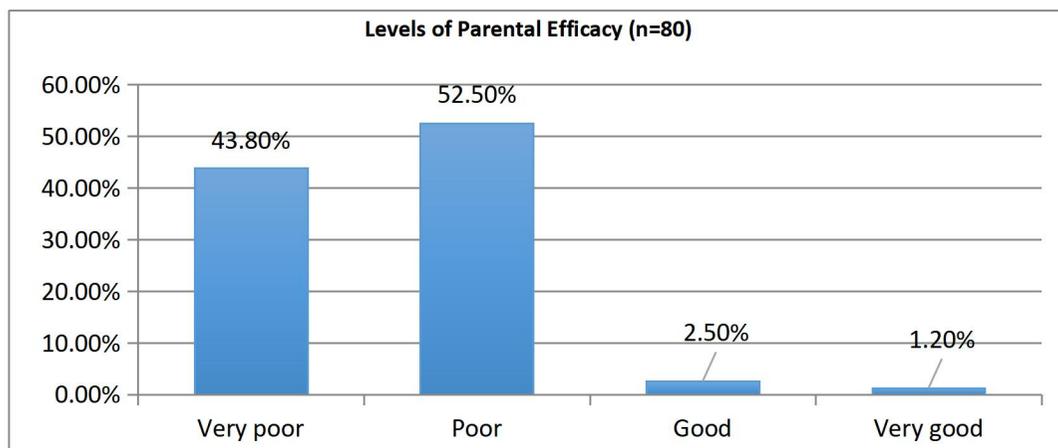


**Table (3): Frequency Distribution of the Studied Parents Regarding Illness Cognition and its Dimensions (Helplessness, Acceptance, and Perceived Benefits) (N=80).**

Items of illness cognition	Levels of illness cognition								Mean $\pm$ SD
	Very low		Low		High		Very high		
	No.	%	No.	%	No.	%	No.	%	
Helplessness	8	10.0	26	32.5	33	41.3	13	16.3	15.34 $\pm$ 3.68
Acceptance	4	5.0	35	43.8	36	45.0	5	6.3	14.96 $\pm$ 3.09
Perceived benefits	3	3.8	36	45.0	37	46.3	4	5.0	15 $\pm$ 2.99
Total illness Cognition	0	.0	42	52.5	35	43.8	3	3.8	45.3 $\pm$ 7.63

**Table (4): Frequency Distribution of Children's Emotional, Behavioral, Prosocial Problems and Parent Efficacy Level (N= 80).**

Problems	Levels of problems								Mean $\pm$ SD
	Mild		Moderate		Severe		Profound		
	No.	%	No.	%	No.	%	No.	%	
Emotional	14	17.5	24	30.0	28	35.0	14	17.5	4.59 $\pm$ 2.14
Behavioral	3	3.8	26	32.5	35	43.8	16	20.0	16.84 $\pm$ 6.17
Total of emotional and behavioral	5	6.3	23	28.7	41	51.2	11	13.8	26.23 $\pm$ 9.11
Prosocial	10	12.5	17	21.3	31	38.8	22	27.5	13.2 $\pm$ 6.24

**Figure (2): Levels of Parental Efficacy to Manage and Deal With Their Child's Behavioral and Emotional Problems (n=80).**

Regarding parental efficacy, 52.5% of parents had poor level of efficacy to manage and deal with the emotional and behavioral problems of their disabled children, while 43.8% had very poor level of efficacy.

**Table (5): Frequency Distribution of the Studied Parents Regarding Parenting Practices and Family Adjustment**

Domains of Parenting practices and family adjustment	Levels of parenting practices and family adjustment								Mean $\pm$ SD
	Very low		Low		High		Very high		
	No.	%	No.	%	No.	%	No.	%	
<b>Parenting practices</b>									
Parental consistency	4	5.0	52	65.0	22	27.5	2	2.5	8.38 $\pm$ 2.37
Parental coerciveness	4	5.0	19	23.8	51	63.7	6	7.5	8.49 $\pm$ 2.63
Parental positive encouragement	14	17.5	30	37.5	30	37.5	6	7.5	4.14 $\pm$ 1.85
Parental child relationship	16	20.0	56	70.0	8	10.0	0	0.0	9.98 $\pm$ 2.52
<b>Total parenting level</b>	3	3.8	62	77.5	13	16.3	2	2.5	30.98 $\pm$ 6.23
<b>Family adjustment</b>									
Family adjustment	13	16.3	53	66.3	14	17.5	0	0.0	9.65 $\pm$ 2.16
Family relationship	3	3.8	37	46.3	38	47.5	2	2.5	5.51 $\pm$ 1.99
Family team work	9	11.3	37	46.3	28	35.0	6	7.5	4.73 $\pm$ 1.83
<b>Total Family adjustment</b>	3	3.8	54	67.5	23	28.7	0	0.0	20.26 $\pm$ 5.54
<b>Total Parenting and Family Adjustment</b>	2	2.5	59	73.8	19	23.8	0	0.0	51.24 $\pm$ 9.99

**Table (6): Correlation Matrix Between Total Problem Score, Prosocial Score Efficacy Score, Total Cognition Score Total Parenting and Family Adjustment Scales, Age of Children, Mother Age, Father Age, Onset of Disease Per Years**

Variables	Total problem score		Prosocial score		Efficacy score		Total Cognition score		Total Parenting and Family Adjustment Scales	
	r	p	r	p	r	p	r	P	r	p
Total problem score	1									
Prosocial score	0.064	0.571	1							
Efficacy score	<b>.573**</b>	<b>0.0001</b>	0.188	0.094	1					
Total Cognition score	<b>.267*</b>	<b>0.017</b>	0.107	0.346	<b>.297**</b>	<b>0.008</b>	1			
Total Parenting and Family Adjustment Scales	0.001	0.99	<b>.334**</b>	<b>0.002</b>	0.007	0.954	0.144	0.204	1	
Age of children (in years)	0.178	0.114	<b>.243*</b>	<b>0.03</b>	0.219	0.051	0.086	0.447	0.099	0.384
Onset of disease (in years)	-0.080	0.48	0.199	0.077	-0.10	0.927	-0.044	0.701	0.109	0.338
Mother age (in years)	0.081	0.476	-0.128	0.258	0.039	0.731	0.01	0.929	-0.077	0.5
Father age (in years)	0.179	0.113	-0.166	0.141	0.126	0.265	0.049	0.663	-0.159	0.159

(r) Correlation coefficient \* Correlation is significant at the 0.05 level (2-tailed). \*\* Correlation is significant at the 0.01 level (2-tailed).

## Discussion

Parents of children with disabilities may exhibit both positive and negative responses to their child's disability. Parents may have negative thoughts and beliefs when they feel unable to help and care for their children. Parents' perceptions of children with disabilities determine how parents educate and care for the child. Parental acceptance of children affects

children's development, social behavior skills, and adaptability (Carasco et al., 2019).

The present study revealed that, the majority of caregivers were mothers while other caregivers were fathers, grandparents, and others (aunts or uncles). Similarly, Hastings et al. (2005) who conducted a study on parents of preschool and school age children with autism found that their studied mothers constituted the

largest proportion of the overall caregivers and other participants were fathers, grandparents, step or adoptive parents, aunts/uncles/cousins, or foster parents/guardians.

According to the demographic data of parents, the current study showed that slightly more than three fifth of mothers were at or above age of 35 years, and more than half of fathers were above 40 years old. More than two fifth of fathers had completed secondary school education, only one fifth completed the university education, and a minority had completed post-graduate studies. Three quarter of fathers were free workers and majority of mothers were housewives.

In accordance with the present findings, **Vilaseca et al. (2020)** in a similar study stated that mothers in their studies aged 22 to 45 years ( $M = 37.3$ ,  $SD = 4.4$ ). Eleven percent had received only elementary schooling, 40% had completed secondary school, 34% had a university degree, and 15% had post-graduate studies. Fathers ranged between 24 to 60 years ( $M = 38.9$ ,  $SD = 5.1$ ). Twenty-two percent had received only elementary schooling, 36% completed secondary school, 31% had a university degree, and 11% had completed post-graduate studies.

Regarding residence, the present result mentioned that more than three fifth of parents live with their children in rural areas. The higher prevalence of identified disorders among children living in rural areas may be related to differences in demographic patterns and risk factors in rural areas, including greater financial difficulties and less access to amenities and treatment resources. This result was in agreement with scattered studies as those of **Smalley et al. (2010)**, **Anderson et al. (2013)**, and **Robinson et al. (2017)**. The previous studies identified notable rural health barriers such as lack of access to transportation and in availability of specialized providers who can help to prevent, diagnose and initiate early treatment programs.

Regarding parents' occupation, the present study revealed that three quarter of fathers were free workers and not employed by the government, while only less than one fifth

were government employees. In addition, the majority of mothers were housewives. Incongruent with, **Vilaseca et al. (2019)**, study which mentioned that 53% of mothers were employed full-time, compared with 89% of fathers. Another 28% of mothers were partially employed and 19% of them cared full-time for their children and were fully responsible for housework.

### Demographic data of children

Parents reported their children's demographic characteristics. According to the current study, parents reported that, half of children were in age group of  $2 \leq 8$  years as the present study included parents of children aged 2-18 years. Regarding gender, more than half of children were boys. In consistent with this study, **Zablotsky et al. (2019)** demonstrated that children with developmental disability aged 3–17 years and the highest percentage was for males. In addition, **Afzal et al. (2015)** found that more than three fifth (61.8%) were males.

Concerning age of diagnosis, the present study found that two fifth of children were diagnosed before age of two years and three fifth were diagnosed at or after age of two years. Early diagnosis of developmental delays and disabilities in children for early childhood intervention can greatly help children and their families with better outcomes throughout their life course.

In consistent with the present study, **Trute et al. (2012)** mentioned that more than half of children were diagnosed under three years of age. In addition, a study was conducted in Hanoi, Vietnam, by **Thuy et al. (2020)**, who stated that a timeframe for parents to identify and diagnose their child's disability was from 9-10 months to 3.5 years old.

Regarding diagnosis of children as reported by parents, the current study found that the highest percentage was for the diagnosis of learning difficulties, followed by autism and epileptic seizure, then down syndrome, and cerebral palsy. In agreement, **Zablotsky et al. (2019)**, also found that learning disability was the most common co-occurring condition among children aged 3-17 years who had ever

been diagnosed with an intellectual disability, autism spectrum disorder, or any other developmental delay.

In contrast, **Zablotsky et al. (2019)** stated that the next most common co-occurring condition among children was ADHD while, ADHD constituted very low percentage in the present study. Results of the previous study added that, the percentage of children aged 3–17 years diagnosed with a developmental disability increased from 16.2% in 2009–2011 to 17.8% in 2015–2017. **Zablotsky et al.** clarified that reasons for these increases were not examined in their study, but the cause of increases might be due to improved awareness among parents regarding early diagnosis, screening, and service accessibility.

Regarding illness cognition and its dimensions (helplessness, acceptance, and perceived benefits), the current study findings demonstrated that nearly equal percentages of more than two fifth of parents had high level of helplessness regarding disability of their children. Moreover, more than two fifth had low level of acceptance and low level of perceived benefits. Concerning total score of illness cognition, more than half of parents had low level of illness cognition regarding their children's disability. This may be referred to the parents' perception, interpretation, and understanding of the illness of their child and its treatment.

In contrast, **Junaidi and Dewantoro (2020)** found that the acceptance of large families and the ability of parents to explain the existence of children with disabilities were perceived by more than half of parents. However, the lowest percentages of parents have feelings of failure as a negative perception and helplessness. The highest percentages of parents have a positive perception as acceptance of these conditions with disabilities as a God's will.

Regarding children adjustment and parental efficacy, the present study assessed the emotional, behavioral, and prosocial problems that the children have and the efficacy of parents to manage these problems. It was found that, more than one quarter of children had

moderate level of emotional problems, more than one third had severe level, and less than one fifth had profound level. However, the current study demonstrated that more than two fifth of children had severe level of behavioral problems, while nearly one third had moderate level and one fifth had profound level. Concerning total score of both behavioral and emotional problems, slightly more than half of children had severe problem's level. Moreover, prosocial problems represented severe problem's level among nearly two fifth of children and represented profound level among more than one quarter of children.

In the same line, **Woodman et al. (2015)** stated that levels of emotional and behavioral problems are estimated to be 3 to 7 times higher in children with intellectual disabilities than typically developing children. In previously, **Rojahn and Meier (2009)** emphasized that children with disabilities are much more likely to experience emotional and behavior problems than typically developing children.

Behavioral and emotional problems among children with disabilities may be referred to some of the factors that tend to increase the risk of such problems in children with disabilities. These factors may include intellectual impairments, deficits in adaptive behavior, communication difficulties, delayed emotional development, or having multiple disabilities as clarified by **Mazzucchelli et al (2019)**.

Parental efficacy refers to confidence of parents in dealing with specific child's behavioral and emotional problems. Regarding parental efficacy, the current study finding revealed that more than two fifth had very poor efficacy level to manage the emotional, behavioral and prosocial problems of their disabled children and more than half of parents had poor efficacy level.

In the same line, **Whittingham et al. (2011)** found that parents who have greater efficacy were more likely to implement positive and effective parenting strategies and were able to manage the emotional and behavioral problems of their children. Moreover, **Woolfson et al. (2011)** emphasized that parenting self-

efficacy was an effective moderator for the effect of child disability on behavior problems. **Smart (2016)** found that parents of children with more severe emotional and behavioral problems were found to have lower parenting self-efficacy.

The present study found that, more than three quarters had low level of parenting practices and more than two third had low family adjustment. This may be attributed to the fact that parents experience difficulties and challenges related to parenting and childrearing, those challenges are often more persistent, more frequent, and/or more severe in children with disabilities and are compounded for parents.

In contrast, **Trute et al., (2012)** demonstrated that family adjustment scores were within the normal range of adjustment and approximately more than one fifth of families in the excellent or strong range of family adjustment while the lowest percentage of the families were in the problem or distressed range.

Consistency is one of the most essential and productive strategies for effective parenting. In practice, this means that parents must be consistent in their schedules, routines, and rules, patterns of discipline, and in how they connect with their child emotionally (**Ryan et al., 2017**).

The current study results revealed that almost two third of parents practiced low level of consistency with their disabled children. According to **Trute et al. (2007)**, this may be due to that parent of children with disabilities experience higher levels of stress and are at higher risk for mental health issues than those with typically developing children.

In concurrent, **Emerson et al. (2014)** stated that parents and specially mothers of children with intellectual disabilities showed significantly higher rates of inconsistent and harsh parenting than mothers of "typically developing" children and that higher rates of inconsistent and harsh parenting were associated with increased rates of conduct difficulties among children with intellectual disabilities.

Coercive parenting is using harsh parental behavior such as scolding, hitting, yelling, threatening, rejection and psychological control to enforce compliance of the child. These parents also use frequent negative commands, name calling, overt expressions of anger and physical aggression. Coercive parents are authoritarian parents. They are intrusive, over-controlling and assert higher power over the child. The coercion is usually arbitrary, peremptory, and domineering as highlighted by **Prinz et al. (2009)** in a previous similar study.

The current study stated that less than three two third of parents practiced high level of coercive parenting with their disabled children. This may be due to that parenting itself is stressful for parents to adjust a child with disability more than typically developing children.

In consistence with this study result **Day et al. (2021)** in their very recent study demonstrated that parents of children with developmental or intellectual disabilities tend to report greater use of coercive parenting practices relative to parents of typically developing children, increasing the risk of adverse child outcomes. Early, before two decades, **Sullivan and Knudson (2000)** mentioned that children with developmental disabilities or developmental delay are more likely to be exposed to coercive parenting compared to their non-disabled peers.

Regarding parental positive encouragement, the current study revealed that an equal percentage of less than two fifth practiced low as well as high levels of encouragement for their children. Parental encouragement fosters independence, high self-esteem, a willingness to explore, experiment, and communicate for the child that it is acceptable to make mistakes and to learn from those mistakes. Parental encouragement is a subtle way that parents can powerfully influence their children's behaviors, attitudes, and habits.

Concerning parent-child relationship, the present study finding demonstrated that more than two third of parents practiced low level of

relationship with their children. In congruence with this study finding, **Totsika et al. (2014)** demonstrated that parents and specially mothers of children with intellectual disabilities had a less close relationship and more conflict with their children when compared to other mothers and having a less close relationship and more conflict predicted concurrent and future child behavior problems. In a similar study, **Young (2018)** confirmed that children with disabilities are at an increased risk of negative interactions with those who are expected to care for them.

Considering family adjustment, the present study results demonstrated that more than two fifth of parents had low level of adjustment regarding family relationship and also more than two fifth had high level. This may be attributed to the disability of their child as parents and indeed all family members of children with developmental disabilities exhibit more challenges that contribute and interfere with their relationships.

In agreement with the current study result, **Ravindranodan and Raju (2007)** mentioned that parents with less marital conflict are less likely to experience rejection of the homemaking role and parenting problem-solving role. In addition, **Aydin and Yamaç (2014)** clarified that parents who were negatively affected by marital conflict might be negative towards the child, and the child might perceive this behavior as more rejecting. One of the most influential factors in parenthood is the mother's relationship with her spouse.

The present study finding revealed that more than two fifth of mothers under study had low level of adjustment regarding family teamwork. This may be due to that three quarters of fathers are free workers who usually have long day work, while the majority of mothers were housewives as this let more mothers to care for their children than their fathers. Indeed, in the Egyptian society, mothers are often considered to be the responsible caregivers for their children even when fathers have no work. In addition, family members and siblings can't understand the needs of a child with a disability so they might not be able to provide child care support.

In the same context, **Benson (2011)** emphasized that long-term care of a child with a chronic disability frequently affects various areas in a parent's life domains (e.g., marriage, career, relationships), which can lead to stress, and often affects the overall functioning of the family.

The present study found high statistical significance between parental efficacy and both of illness cognition and total problems score. In addition, there were statistically significant correlations between prosocial problem score and both age of children, and total parenting and family adjustment. Incongruent with **Barber and Harmon (2002)** and **Pinquart (2016)**, the present study result did not detect any statistical significance between parenting and total problems scores.

### Recommendations

**Based upon results of the present study, it was recommended that:**

Family-based interventions should be introduced by medical, psychological, and educational professionals as an urgent need for parents and all family members to empower raising a child with a disability.

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