

Parental Patterns of Care for their Children with Mental Disability

Gehan Fakhry ELYamany, Dr. Zeinab Fathy El-Sayed, Dr. Mona Mohamed Hafez

Pediatric Nursing, Faculty of Nursing, Ain Shams University-Cairo-Egypt.

Abstract

Background: Mental disabilities are a lifelong condition that cannot be "cured" however, there are ways to enrich their lives, help them have a pleasant childhood through parents as a care giver. **Aim:** The study aimed to assess the parental patterns of care for their children with mental disabilities. **Study Design:** A descriptive study design. **Setting:** The study was conducted at two governmental intellectual development schools at Embaba and El-Dokki. **Sample size:** involved (150) studied children suffering from mental disabilities and their accompanying parents. **Tools for Data Collection: (I)** A pre-designed structured interviewing questionnaire to assess parents' knowledge about mental disabilities. **(II)** assessment sheet for parental patterns of care. **(III)** Parents' socialization styles scale. **Results:** the study results revealed that the mean age of studied children was (10.4±1.9), while the mean age of their mothers was (37.7±1.4). The great majority of children receive care through mothers. More than half of the parents had unsatisfactory knowledge regarding disease of mental disabilities, approximately less than half of the children were had average pattern of care from parents in most daily living activities. **Conclusion:** The parents' knowledge was unsatisfactory regarding mental disability. Also, the level of parental patterns of care was ranged from poor to an average level. There is a positive correlation between parents' knowledge and level of parents' care. **Recommendations:** it could be recommended: continuous assessment for the level of knowledge of parents and implementation training programs for parents having children with mental disabilities to keep them updated.

Keywords: Mental, disability, Parents, Children, Knowledge, Socialization Style.

Introduction

Mental disabilities mean a condition of arrested or incomplete development of mind in children before age 18 years old arising from inherited cause or disease or injury. World Health Organization (WHO) reported that 10-20% of all children and adolescents have some form of mental disabilities, while the mental disability represented 55% among children in intellectual developmental schools than other different disabilities (WHO, 2015).

The goal of parental care for children with a mental disability is to provide the best quality of life for their children. Caring for a child with a disability can have both positive and negative effects on parents. Each family's situation and coping ability is

different based on the type and severity of disability of their children (Branford, 2013).

Many children with a mental disability need help with adaptive skills, which are skills needed to live, play, and work in the community. Daily living activities. Parents can help a child work on these skills at both school and home. Some of these skills include: communicating with others; taking care of personal needs (dressing, bathing, health and safety; home living (helping to set the table, cleaning the house, or cooking dinner);

Knowing the rules of conversation (Green & Allister, 2015).

In the light of the previous mentioned review; the researcher conducted this study

for assessment the parent's patterns of care for their children having mental disabilities

Aim of the study

The study was aimed to assess the parental patterns of care for their children with mental disabilities.

Subjects and Methods

Design: A descriptive design was used to conduct this study.

Setting: The study was conducted at the two governmental schools of intellectual educational schools in Embaba and El-Dokki affiliated to ministry of education.

Subjects: A purposive sample that included (150) studied children suffering from mental disabilities and their accompanying parents.

Tools for data collection:

Data were collected by using the following tools:

I-Structured interviewing questionnaire sheet:

It was designed by the researcher in the light of the relevant and current literature and written in simple Arabic language to suit understanding of the study subjects and to gather data in relation to:-

- Characteristics of the mentally disabled children which include: (age, gender, degree of disability, educational level, birth order and residence).

- Socio-demographic characteristics of the parent's accompanying them include that: (age, level of education, occupation, and monthly income).

- Data regarding medical history and health condition for mentally disabled children's such as diagnosis, duration of disability family history of disease, exposure

to any infectious disease or head trauma at birth.

- Parents level of knowledge regarding concept of mental disabilities its manifestations and complications.

❖ Scoring system:

According to answer, a correct response was scored 1 and incorrect zero for each area of knowledge, the scores of the items was summed –up and divided by of items regarding the knowledge of studied parents 100scores, the answers were checked with key answer and the total scores were summed-up and converted into a percent score categorized into two levels:

- Score from < 60 % referred to unsatisfactory knowledge

- Score from $60 \leq 100$ % referred to satisfactory knowledge

II- Assessment sheet of parental patterns of care for mentally disabled children:

It was developed by the researcher and was written into simple Arabic language to suit nature of the study. The patterns of care is three point scale according to the degree of patterns, the numerical values allotted to each response was always, sometimes and never

Patterns of care which included:

- Self-care (8 items)
- Activities at home(5 items)
- Activities outside the home (5items)
- Psychological care (7 items)
- Social care (9 items)
- Environmental care (7 items)

❖ Scoring system: according to the degree of patterns of care the always scored one sometimes scored two and that never was scored three. These scores were summed-up and converted into a percent score:

- Score less than 50% referred to poor level pattern of care.

- Score from 50 – 75% referred to average level pattern of care.
- Score more than 75 %referred to good level pattern of care.

III- Parents Socialization Styles

Scale:

This scale was adopted from Ali, (2014) it aimed to assess parenting socialization styles used by parents toward their children with mental disabilities the scale consists of “35”statements at measure the following aspects: punitive style (13 items), emotional deprivation style (11 items) and guidance style (11 items).

❖ **Scoring system:** the scores of parenting socialization styles of children and accompanying parents toward mentally disabled children, the following scores (2)points for never (1)points for sometimes and (zero)for always it contain three categories punish style, emotional deprivation and guidance style.

- Score < 50% referred to low used parents socialization style
- Score from 50-75% referred to moderate parents’ style used for their children.
- Score more than 75% referred to high used parents’ socialization style

Methods for data collection:

An official approval was obtained to carry out this study from the Dean of Faculty of Nursing, Ain Shams University Also a letter containing the title and aim was directed to the Central agency for public mobilization and statistic, and also to ministry of education and directors of the previously mentioned settings

Content Validity and Reliability:

Content Validity The tools of data collection were tested by three experts from pediatric nursing, Ain Shams University to gain their experiences and opinions regarding the tools contents and modification was done accordingly.

Content reliability of the tool was tested to ensure that an assessment tool produces stable and consistent result over times. Reliability of the study tools was done tested statistically (**0.84**).

Pilot Study:

A pilot study was carried out including 10% (n =15) of sample size to evaluate the applicability, time needed for completing answers the tools of the Results of the data obtained from the pilot study were helped in modifications of study tools, where certain items were corrected, omitted or /and added as necessary The pilot participants were included in the main study sample.

Field Work:

The study was carried out over 3months for first week of February, (2018) up to the end of April (2018). The researcher was available in the study setting 4 days/week two days for each intellectual developmental school at Embaba and El-dokki at governmental Giza from 8.5 AM to 1 PM parents was individually interviewed by researcher for 30-45 minutes meeting about five parents daily.

Ethical consideration:

The study proposal was approved by scientific research ethics. Committee of faculty of Nursing /Ain Shams University. Also an official permission to conduct the study was secured from pertinent authorities all participants gave their oral They were assured, also that, anonymity, confidentiality was guaranteed. Also all the gathered data was used for research purpose only, and they have the right to withdraw the study at any time and without given any reason.

Results

Table (1): As regards the characteristics of studied children, this table showed that, more than half (53.4%) of them aged between 10 < 12 years old with mean age (10.4±1.9), while two thirds (60.7%) of them were males, more than three quarters (79.3%)

of them were illiterate. In addition to residence more than two thirds of them (65.3) were lived in rural area. Also one third (31.3%) of them were ranked as fourth child, in the family, 68.0% of studied children were diagnosed mental disability.

Table (2): As regards the characteristics of studied parents, this table cleared that, half (50.7 %) of them were in age group between 30 <40 years, while more than three quarters (78.0%) of parents were illiterate. Also (80%) of parents were not working.

Table (3): this table showed that, more than half (53.7%, 52.7% & 53.3%) of the studied parents were had unsatisfactory answered about, onset of symptoms & degree of mental disabilities respectively. Moreover near to two thirds of them (57.3%, 58.0%, 57.3%&62.7) of them unsatisfactory knowledge about causes, complications, treatment& different methods of dealing with mentally disabled child respectively.

While only half (50.0%) of the studied parents have satisfactory knowledge about symptoms of mental disabilities.

Table (4): this table showed that near to two thirds of studied parents (56.0%) have unsatisfactory total knowledge regarding disease of their children with mental disabilities, while, (44.0) of them have Satisfactory level of knowledge about the mental disabilities.

Table (5): this table shows that the parenting socialization styles used by parents toward their children suffering from mental disabilities the finding demonstrate that, the punitive style is the highest style (62.0%) used by parents. while the guidance style was lowest style (16.7) used by parents.

Table (6): This table showed that, positive correlation between parent's level of knowledge about mental disability disease and level of care for their mentally disabled children P value (0.03).

Table (1): Number and Percentage Distribution of studied children according to their characteristics (n=150).

Child's characteristics	No	%
Age (years):		
6 < 8 years	20	13.3
8 < 10 years	50	33.3
10 < 12 years	80	53.4
	Mean ±SD	10.4±1.9
Gender:		
Male	91	60.7
Female	59	39.3
Level of educational:		
Illiterate	119	79.3
Primary	31	20.7
Residence:		
Rural	98	65.3
Urban	52	34.7
Childs ranking:		
First	9	6.0
Second	35	23.3
Third	38	25.4
Fourth	47	31.3
Fifth	21	14.0
Type of mental disabilities:		
Mental only	102	68.0
Physical & mental disability	48	32.0

Table (2): Number and percentage distribution of studied parents according to their characteristics (n=150).

Parents characteristics	No	%
Age of parents in years:		
< 20 years	14	9.3
20< 30 years	48	32.0
30< 40 years	76	50.7
>40 years	12	8.0
Level of educational :		
Illiterate	117	78.
Read and write	29	19.3
Highly educated	4	2.7
Working:		
Working	30	20.0
Not working	120	80.0

Table (3): Number and percentage distribution of the studied parents knowledge regarding to mental disabilities (n=150).

Items	Satisfactory knowledge		Unsatisfactory knowledge	
	No	%	No	%
Definition of mental disabilities	62	41.3	88	53.7
Causes of mental disabilities	64	42.7	86	57.3
Onset of symptoms in years	71	47.3	79	52.7
Degree of mental disabilities	62	41.3	88	53.3
Clinical manifestations	75	50	75	50.0
Complication s of mental disabilities	63	42.0	87	58.0
Treatment of mental disabilities	64	42.7	86	57.3
Different methods of dealing with mentally disabled child	56	37.3	94	62.7

Table (4): Number and Percentage Distribution of the studied parents according to their total knowledge regarding to mental disabilities (n =150)

Knowledge of mental disabilities	No	%
Satisfactory	66	44.0
Unsatisfactory	84	56.0
Total	150	100

Table (5): Numbers and Percentages Distribution of the studied parents according to their total socialization style toward their children suffering from mental disabilities (n=150).

Parenting socialization styles	No	%
Punitive style:		
• Low score	10	6.7
• Mild score	47	31.3
• High score	101	67.3
Emotional deprivation style:		
• Low score	4	2.7
• Mild score	93	62.
• High score	45	30.0
Guidance style:		
• Low score	72	48.0
• Mild score	53	35.3
• High score	25	16.7

Number not mutually

Table (6): Correlation between Parent's Level of Knowledge and level of Care for their Mentally Disabled Children (n=150).

Items	Parent's knowledge	
	r-test	P value
Level of care for mentally disabled children	0.78	0.03

Discussion

The finding of the present study (**Table 1**): revealed that, more than half of the studied children were in the age group of 10 < 12 years with Mean \pm SD 10.4 \pm 1.9, These result was highly supported by **Mohammed (2014)**, who studied assessment burnout feeling among family member as a care giver of mentally retarded children, who mentioned that males affected by mentally disabled more often than female and the age of children ranged between 6 < 12 years, while this result contradict with study done by **Ahmad (2015)**, who studied health status and factors of mentally challenged children in school of mentally disabled children, mentioned that, the majority of mentally challenged children were in age from 5-9 years, while more than two thirds of them were males. These results was highly supported by **Awadalla et al. (2013)** who studied determination of maternal adaptation to mentally disabled child in ELminia, Egypt and found male children out numbered the female children by 3:1. Also this results in the same line with **Barakat & Linney (2016)**, studied children with physical handicaps and their mother relation of social support maternal adjustment and child adjustment and found that, the majority of children were male.

In relation to studied children characteristics namely; level of education, the present study illustrated that, more than three quarter of children were illiterate. This results is highly supported by **EL Saady (2014)**, who studies the epidemiology of disabilities among children at Mansheyet

Naser in Cairo city, and reported that, the majority of disabled children were not write and read. From the researcher point of view, due to low intelligence and poor academic performance, learning slow rate which due to the appropriate methods of teaching not used in schools.

As regards residence of the studied children the results revealed that, more than two thirds of the studied children were lives in rural area. Also ranked as fourth child in family. This finding was highly supported by **Sikandar & Pranati. (2015)**, who studied impact of disability of mentally retarded children on their parents Indian mentioned that, who found that the majority of mentally children live in rural area. From the researcher point of view it may be due to the bad effect of living in rural area than urban area and unavailable health care services, and faulty concepts unaware about mental disability.

Table (2): As regards the characteristics of studied parents, the present study showed that, Half of them were in age group between of 30 < 40years. This study was supported with **EL Malke (2014)**, who studied the effect of education program on parent of mental retarded children in their adjustment to their children problem Monufia University, who reported that, about two thirds of mother and most fathers of mentally retarded children aged between 35-45 years old. Also was confirmed by **Maryline & Flinsi (2015)**, who studied assessment the role of parents in the care of mentally challenged children selected special schools who reported that, the

majority of studied sample were mothers between age of 35 and above.

In relation to education level of parents, more than three quarter of parents were illiterate the result was confirmed with the study of *Demaso et al. (2014)*, who studied the impact of maternal perceptions and medical severity on the adjustment of children with mental handicaps who mentioned that, fathers and mothers of children with intellectual disabilities were differed. Fathers seemed to have a slightly better education than mothers. Also, *EL Atreby (2014)*, who studied community screening for common disabilities below fifteen years in Cairo University who found that, near to three quarters of mothers having disabled children was illiterate.

As regards the parents work, the present study revealed that, the majority of the parents had not working. This finding was in same line with performed by *Fathy (2015)*, who carried out a study about assessment of parents perception of support need to care for their mentally retarded children found that, the majority of mothers of disabled children were housewives.

Table (3): As regard to knowledge of studied parents sample regarding to mental disabilities results revealed that ,more than half of the studied parents having satisfactory knowledge about were, onset of symptoms & degree of mental disabilities respective, while near to thirds of them unsatisfactory knowledge about causes, complication, treatment& different method of dealing with mentally disabled child respectively. This study was supported by *Khatib (2016)* who study parental knowledge regarding mental retardation and special education. Majority of 78% of the family caregivers had inadequate knowledge, 20% had moderately adequate knowledge and only 2% of the family caregivers had adequate knowledge identification of signs and symptoms of mental retardation the

researcher belief this finding due to unawareness and low educational level of parents. From the researcher point of view this may be due to the absence of mass media role in raising awareness about mental disabilities among parents

Table (4): in relation to parents total knowledge this result finding that, near to two thirds of studied parents had unsatisfactory total knowledge regarding to mental disabilities support by *Vijayarani et al. (2016)* who study knowledge of family caregivers on care of mentally challenged children at selected institution, Bangalore, this results found that, 78% of the family caregivers had inadequate total knowledge.

Table(5): As regards of the studied parents according to their total parents socialization styles toward their children suffering from mental disabilities this finding showed that the punitive style is the highest score more than two thirds . While more than two thirds of the parents were mild score used emotional method, Moreover slightly less than half of the parents were low score used guidance style.*Brown (2017)* the impact of parenting on conduct disorder in Jamaican male adolescents reported that the low levels of cognitive found among mental retarded children in Jamaican suggest that the parents of this children used punitive style for their children

Table (6): It was observed from the current study that there was positive correlation between parent's level of knowledge about mental disability disease and level of care for their mentally disabled children. This result was supported by *El-Ganzory et al. (2014)*, who studied the effect of counseling on patterns of care, stress and life burden on parents of mentally retarded children. In Barwani, identified that, low level of knowledge associated with poor level of care of mentally disabled children. From the researcher point of view, the most

parents having inadequate knowledge about disease, which affects on the level of care for children , most parent make self care skills for their children as bathing .so most parents used over protection to protect their children from any hurts instead learning the children skills to be become independence self care.

Conclusion

Based on the findings of the present study, the parents' knowledge was unsatisfactory regarding to mental disability. Also, the levels of parental patterns of care were ranged from poor to an average level care in daily requirements such as bathing, eating and wearing clothes. Statistically significance differences in parenting socialization styles such as punitive style, emotional style and level of knowledge about mental disabilities. While the positive correlation between parent's level of knowledge about mental disability disease and level of care for their mentally disabled children

Recommendations

- Training programs and courses for parents about needs of mentally disabled children should be provided to help the parents deal with their children
- Utilize diverse communication channels, including community media, mass and traditional media, such as TV, puppetry, storytelling and interpersonal communication to eliminate stigma and to promote positive attitudes towards children with disabilities and their families.
- Counseling the parents with mentally retarded children. To reduce the level of social problems and to gain knowledge about their child's future and also about the help available from the society and government.

References

- Ahmad, N., (2015):** Study of health status and etiological factors of mentally challenged children in school for mentally challenged. Master Thesis. Faculty Medicine, Cairo University 7(6): 100:107
- Awadalla, H. (2013):** Determinants of maternal adaptation to mentally disabled children Master Thesis. Faculty Medicine in El Minia, Egypt. Pp 759-764.
- Barakat, L. & Linney, J, (2016):** Children with physical handicaps and their mothers: The interrelation of social support, maternal adjustment, and child adjustment. Journal of Pediatric Psychology, 17, 725-739.
- Brown, L., (2017):** The impact of parenting on conduct disorder in Jamaican male adolescents journal of Medical psychology 67, pp 37-50
- Demaso, D., Campis, L. & Wypij, D. (2014):** The impact of maternal perceptions and medical severity on the adjustment of children with mental hand capes disease. Journal of Pediatric Psychology, 16, 137-149
- EL Atreby, L., (2014):** Community Screening for Common Disabilities Blow Fifteen Years. Master Thesis., Faculty Medicine, Cairo University.
- EL Malk, M. (2014):** Effect of education program on parent of mental retarded children in their adjustment to their children problem, Doctoral thesis. Psychiatric Nursing Faculty of Nursing, Monofia University.
- EL Saady, H., (2014):** Epidemiology of Disabilities Among Children in An Under Privileged Area, Cairo City: Community Based Study, Master Degree in Epidemiology, Faculty of Medicine, Ain Shams University pp 102-110

- El-Ganzory, G., Abo El Matty G., & Abdel Rahman, M. (2014):** Effect of counseling on patterns of care, stress and life burden on parents of mentally retarded children. *Life*, 10: 1850-1858.
- Fathy, N. (2015):** Assessment of Parental perception of support needed to care for their mentally retarded children, master Degree in pediatric nursing, faculty of nursing, Cairo University
- Khatib ,B. (2016):** Parental knowledge regarding mental retardation and special education. *Karnataka J Agric Sci.*; 27:372-374
- Maryline &Flinsi (2015)** who study assessment the role of parents in the care of mentally challenged children selected special schools Of Tamilnadu
- Mohammed, A., (2014):** Burn out and Patterns among Family Members of Mentally retarded Children. {Master thesis} in Psychiatric Nursing Faculty of Nursing, Ain Shams University, pp.5-60
- Srikander A, & Pranti W,(2015):** Impact of disability of mentally retarded persons on their parents. *Indian Journal of Psychological Medicine*; 30, (2)98-104
- Vijayarani, G., (2016):** Who study Knowledge of family caregivers on care of mentally challenged children at selected institution, Bangalore.