

Psychological Problems and Coping Patterns among Parents of Children with Neuromuscular Diseases

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Abstract

Background: Neuromuscular diseases are chronic and have a large impact on patients and their families. **The study aimed to:** Assess psychological problems and coping patterns among parents of children's with neuromuscular diseases in pediatric intensive care unit. **Research design:** A descriptive research design was used to conduct the study. **Setting:** Study was conducted at pediatric intensive care unit affiliated to Benha university hospital, Qalyubia, Egypt. **Sample:** A total of 80 parents of children with neuromuscular diseases from the above mentioned setting. **Tools: Interview Questionnaire including 3 tools: Tool (I):** Demographic and clinical characteristics data for parents and children. **Tool (II)** Beck depression inventory scale and Taylor manifest anxiety scale. **Tool (III):** Parental coping strategy **Results:** Findings of the present study showed that, 58.8% of the parent of children with neuromuscular disease had moderate depression. 30.0% of the parents of children with neuromuscular disease had moderate level of anxiety. 78.75% of the parents of children with neuromuscular disease had effective coping. **Conclusion:** Parents of children with neuromuscular diseases prone to moderate level of anxiety and depression and had effective coping strategies. Parents of children with neuromuscular diseases needed different types of support that to continual care of their child. **Recommendation:** Psychosocial counseling program can be designed and administered to parents of child with neuromuscular disease to improve their psychological problems such as (anxiety, and depression) **Further research** is needed to shed light on the gaps in the support chain and the potential to improve the current care, to identify evidence-based family interventions that aim to support individual family members' well-being, integrity, and family functioning through the course of the disease and at important transitions.

Keywords: Neuromuscular Diseases, Parent Psychological Problems, Coping patterns.

Introduction:

Neuromuscular diseases is a general term that encompasses large number of diseases with different presentations, The terms muscle disease, myopathy, neuromuscular conditions and neuromuscular disorders all describe a large group of conditions which affect either the muscles, such as those in the arms and legs or heart and lungs, or the nerves which control the muscles (Kanso, 2020).

Neuromuscular disease is a condition that can be present at birth (congenital, often resulting from a mutation or mutations in the encoding genes), yet symptom onset may be delayed until later in an individual's lifetime. Neuromuscular diseases are classified into four main groups including: Motor neuron diseases, Neuropathies, Neuromuscular junction

disorders, Myopathies. The severity of conditions and how they affect individuals varies from person to person (Chikkannaiah & Reyes, 2021).

Children with neuromuscular diseases experience common complications, primarily due to immobility and weakness. Musculoskeletal complications include hip dysplasia with associated hip subluxation or dislocation, neuromuscular scoliosis, and osteoporosis and resulting fractures. Constipation, gastro esophageal reflux, and obesity and malnutrition are commonly experienced gastrointestinal complications. Disordered sleep also is frequently observed, which affects both children and caregivers (Kanso, 2020).

Neuromuscular diseases are chronic and have a large impact on patients and their families. While there is no cure for a neuromuscular disorder, there are an increasing number of therapies and treatments available that can improve children's quality of life and support physical functions. Earlier diagnosis and treatment of neuromuscular disorders optimises long-term function (**Patel et al, 2020**).

Parents, and especially mothers, are at risk of psychological distress, anxiety, depression, somatization, hopelessness, and posttraumatic stress symptoms, which in turn may influence mother's responsiveness. The families may be helped by early psychosocial interventions to alleviate stress and reduce children's emotional and behavioral problems (**Grunberg et al., 2021**).

Parents of children with neuromuscular diseases try to tolerate difficult conditions of care giving stress, control themselves, and behave patiently with the child and family members. Mothers attempt to resist hard feelings despite their worries about the future of their child's disease. Some parents use maladaptive (negative) coping strategies like crying to release their emotions, denying, worrying, and adopting aggressive behavior with medical staff. On the other hand, some parents use other coping strategies such as watching T.V, reading books, spending time out of home while their child was staying in pediatric intensive care unit (**Obeidat et al, 2020**).

Nurses, as social support personnel for sick children and their caregivers should provide empowerment-based health care education to parents of children with neuromuscular diseases children, improve parents caring knowledge and skills. Nurses should inform caregivers about the medical treatment and nursing information, and promptly appease any anxiety and confusion. In addition, nurses should offer lectures on nursing knowledge in the ward, establish a follow-up system, and select appropriate ways to answer questions from caregivers of different educational backgrounds (**Foli & Thompson, 2019**).

Significance of the Study:

Neuromuscular diseases are chronic and have a large impact on patients and their families. While there is no cure for a neuromuscular disorder, there are an increasing number of therapies and treatments available that can improve children's quality of life and support physical functions. Earlier diagnosis and treatment of neuromuscular disorders optimizes long-term function (**Patel et al, 2020**).

Neuromuscular diseases (NMDs) affect approximately one every 3,500 children worldwide, and Xlinked Duchenne muscular dystrophy (DMD) has the highest incidence among them (**Ravi et al, 2019**).

In Egypt neuromuscular diseases incidence per 100,000 was 26.8 for muscular dystrophy, 11.49 for myotonia, 11.49 for myositis, 17.24 for systemic myopathy and 9.57 for myasthenia (**Crisafulli et al, 2020**).

Therefore, it's important to provide psychosocial support for parents of children with neuromuscular diseases to reduce stressors and improve mental health wellbeing. So the psychiatric mental health nurse should understand neuromuscular diseases etiology, proactively managing the ongoing the physical impact of NMD on children daily life, and should be able to provide psychological and mental health support for children and their parents (**Birdsey, 2021**).

Aim of the study:

This study aim to assess psychological problems and coping patterns among parents of children's with neuromuscular diseases in pediatric intensive care unit.

Research question:

1. What are the psychological problems among parents of children's with neuromuscular diseases?
2. What are the coping patterns that used by parents of children's with neuromuscular diseases to adapted with psychological problems they faced?

Subjects and Methods:**Research design:**

A descriptive research design was used in carrying out the current study.

Setting:

The study was conducted at pediatric intensive care unit affiliated to Benha university hospital, Qalyubia, Egypt. The PICU contains 20 beds divided in 8 rooms. Benha university hospital very huge hospital with a land scape over two thousands and five hundred square meters. It consists of two buildings; the main building consists of eight floors with capacity of six hundred beds.

The researcher held the meeting by interviewing each parents individually at rest area .rest area is a large and well-ventilated room containing 30 to 35 chairs.

Subjects:**Sample Size:**

A total of 80 parents of children with neuromuscular diseases from the above mentioned setting.

Sample type:

A convenience sample of (80) parents of children who admitted to the previously mentioned setting.

The sample size was calculated based on:

$$N = \frac{N \times p (1-p)}{\{N-1 \times (d^2 \div z^2) + p (1-P)\}}$$

- Type I error with significant level (α) = 0.5.
- Type II error by power test (1-B) = 90%.

The minimum sample were (80) cases (*Suresh & Chandrashekara, 2012*).

Inclusion criteria for parents of children with neuromuscular disease include:

- Primary care givers.
- Stay with child in same house hold
- Age of parents is between 25:30 years old.
- Caring for child with neuromuscular diseases from birth to 6 months.

Inclusion criteria for children with neuromuscular disease include:

- Age of child up to 17 years old.
- Both sexes.

- Child diagnosis with neuromuscular disease at least six months.

Tools for data collection:

The data were collected using the three following tools:

Tool (I):- Socio - demographic and clinical characteristics data:

A. For parent: it includes age, sex, marital status, family members, level of education, and occupation.

B. For children: it includes ages, sex, Child sibling number, Ranking of the child among his sibling , onset of disease, heredity of the disease in the family, activities that require the most help, Time of child care, family help with care, problems while taking care of a child.

Tool (II):- Assess psychological problems for parents of children with neuromuscular diseases:**1) Beck depression inventory scale.**

It had been originally developed by **Aaron beck (1978)**, and Arabic version (BDI-II) modified by **Gharib Abd Elfattah (1996)**, to measure the intensity, severity&depth of depression. The inventory is composed of items relating to depressive symptoms such as hopelessness, irritability, cognitive such as guilt or feeling of being punished as well as physical symptoms such as fatigue, weight loss & lack of interest in sex .The scale consists of 21 questions, each with four possible responses.

❖ Scoring system:

Each items is rated on 4 point score ranging from zero to three, the maximum scores for entire scale is 63, which would be the maximum degree of depression measurable by this scale. The following charts were used in estimating each degree of depression:

0-9 referred to	" Minimal depression "
10-18 referred to	" Mild depression "
19- 29 referred to	" moderate depression "
30- 63 referred to	" Severe depression "

2) Taylor manifest anxiety scale:-

It is originally developed by **Janet Taylor (1953)** , and Arabic version of Taylor manifest anxiety scale modified by **Mostafa Fahmi and Mohamed Ahmed Ghali**, to measure the severity of anxiety of parents of children with

neuromuscular diseases. It consists of 50 statements, describe the different aspect of anxiety disorder including psychological, somatic or autonomic symptoms.

❖ Scoring system:

Each item was rated on true & false. If the answer is true the score will be one and if it is false the score will be zero. The false items: 1, 2, 3, 6, 9, 11, 14, 16, 23, 25, 30 & 38. The total scores range from 1-50 when the scores of true were summed; row scores for each scale show that:

- 0-16 referred to " non anxiety "
- 17-20 referred to "Mild anxiety "
- 21-26 referred to " Moderate anxiety "
- 27-29 referred to " Severe anxiety "
- 30- 50 referred to " Very severe anxiety "

Tool (III):- Parental coping strategy

It was developed by **Yeh (2001)**, to measure the coping methods among parents of children with neuromuscular diseases. It was consisted of 68 items divided into 12 subscales as following:

- Learning which consist of "10 question"
- Struggling which consist of "5 question"
- Interaction with child which consist of "6 question"
- Interaction with spouse which consist of "7 question"
- Interaction with healthy sibling which consist of "5 question"
- Emotion support which consist of "4 question"
- Information support which consist of "5 question"
- Actual support which consist of "4 question"
- Maintaining stability which consist of "8 question"
- Maintain optimistic state of mind which consist of "6 question"
- Searching for spiritual meaning which consist of "4 question"
- Increasing religious activates which consist of "4 question"

❖ Scoring system:

Each item was rated on four responses: strongly disagree = 1, disagree = 2, agree = 3, and strongly agree = 4.

The answer of each item converted to numerical data. The total score for all items was 272 scores categorized into:

- Effective coping 60% or more.
- Ineffective coping less than 60%.

Tools validity and reliability

To achieve the criteria of trustworthiness of the tools of data collection in this study, the tools were tested and evaluated for their face and content validity, and reliability. Face and content validity are tested by five experts from faculty members in the nursing field from Ain Shams and University. The reliability of the developed tool used was assessed through the internal consistency method using the Cronbach alpha coefficient test 0.77.

Reliability	No. of items	No. of cases	Cronbach Alfa
Parental coping strategy	68	80	0.77

Pilot Study:

A pilot study was applied on 10% (8) of parents of children's with neuromuscular diseases for the testing arrangement of the applicability of the items of the data collection tools and time consuming for each tool. This group of parents was included to the study sample. Data obtained from the pilot study analyzed and minor modifications were done for the used tools under supervision of the researcher supervisors.

Field of work:

An official approval letter clarifying the purpose of the present study was issued from the Dean of the Faculty of Nursing at Ain Shams University to the General Director Benha University Hospital and Scientific Research Ethical Committee in the Faculty of Nursing as an approval to conduct this study. The previously mentioned setting was attended by the researcher three days/week (Monday, Tuesday and Wednesday) from 9.00 a.m. to 2 p.m. This study started from beginning of January 2022, till the end of March 2022, covering three months for data collection.

Firstly, the researcher held the first meeting by interviewing each parents and their ill children individually after the doctor

examination to introduce him-self and briefly explained the nature and the purpose of the study. They were informed that participation in this study was voluntary and they had the right to withdraw at any time without giving any reason. Oral approval of parents and their ill children to share in this study was achieved.

Secondly, an interviewing questionnaire was distributed to each parents and their ill child to assess children's and parents socio-demographic characteristics, knowledge regarding child's illness and care. The questionnaire took about 10-20 minutes to be completed.

Then the researcher distributed the semi-structured questionnaire to assess psychological problems and coping pattern of parents of children with neuromuscular diseases. It was filled in by the parent in a time ranged from 20 to 30 minutes to be completed.

Administrative design:

An official permission letter was obtained from the Dean of the Faculty of Nursing / Ain Shams University after agreement of the Scientific Research Ethical Committee to the General Director Benha University Hospital at which the study was conducted, explaining the purpose of the study and requesting the permission for data collection from the study group.

Ethical considerations:

The ethical research considerations in this study included the following:

- The research approval was obtained from the Scientific Research Ethical Committee in the Faculty of Nursing, Ain Shams University before initiating the study work.
- The researcher clarified the objective and aim of the study to all the parents included in the study.
- Oral consents were obtained from all the studied parents.
- The questionnaire didn't include any immoral statements that touch parent's beliefs, dignity, culture, tradition and religious issues.
- All parents were informed that they are allowed to choose to participate or not in the

study and that they have the right to withdraw from the study at any time without giving any reason and confidentiality of the information was assured.

- All parents were informed that the collected data would be used only for the present study, as well as for their benefits.

Statistical design:

Data were collected, coded and entered into a personal computer (P.C). They were analyzed using Statistical Package for Social Science (SPSS), under windows version 20. The collected data were organized, revised, analyzed, tabulated using number and percent distribution. Proper statistical tests were used to determine whether there were statistically significant differences between the variables of the study. The statistical tests used in this study were:

1- Chi-square test X²/ Fisher Exact Test for qualitative variables.

2- Mann Whitney (U) test to find correlations between quantitative data.

- $P > 0.05$ there is a statistically insignificant difference
- $P < 0.05$ there is a statistical significant difference
- $P < 0.01$ there is a statistical highly significant difference

Results:

Table (1): show that, 55.0% of the parents were in age group 36-50 with mean age 36.08 \pm 6.22. Also, 42.5% of them had secondary level of education. In relation to job, 40.0% of the studied caregivers were employee. Additionally, 58.8% of them were from urban residence.

Table (2): shows that, 46.3% of children in age group 2-5 years, 61.3% of children were boys. Related to child health problem responsibility 61.2 % of parents need help their child in dressing activities. Regarding problems that encounter parents while taking care of a child with neuromuscular diseases, 50.0% reported that they can't understand what their child wants. Concerning to the needs that enable parents to take care of their child, 55.0 % of them need different service (cooperation of

other family members in care, existence of specialized rehabilitation centers, counseling from other family, the medical advice to deal with my child, medical information about the disease, prognosis of child disease).

Figure (1): illustrates that, 58.8% of the parent of children with neuromuscular disease had moderate depression.

Figure (2): illustrate that, 30.0% of the parents of children with neuromuscular disease had moderate level of anxiety.

Table (3): show that, 78.75% of the parents of children with neuromuscular disease had effective coping.

Table (3): shows that there was a significant statistical relationship between gender of the studied parents and their total depression level at p-value= 0.031. While, there was no significant statistical relationship between age, education, job and residence of the

studied parents and their total depression level at p-value= 0.721, 0.968, 0.329 and 0.277 respectively.

Table (4): shows that there was a significant statistical relationship between gender and education of the studied parents and their total anxiety level at p-value= 0.034 and 0.026 respectively. While, there was no significant statistical relationship between age, job and residence of the studied parents and their total depression level at p-value= 0.241, 0.585 and 0.114 respectively.

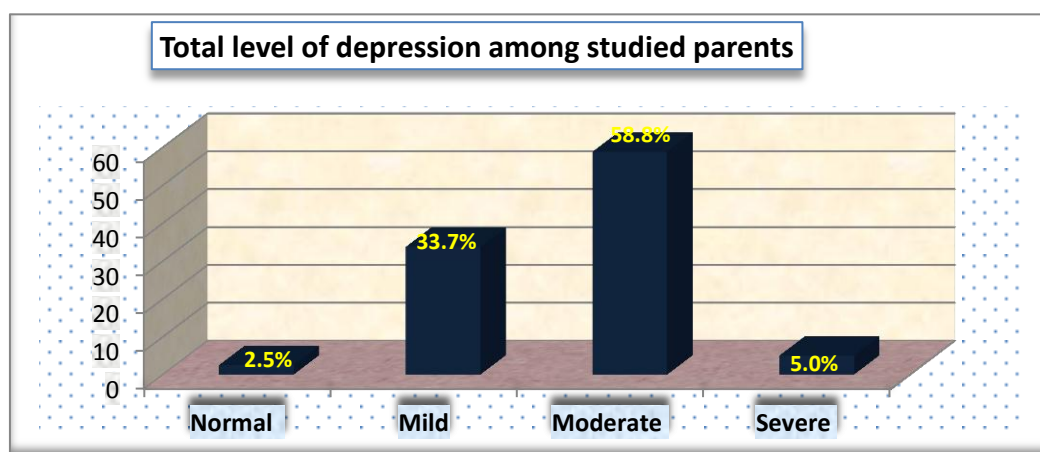
Table (5): shows that there was a significant statistical relationship between education of the studied parents and their total coping level at p-value= 0.028. While, there was no significant statistical relationship between age, gender, job and residence of the studied parents and their total depression level at p-value= 0.428, 0.197, 565 and 0.584 respectively.

Table (1): Distribution of the parents according to their socio- demographic characteristics (n=80).

Items	N	%
Age (in years)		
20-35	36	45.0
36-50	44	55.0
Range	23-48	
Mean ± SD	36.08±6.22	
Education		
Illiterate	8	10.0
Read/write	11	13.8
Primary	1	1.3
Prep	2	2.5
Secondary	34	42.5
University	17	21.3
Post graduate	7	8.8
Job		
Employee	32	40.0
Crafts	10	12.5
On pension	1	1.3
No work / housewife	30	37.4
Others	7	8.8
Residence		
Rural	33	41.3
Urban	47	58.8

Table (2): Distribution of children with neuromuscular diseases according to their socio-demographic characteristics of (n=80).

Items	N	%
Children's age (in years)		
Newborn-1 year	20	25.0
2- 5	37	46.3
6 - 10	14	17.5
11 - 15	9	11.3
Children sex		
Boys	49	61.3
Girls	31	38.8
Child sibling number		
One	5	6.3
Two	21	26.3
Three	31	38.8
Four	23	28.8
Ranking of the child among his sibling		
The 1 st	28	35.0
the 2 nd	36	45.0
The 3 rd	15	18.8
the 4 th	1	1.3
The last	0	0.0
What is the age of discovered disease		
At the birth	39	48.8
1 month to< 1 year	24	30.0
1 year to 5 years	17	21.0
Is there heredity of the disease in the family?		
Yes	33	41.3
No	47	58.8
What are the activities that require the most help?		
Assistance to and the bed or seat	29	36.2
Using the bathroom to defecate	18	22.5
Bathing	62	77.5
Dressing activities	49	61.2
Feeding	23	28.7
Take medicine	45	56.2

**Figure (1):** Total Level of Depression among the studied parent of children with neuromuscular disease (n=80).

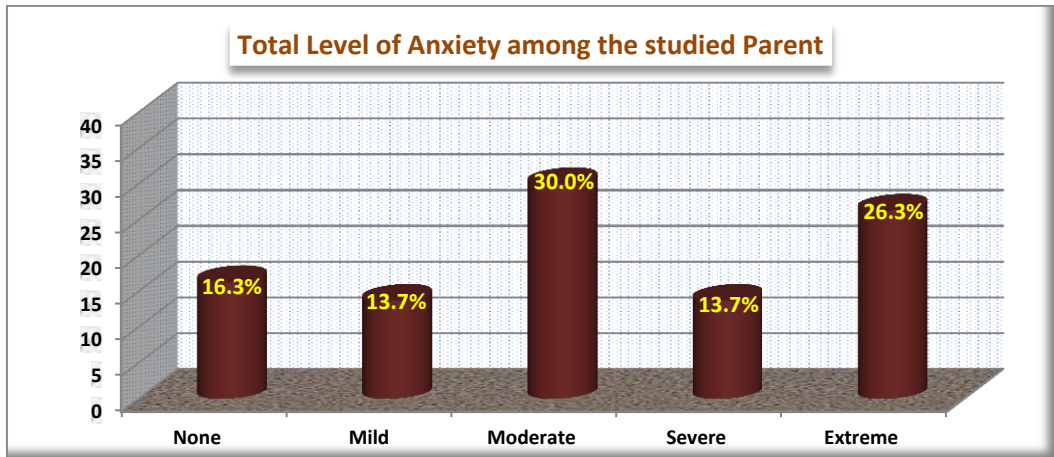


Figure (2): Total Level of anxiety among the studied parent of children with neuromuscular disease (n=80).

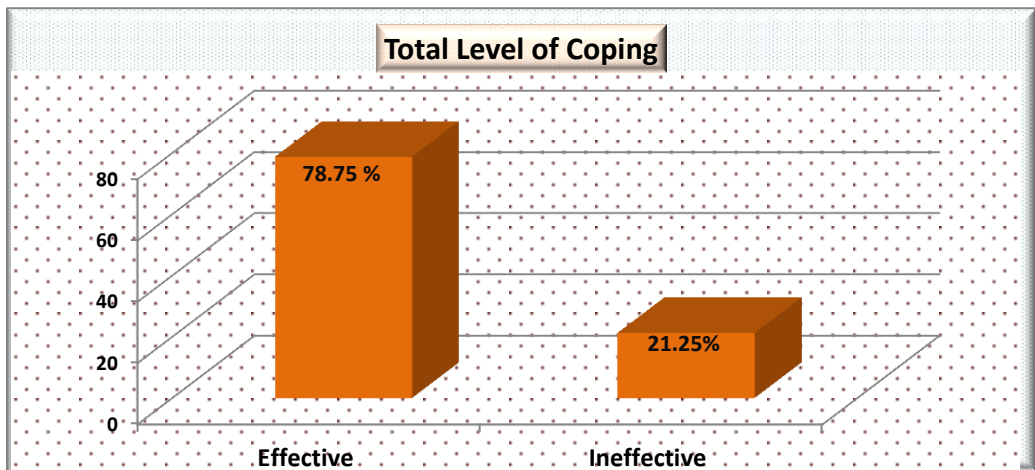


Figure (3): Total Level of coping among the studied parent of children with neuromuscular disease (n=80).

Table (3): Relationship between demographic characteristics of the studied parents and their total depression level (n=80).

Socio-demographic characteristics	N	Mean Rank	Mann Whitney (U) test	P-value
Gender				
Fathers	31	35.58	1.510	0.031*
Mothers	49	43.61		
Age(in years)				
20-35	36	39.44	0.369	0.712
36-50	44	41.36		
Education				
Illiterate	8	41.31	1.370	0.968
Read/write	11	37.14		
Primary	1	36.50		
prep	2	49.25		
Secondary	34	38.56		
University	17	43.35		
Post graduate	7	45.34		
Job				
Employee	32	38.78	4.618	0.329
Crafts	10	40.10		
On pension	1	12.50		
No work / housewife	30	45.82		
Others	7	30.14		
Residence				
Rural	33	43.86	1.088	0.277
Urban	47	38.14		

Table (4): Relationship between demographic characteristics of the studied parents and their total anxiety level (n=80).

Socio-demographic characteristics	N	Mean Rank	Mann Whitney (U) test	P-value
Gender				
Fathers	31	44.90	1.512	0.034*
Mothers	49	37.71		
Age(in years)				
20-35	36	38.03	1.182	0.241
36-50	44	42.52		
Education				
Illiterate	8	38.44	13.671	0.026*
Read/write	11	34.05		
Primary	1	63.50		
prep	2	73.25		
Secondary	34	37.53		
University	17	36.94		
Post graduate	7	63.43		
Job				
Employee	32	39.14	2.389	0.585
Crafts	10	33.20		
On pension	1	31.00		
No work / housewife	30	42.28		
Others	7	50.86		
Residence				
Rural	33	45.39	1.732	0.114
Urban	47	37.06		

Table (5): Relationship between demographic characteristics of the studied parents and their total coping level (n=80).

Demographic characteristics	Total Coping Level				X ² / Fisher Exact Test	P- value
	Effective		Ineffective			
	N	%	N	%		
Gender						
Fathers	23	28.8	8	10.0	0.628	0.428
Mothers	40	50.0	9	11.2		
Age (in years)						
20-35	26	32.5	10	12.5	1.667	0.197
36-50	37	46.2	7	8.8		
Education						
Illiterate	6	7.5	2	2.5	1.907	0.028*
Read/write	8	10.0	3	3.8		
Primary	1	1.2	0	0.0		
prep	1	1.2	1	1.2		
Secondary	27	33.8	7	8.8		
University	14	17.5	3	3.8		
Post graduate	6	7.5	1	1.2		
Job						
Employee	25	31.2	7	8.8	2.958	0.565
Crafts	6	7.5	4	5.0		
On pension	1	1.2	0	0.0		
No work / housewife	25	31.2	5	6.2		
Others	6	7.5	1	1.2		
Residence						
Rural	25	31.2	8	10.0	0.301	0.584
Urban	38	47.5	9	11.2		

Discussion:

Caring for a child with a neuromuscular condition presents many challenges, including managing the emotional impact of the diagnosis, managing extended periods of profound uncertainty, navigating the complexities of the healthcare system, managing the child's physical symptoms, and supporting their emotional needs, the psychosocial needs of individuals and their families have traditionally been considered as ancillary to the child's physical health needs. Caregivers experience multiple stressors and often encounter caring burden and high prevalence rates of anxiety and depression (Birdsey, 2021).

Coping of parents of children with neuromuscular diseases, parents may feel isolated when they find out their child has a neuromuscular disease. Feelings of helplessness and despair are common as they initially learn about the disease, but these feelings often turn to hope and determination as they discover ways to be active in their child's treatment. As

the child gets older, it's common for parents to hide many of their feelings to appear strong for their child and the rest of the family, but it's important parents deal with anxiety and depression before those emotions negatively impact their health (Obeidat et al, 2020).

The study aimed to assess psychological problems and coping patterns among parents of children with neuromuscular diseases.

As regards to gender of caregiver, the present study illustrated that less than two thirds of the studied parents were mothers and rest of them were fathers. From researcher point view, this result might be due to mother source of compassionate, care and had ability to provide dealing with their child especially during diseases. This result supported with study by Xu et al., (2020) who conducted study about "Evaluation of assessment of caregiver experience with neuromuscular disease" and founded that most of the studied caregivers were mothers.

As regard to sex of the studied children, the result of present study demonstrated that

less than two thirds of the studied children were males. this outcome consistent with study by **Yu et al., (2022)** entitled " Impact of COVID-19 pandemic on the psychosocial well-being of children with neuromuscular disorders" and reported that more than half of the studied children with neuromuscular disorders were males. moreover, this finding supported with study by **Garrity et al., (2019)** who conducted study about " Parent-to-parent advice on considering spinal fusion in children with neuromuscular scoliosis" and showed less than two thirds of the studied children with neuromuscular were males.

Related to activities that require the help, the present study showed that less than of two thirds of the studied parents need help their child in dressing activities. From researcher point view, this result might be due to most of the studied child were preschool age. this finding in same line with study by **Gosar et al., (2021)** who conducted study about " Adaptive skills and mental health in children and adolescents with neuromuscular diseases" and reported that children's with neuromuscular diseases showed motor and Self-Care skills and a below those of healthy peers.

According to the needs of parents to take care of their child, the result of current study illustrated that half of the studied parents need to existence of specialized rehabilitation centers. from researcher point view, this result might be due to needs of their children to care with specialized health care team at any time. this finding was agreement with **Bos et al., (2019)** who conducted study about " The prevalence and severity of disease-related disabilities and their impact on quality of life in neuromuscular diseases" and represented that there lack of specialized rehabilitation centers and most of the studied sample need specialized rehabilitation centers.

According to total level of depression among the studied parent of children with neuromuscular disease, the current study illustrated that, less than two thirds of the studied caregivers had moderate depression, from researcher point view, this result might be due to parents having a child with developmental or psychological problems is always stressful for their parents who are taking

care of them, even when the child is a grown up person, which would cause a constant incompatibility of parents with their child's diseases. These parents, other than bearing financial pressures, are always facing emotional pressures such as feeling ashamed or feeling guilty, anxiety and stress. this result supported with study by **Rutkowski et al., (2021)** who conducted study about " Parent Perspectives on Neuromuscular Disorders: From Diagnosis, to Parenting and Living With, to Advance Care Planning and Preparing for Death" and more than half of the studied parents of children with Neuromuscular Disorders had moderate depression.

As regards to Total Level of anxiety among the studied parent of children with neuromuscular disease, the result of current study illustrated that, less than one third of the studied parents had moderate level of anxiety. From researcher point view, this result might be due to parents investing a lot of time with their child to meet their needs, he also said that the more time spend with the child. this result supported with study by **Birdsey, (2021)** who conducted study about " CBT for anxiety related to parenting a child with a life-limiting neuromuscular condition" and illustrated that less than three quateres of the studied parents had anxiety and more than one third of them had moderate level of anxiety. conversely, this finding contraindicated with **Grossoehme et al., (2022)** who conducted study about " Assessment of the relationship between disease progression and goals of care by individuals with Duchenne muscular dystrophy and their caregivers" and reported that most of the studied caregivers report very high levels of anxiety .

Regarding to Total Level of coping among the studied parent of children with neuromuscular disease, the present study **showed that**, more than three quarters of the studied parents had effective coping. this result consistent with study by **Tesei et al., (2020)** who conducted study about "Mental health and coping strategies in families of children and young adults with muscular dystrophies" and reported that most of studied parents have effective coping.

As regards to Relationship between demographic characteristics of the studied parents and their total depression level the present study illustrated that, there was a significant statistical relationship between gender of the studied parents and their total depression level at $p\text{-value} = 0.031$. While, there was no significant statistical relationship between age, education, job and residence of the studied parents and their total depression level at $p\text{-value} > 0.05$. this result **Goemans, (2019)** who conducted study about " Neuromuscular Disorders in Children" and displayed that there was a significant statistical relationship between gender of the studied parents and their total depression level at $p\text{-value} < 0.05$.

The present study showed that, there was a significant statistical relationship between gender and education of the studied parents and their total anxiety level at $p\text{-value} < 0.05^*$ respectively. While, there was no significant statistical relationship between age, job and residence of the studied parents and their total depression level at $p\text{-value} > 0.05$. from researcher point view, this result might be due to educated parents are more aware of possible illness-related threats. this finding matched with study by **Yilmaz, (2020)** entitled "Mothers with disabled children: needs, stress levels and family functionality in rehabilitation" and concluded that there was a significant statistical relationship between gender and education of the studied parents and their total anxiety level at $p\text{-value} < 0.05^*$

Regarding to Relationship between demographic characteristics of the studied parents and their total coping level, the result of present study illustrated that there was a significant statistical relationship between education of the studied parents and their total coping level at $p\text{-value} = 0.028$. While, there was no significant statistical relationship between age, gender, job and residence of the studied parents and their total coping level at $p\text{-value} > 0.05$. From researcher point view, this result might be due to with increase level of education increase ability to deal with problems. this finding similar with result of **Travlos et al., (2017)** who conducted study about "Quality of life and psychosocial well-being in youth with neuromuscular disorders who are wheelchair

users" and concluded that there was a significant statistical relationship between education of the studied parents and their total coping level at $p\text{-value} < 0.05^*$. On the contrary, this finding dissimilar with result of **Piran et al., (2017)** who conducted study about " Caregiving burden of children with chronic diseases" and showed that there was no significant statistical relationship between education and their total coping level at $p\text{-value} > 0.05$.

Regarding the correlation between studied variables, there was a statistically significant negative correlation between total coping of the studied parents and their total anxiety symptoms at $P\text{-value} = 0.00$, moreover there was a statistically significant negative correlation between total coping of the studied parents and their total depressive symptoms at $P\text{-value} = 0.018$. These results supported with the study by **Tesei et al., 2020** who conduct study about Mental health and coping strategies in families of children and young adults with muscular dystrophies and found that there was high negative correlation between coping strategy among families and their depression level. Also, agree with the study by **Galal Abdelrahman et al., 2022** who conduct study about psychological distress and coping strategies among parents with deaf and mute children and stated that there was negative correlation between anxiety and stress level with using coping pattern at $p\text{ value} < 0.01^{**}$.

Conclusion:

In the light of the current study findings, it can be concluded that,

- Parents of children with neuromuscular diseases prone to moderate level of anxiety and depression and had effective coping strategies .parents of children with neuromuscular diseases needed different types of support that to continual care of their child .
- The present study recommends that Assessment of parental stress, parental health related quality of life and family functioning should be part of the basic of care for families with affected child with neuromuscular disease.

Recommendation:

- Psychosocial counseling program can be designed and administered to parents of child with neuromuscular disease to improve their psychological problems such as (anxiety, and depression).
- Applying educational interventional program for enhancing mental health of family caregiver of Children with neuromuscular disease.
- Apply evidence-based intervention strategies for families of Children with neuromuscular disease facing hardship, risk and weakness during a child's disease.
- Assessment of parental stress, parental health related quality of life and family functioning should be part of the basic of care for families with affected child with neuromuscular disease.

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