

The Coping Pattern and Awareness of Parents for their Children Complaining from Spinal Muscular Atrophy

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Abstract

Spinal Muscular Atrophy (SMA) is a life-limiting genetic disorder that affects the muscles and causes weakness and wasting. Parents of children with SMA face significant challenges in caring for their children, including coping with the emotional and practical aspects of the condition. **Aim of the study:** To assess the Coping pattern and awareness of parents for their children complain from spinal muscular atrophy **Research design:** A descriptive research design was used in this study. **Setting:** The study was conducted in the outpatient clinics of Health Insurance in Cairo two clinics in Naser clinic and clinic of Naser City Hospital **Sample:** A purposive sample was used in this study. The sample was equal 367 of parents of diagnosed cases with SMA. **Tools:** One tool used: structured Interviewing questionnaire. It consist of 6 parts: 1) Socio-demographic characteristics, 2) Family and child past history, 3) Parents' knowledge related to SMA disease, 4) Parents' attitude regarding their SMA children, 5) The parents' reported practice regarding their children motor skills, 6) Jaloweic Coping Scale. **Results:** The study result revealed that, 79.6% of parents had poor level of knowledge, 51.2% had adequate level of practice, 52.3% had negative attitude regarding Children Complaining from SMA. Also, 70.8% had positive coping pattern. (P= 0.000). **Conclusion:** Significant relation between knowledge, practice, attitude and coping and all demographic characteristics except residence, job with attitude. There was statistically significant relation between parents' knowledge, practice, and total attitude. (P= 0.000). **Recommendation:** Procedure pamphlets and booklet containing all essential information about SMA should be disseminated at hospitals among parents of children complaining from SMA.

Key words: Spinal Muscular Atrophy, Coping pattern, Awareness, Parents, Children

Introduction

Children are defined as young human beings who have not yet reached adulthood, typically ranging in age from infancy to adolescence. Despite their youth, children are capable of remarkable growth and development, both physically and mentally. During the early years of life, children undergo rapid physical changes as they learn to walk, talk, and interact with the world around them. As they grow older, they continue to develop socially and emotionally, building relationships with family members, friends, and peers, and discovering their own unique interests and talents (Christian & Smith, 2018).

Spinal muscular atrophy (SMA) is a rare genetic disorder that affects the part of the nervous system responsible for controlling voluntary muscle movement. SMA is caused by a mutation in the SMN1 gene, which produces a protein called survival motor neuron (SMN). Without enough SMN protein, the nerve cells that control muscle movement degenerate, leading to muscle weakness and atrophy (Wirth et al., 2020).

Spinal muscular atrophy (SMA) progressively destroys motor neurons which control essential skeletal muscle activity leading to muscle weakness and atrophy. Motor neurons control movement in the arms, legs, chest, face, throat, and tongue. When there are disruptions in the signals between motor neurons and muscles, the muscles gradually weaken, begin wasting away and develop twitching called fasciculation (WHO, 2021).

Spinal muscular atrophy (SMA) can present in children at different ages and with varying severity. SMA is the number one genetic cause of infant mortality. Children with SMA face a range of challenges related to their condition, including difficulty with mobility, breathing, and swallowing, as well as increased risk of infections and other health complications. These challenges can impact not only their physical health, but also their emotional and psychological well-being (Wirth et al., 2020).

Coping patterns for children with SMA can vary widely depending on the child's age, personality, and severity of symptoms. Coping mechanisms are the strategies that people use to manage stressful or difficult situations and emotions. Some children with SMA may rely on social support from family and friends, while others may find comfort in hobbies or creative activities. In addition to these coping mechanisms, interventions such as behavioral therapy and mindfulness practices may also help children with SMA manage their emotions and improve their overall quality of life (Muscular Dystrophy Association, 2021).

Awareness of parents for their children complaining from SMA is essential to provide the necessary support and resources to help their children thrive. One of the most important aspects of parental awareness for children with SMA is understanding their child's unique needs and limitations. Parents should also be aware of the physical interventions and treatments that can help their child manage their symptoms (Brandt et al., 2021).

Parents should also be aware of the emotional and psychological impact that SMA can have on their child. Children with SMA may experience feelings of frustration, isolation, and anxiety related to their physical limitations and the challenges they face in daily life. Parents can help support their child's emotional well-being by creating a safe and nurturing environment, and providing social support and encouragement (Brandt et al., 2021).

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Community health nurses can provide important support for individuals and families affected by spinal muscular atrophy (SMA). Community health nurses can provide health education and promotion, disease prevention and management, access to community resources, and emotional support and advocacy for individuals with SMA. By working collaboratively with individuals and families, local organizations, and government agencies (**Ministry of Health and Population in Egypt, 2022**).

Significance of the study

Egyptian Ministry of Health and Population revealed the details of activating the initiative of President Abdel Fattah El-Sisi of the republic to treat muscular dystrophy patients free of charge and detect genetic disease early in Egypt, and provide medical service through the availability of gene therapy for infected children, as part of the concern for public health and achieving Egypt's vision 2030, confirming that 24 centers have been allocated to receive and evaluate cases, in addition to 3 centers for the treatment of patients after their evaluation and classification. There are no previous statistics in Egypt until the beginning of the presidential initiative (**Ministry of Health and Population in Egypt, 2021**).

President Abdel-Fattah El-Sisi has played a major role in treating patients with SMA, and we reveal in the following lines what the initiative has provided so far. Receiving 8.124 cases in clinics designated to receive children with muscular dystrophy at the level of the Republic. Providing free gene therapy services to injured children. 413 cases of muscular dystrophy were diagnosed after conducting the necessary clinical tests, genetic tests and partial biology. 95 cases were transferred from them after completing their medical file. Completion of gene therapy injections for 28 children with SMA (**Ministry of Health and Population in Egypt, 2022**).

Aim of the Study

To assess the Coping pattern and awareness of parents for their children complain from spinal muscular atrophy.

The aim will be achieved through the following objective:

- 1- Assessing knowledge and reported practice of parent for their children complain from spinal muscular atrophy.
- 2- Appraising parents' attitude for their children complain from spinal muscular atrophy.
- 3- Identifying coping pattern of parent for their children complain from spinal muscular atrophy.

Research questions:

- 1- What is the parents' knowledge, attitude and reported practice regarding children with spinal muscular atrophy?
- 2- What is the coping pattern of parent for their children complain from spinal muscular atrophy?
- 3- Is there relation between parents' knowledge, attitude, reported practice and their coping pattern for their children complain from spinal muscular atrophy?



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Subject and Methods

Research design:

A descriptive research design was used in this study.

Setting:

The study was conducted in the outpatient clinics of Health Insurance in Cairo two clinics in Naser clinic and clinic of Naser City Hospital)

Sampling:

A Purposive sample was used to achieve the aim of the study with the following inclusion criteria:

- Parent aged 18 years and more.
- Responsible for providing care for the children complain from S M A.
- Accept to participate in the study
- Available at the time of data collection

Tool for data collection:

Structured Interviewing questionnaire

It was developed by investigator after reviewing the national and international related literature and approved by Supervisions. It was written in Arabic language and consists of six parts **as the following:**

Part (1): Socio-demographic characteristics of parents such as age, gender, residence, social status, level of education, occupation, and Child's Demographic Characteristics such as age, sex.

Part (2): Family and child past history, such as number of family history with SMA, Consanguinity between parents, mother's problems during pregnancy, problems during childbirth and child growth during first 2 years.

Part (3): Parents' knowledge related to SMA disease, such as meaning, signs and symptoms, severity of disease, reasons for outpatient visit detection, time required, importance of early intervention and importance of physical and rehabilitation treatment. This part composed of 7 close end questions and it was used to determine knowledge of parents about the spinal muscular atrophy.

Scoring system

Each knowledge question was scored by zero for wrong or no answer, one for «correct incomplete » and two for (complete correct). The total knowledge scores ranged from 0-14, were evaluated as follows:

- Poor less than 50% (1-6.9)
- Average from 50%:75% (7-10.5)
- Good more than 75 % (11-14)

Part (4): Parents' attitude regarding their SMA children such as nature of the disease - child problems, family problems, feelings of frustration and psychological pressure and parents' ability to self-management. This part composed of 23 close end questions and it was used to determine attitude of parents about the muscular spinal atrophy.

Scoring system

23 closed ended questions. Each question was scored by one for «never», two for a «sometimes » and three for «always» questions an summed up with mean and standard deviation and also 69 scores divided into two category in the following :

- Negative less than 50% (1-34.4)
- Positive from 50%:100% (34.5-69)

Part (5): The parents' reported practice regarding their children motor skills such as motor skills improvement, personal care skills, hand-washing skills, nutrition, dental cleaning skills and develop the skill of prepare bath. It includes 48 closed ends question.

Scoring system

48 closed ended questions. Each practice question was scored by one for a «done practice», zero for a «not done ».

- Inadequate less than 50% (0: 23.9)
- Adequate from 50%:100% (24:48)

Part (6): Jaloweic Coping Scale: was developed by Jaloweic and Power in 1981. And then translated into Arabic and used by Abd El Meguid (Abd El Meguid, 2000) and was approved for validity and reliability by (Fadila, 2007), it indicated that the scale has reliability of 0.78. Jaloweic coping scale consists of 40 items, classified into 15 problem-oriented coping behaviors, and 25 affective oriented behaviors.

Scoring system

The scale uses 5-point Likert scale with response options of always (4), often (3), about half the time (2), occasionally (1), and never (0). The higher score indicates greater use of particular coping behavior with 160 total score that divided to two category as the following:

- Negative less than 50% (0-79.8)
- Positive from 50%:100% (79.9-160)

Validity:

The study tools were tested for content and face validity by jury test of five experts in the field of nursing community and pediatric to evaluate the individual items as well as the entire instrument as being relevant and appropriate to test what they wanted to measure. The face validity of the questionnaire was calculated based on experts' opinion after calculating content validity index (%) of its items and it was 94%.

Reliability:

To assess reliability, the study tool was tested by the pilot subjects for calculating Cronbach's Alpha which was 0.80 for knowledge questionnaire, 0.85 for practice questionnaire and 0.99 for attitude and coping questionnaire.

- ***Ethical considerations:***

An official permission to conduct the proposed study obtained from the Scientific Research Ethics Committee of faculty of nursing Helwan University. Participation in the study is voluntary and subjects given complete full information about the study and their role before signing the informed consent. The ethical considerations included explaining the purpose and nature of the study, stating the possibility to withdraw at any time, confidentiality of the information where it was not accessed by any other party without taking permission of the participants. Ethics, values, culture and beliefs will be respected.

II- Operational Item:

Preparatory phase:

It included reviewing of past, current, national and international related literature and theoretical knowledge of various aspects of the study using books, articles, internet, periodicals and magazines to develop tools for data

Pilot study:

A pilot study was carried out on 10% (37) from the study subjects and was included in the total sample.

Field work:

Data collected within three months of year (2023) two days /week from 9am - 2pm at Sunday and Wednesday, till the needed sample completed, interview of parents, oral approval obtained from parents after the investigator introduce her to each parent, then explain the purpose of the study to assess knowledge, attitude, practice and coping pattern of parents for their children complaining from spinal muscular atrophy. Study collected through structure face to face interview and the entire tool filled by the investigator. The investigator utilize one tool that divide into six parts, the tool will need 30-40 minutes to fill. Data collected from 10 participants three days weekly for 3 months.

III- Administrative Item:

Approval to carry out this study obtained from Dean of Faculty of Nursing, Helwan University. An official letter from the responsible authorities at the Faculty of Nursing Helwan University will be directed to the heads of Health Insurance organization in Cairo (2 clinics) (Nasser clinic and clinic of Naser City Hospital) for conducting the study.

IV-Statistical Item:

The collected data were organized, tabulated and statistically analyzed using SPSS software (Statistical Package for the Social Sciences, version 16, SPSS Inc. Chicago, IL, USA). For quantitative data, the range, mean and standard deviation were calculated. For qualitative data, which describe a categorical set of data by frequency, percentage or proportion of each category, using Chi-square test (Chi 2). Correlation between variables was evaluated using Pearson's correlation coefficient (r). Significance was adopted at $p < 0.05$ for interpretation of results of tests of significance.

Results

Table (1): shows that 44.4% of parents aged from 35 to 45 years old. 60.5% of parents are female. 100% of sample are married. 55.6% of parents have secondary school and only 3% have basic education. According to residence the result reveals that 69.2% of parents are from urban area. Regarding job the result reveals that 54.2% of parents are not working. Concerning family monthly income the result reveals and 97% of parents have not enough income.

Table (2): Shows that 30.8 % of children aged 4 to less than 6 years while only 14.2% is from 2 to 4 years. Regarding sex, the result reveals that 54.5% of the children are male. According to educational level of children, the result reveals that 67.8% of children are at KG.

Table (3): shows that, 79.6% of parents had poor level of knowledge while only 20.4% of parents had average level of knowledge.

Table (4): shows that 51.2% of parents had adequate level of practice while 48.8% of parents had inadequate level of practice.

Figure 3: shows that 52.3% of parents had negative attitude regarding Children Complaining from Spinal Muscular Atrophy while 47.7% of parents had positive attitude.

Figure 4 shows that 70.8% had positive coping pattern while 29.2% of parents had negative coping.

Table (20): Illustrate that, there are highly statistically significant relation between parents total knowledge, total practice and their total attitude ($P = < 0.000$). Also, there was highly statistically significant relation between parents total attitude and their total coping ($P = < 0.000$). But there are not statistically significant relation between total knowledge, practice, and coping pattern.

Table (1): Number and percentage distribution regarding Sociodemographic characteristics of parents for their Children Complaining from Spinal Muscular Atrophy (n= 367).

Parent demographic characteristics	No	Percent
Age		
✓ 18 - 25 years	48	13.1
✓ 25 – less than 35 years	120	32.7
✓ 35 - 45 years	163	44.4
✓ More than 45 years	36	9.8
Sex		
✓ Male	145	39.5
✓ Female	222	60.5
Social status		
✓ Married	367	100
Education levels		

✓ Read and writes	41	11.2
✓ Basic education	11	3
✓ Secondary education	204	55.6
✓ University education	111	30.2
Residence		
✓ Rural	113	30.8
✓ Urban	254	69.2
Job		
✓ Working	168	45.8
✓ Not working	199	54.2
Family monthly income		
✓ Not enough	356	97
✓ Sufficient for basic needs only	11	3

Table (2): Number and percentage distribution regarding demographic characteristics of Children Complaining from Spinal Muscular Atrophy (n= 367)

Child demographic characteristics	No	Percent
Child age		
✓ less than 1 years	68	18.5
✓ 1 – 2 years	55	15
✓ 2 – 4 years	52	14.2
✓ 4 – less than 6 years	113	30.8
✓ 6 – 12 years	79	21.5
Sex		
✓ Male	200	54.5
✓ Female	167	45.5
Education levels		
✓ K. G	249	67.8
✓ Primary	79	21.5
✓ Non	39	10.6

Table (3): Number and Percentage Distribution of Total knowledge among parents regarding Children Complaining from Spinal Muscular Atrophy (n= 367)

Total parent's knowledge	Studied Sample		χ^2	P
	No.	%		
Levels of total parents knowledge:			117.4	0.000

Poor	292	79.6		
Average	75	20.4		
Good	--	--		
Range	11			
Mean ± SD	7.43±3.13			

Table (4): Number and Percentage Distribution of Total reported practices among parents regarding Children Complaining from Spinal Muscular Atrophy (367)

Total parent's reported practices	Studied Sample		χ^2	P
	No.	%		
Levels of total parents practices:				
Adequate	188	51.2	233.5	0.000
Inadequate	179	48.8		
Range	36			
Mean ± SD	24.34±9.02			

Figure (1): Percentage Distribution of Total attitude among parents regarding Children Complaining from Spinal Muscular Atrophy (n= 367)

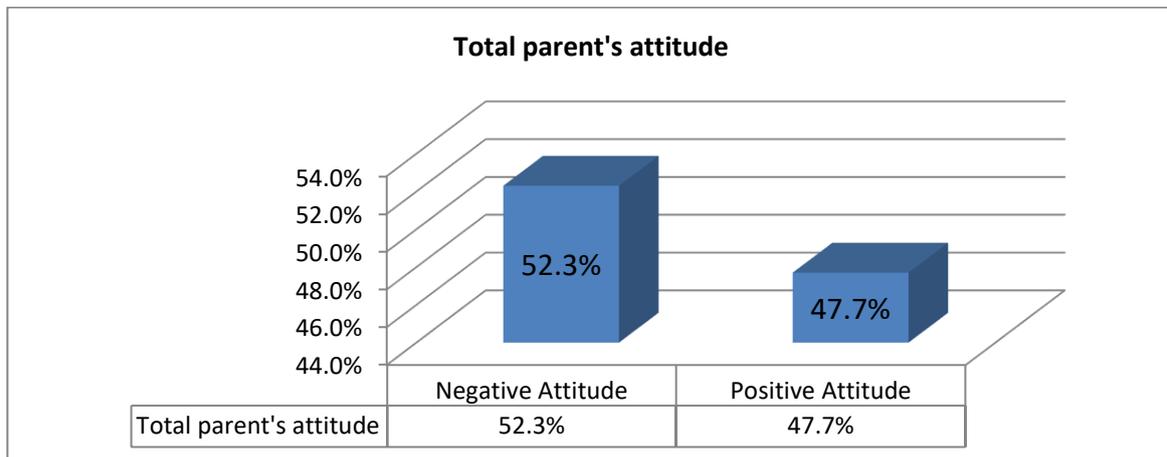


Figure (2): Percentage Distribution of Total coping pattern among parents regarding Children Complaining from Spinal Muscular Atrophy (n= 367).

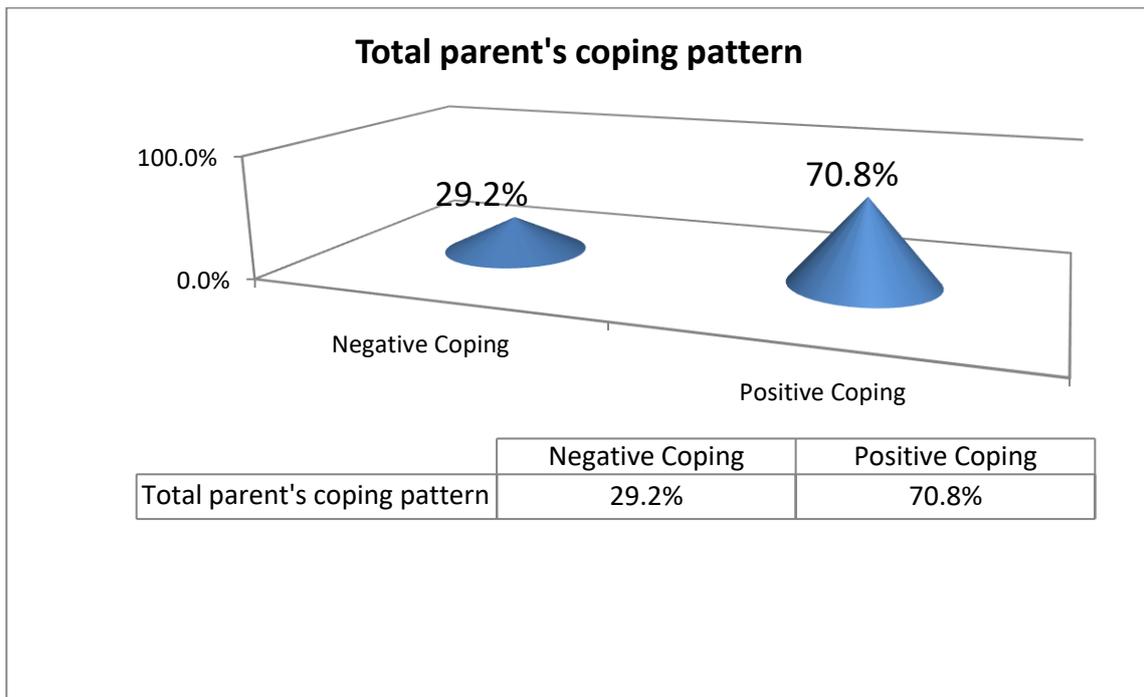


Table (5): Correlation between Knowledge, practices, attitude and coping pattern of the studied parents (N=367).

Knowledge practices and attitude	Changes of scores of total knowledge, practices, attitude and coping							
	Knowledge		Practices		Attitude		Coping	
	r	p	r	P	r	p		
Knowledge	-----	----	0.161	0.002**	0.341	0.000**	0.037	0.161
Practices	0.161	0.002**	----	-----	0.278	0.000**	0.007	0.898
Attitude	0.341	0.000**	0.278	0.000**	-----	-----	0.500	0.000**
Coping	0.037	0.161	0.007	0.898	0.500	0.000**	-----	-----

Discussion

Spinal Muscular Atrophy (SMA) is a genetic disease affecting the central nervous system and voluntary muscle movement (skeletal muscle). The majority of patients with SMA face serious complications such as scoliosis, feeding problems and insufficient coughing and breathing, caused by the typical pattern of axial, bulbar and proximal weakness. Disability negatively affects the quality of life of adults with SMA (**Ghoniem et al., 2023**).

Having a child with SMA probably also has a significant impact on the lives of primary caregivers which leading to levels of burden experienced by individuals with SMA and their families. In addition, parents of children with SMA experience higher levels of parenting stress than those of healthy children. SMA severity, reduced social support, child behavior and family resources were found to be factors associated with high degrees of stress or reduced quality of life (**Cremers et al., 2019**).

Regarding age of the studied parents, the results of the present study revealed that less than half of the studied parents aged from 35 to 45 years old. This result was in the same direction with a study done by **Acar et al., (2021)** in Turkey under the title "The burden of primary caregivers of spinal muscular atrophy patients and their needs" and showed that the mean age of mothers was 35.11 (30-50) years, and the mean age of fathers was 39.36 (35-58) years.

For sex of the studied sample, the results of the present study revealed that sixty percent of parents were female. This result was in the same direction with a study done by **Morcov et al., (2021)** in Romania under the title " Findings regarding emotion regulation strategies and quality of life's domains in families having children with spinal muscular atrophy" and showed that more than half mothers of patients with SMA (59.3% of respondents) were the most common. From the researcher point of view, this finding might be due to women assume more responsibilities in the care of their children and with high level for disabled children.

In relation to family and child past history of children complaining from spinal muscular atrophy, the present study showed that most of the family member didn't affect. About two third (67.8%) not consanguinity between parents. As regard child age diagnosed with SMA, the result reveals that more than one third of them from 1 to 5 years old. According to type of SMA, the result reveals that 48.3% of children have type2 SMA. Only (21.5%) of mothers had problems during pregnancy; 68.4 were preeclampsia and 31.6% were gestational diabetes. About (63%) of mothers had problems during childbirth. According to type of birth, more than half of mothers (52.6%) had normal vaginal delivery. Sixty percent of child had normal growth during first 2 years.

These findings agreed with **Panda et al., (2023)** who carried out a study in India under the title "Behavioral problems in infants and young children with spinal muscular atrophy and their siblings: A cross-sectional study" and mentioned that more than half of children (53.5%) aged from one

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to three year without family history to this disease. But, more than one third of their mothers (36.5%) had problems during their pregnancy and birth.

According total knowledge among parents regarding children complaining from spinal muscular atrophy, the present study revealed more than three quarters (79.6%) of parents had poor level of knowledge while only (20.4%) of parents had average level of knowledge.

These results indicate that parents need more education and training regarding all aspects of their children disease with a good communication from health team and easy access to medical care due to the complex health care needs of SMA children. These results were similar to **Tan & Karakas (2022)** who conducted a study in Turkey under the title "The Health literacy and self-efficacy levels of parents of patients with spinal muscular atrophy" and found that more than half (60.0 %) of mothers had poor total level of knowledge regarding spinal muscular atrophy.

Regarding total reported practices among parents regarding children complaining from spinal muscular atrophy, the present study revealed that more than half of parents (51.2%) had adequate level of practice while (48.8%) of parents had inadequate level of practice. This result may be due to the parents of children are interested to care of their child and provide them with any needs.

This finding was in agreement with **Morcovet al., (2021)** who found that a good level of practice was found among more than half (54.5%) of the parents. The results were inconsistent with **Ghoniem et al., (2023)** who noted that more than half (52.0%) of studied mothers had unsatisfactory total reported practices.

Concerning total attitude among parents regarding Children complaining from spinal muscular atrophy, the present study illustrated that more than half of parents (52.3%) had negative attitude regarding children complaining from spinal muscular atrophy while (47.7%) of parents had positive attitude.

From the researchers' point of view, these results may be due to parents need additional education and training about dealing with different aspects of care needed to such children which understanding their child condition and diagnosis, the possibility of child's future, the risk of the same disease when having another child, and the plenty of time wasted due to the child's condition causing negative attitude among them.

These results were supported with a study performed by **Ghoniem et al., (2021)** who concluded that more than two thirds (66.0 %) of the studied mothers had negative attitude. As well as, **Sari et al., (2022)** at the study entitled "Psychological burden in spinal muscular atrophy patients and their families: a systematic review" in Indonesia clarified that more than half of caregivers had negative attitude towards their children care.

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In relation to total coping pattern among parents regarding children complaining from spinal muscular atrophy, the current study demonstrated that more than three quarters (70.8%) had positive coping pattern while less than one third (29.2%) of parents had negative coping pattern.

From the researcher point of view, this result may be explained by that health team communication with caregivers and access to relevant care was perceived positively, there are improvements to be made with regard to the impact of the disease on the family and emotional aspects and improving coping pattern among parents.

This result was coincided with a study performed by **Tosi et al., (2023)** in Italy entitled "Neurocognitive profile of a cohort of SMA type 1 pediatric patients and emotional aspects, resilience and coping strategies of their caregivers" who concluded that most of the studied caregivers reported positive coping pattern in coping with their children needs. Conversely, **Inhestern et al., (2020)** found that the high percent of parents had difficulties in coping pattern to their children.

Concerning correlation between knowledge, practices, and coping pattern of the studied parents, the current study showed that there was highly statistically significant relation between parents total knowledge, total practice, total coping and their total attitude. Also, there was highly statistically significant relation between parents total knowledge and their total practice.

This result could be due to improving level of parents' knowledge regarding all aspects of children disease leading to enhance level of their practice and attitude that subsequently improve level of coping.

As well as, **Shahar-Lahav et al., (2019)** reported that a positive correlation was found between knowledge, practice and coping level of parents. On the same line, **Ghoniem et al., (2023)** stated that there was a positive correlation between the parents knowledge, practice and attitude level.

Conclusion

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

The majority of parents of children with Spinal Muscular Atrophy have poor knowledge about Spinal Muscular Atrophy, about half of parents have adequate practices regarding children complaining from Spinal Muscular Atrophy. Also about half of parents have negative attitude regarding children complaining from Spinal Muscular Atrophy. More than two third of parents have positive coping pattern with their children complaining from Spinal Muscular Atrophy. There was statistically significant relation between parents' Sociodemographic data and their knowledge, practice and attitude regarding their children with Spinal Muscular Atrophy except some. There was statistically significant relation between parents' knowledge, practice, and their total attitude. Also, there was statistically significant relation between parents' attitude and their coping pattern.



Recommendations

- Procedure pamphlets and booklet containing all essential information about Spinal Muscular Atrophy should be disseminated at hospitals among parents of children complaining from Spinal Muscular Atrophy.
- Design posters and put in outpatient clinic of Spinal Muscular Atrophy that would help parents to improve ' knowledge and attitude regarding their Spinal Muscular Atrophy children.
- Educational program to gain updated knowledge about their Spinal Muscular Atrophy children.
- Implementation educational training program in outpatient clinics and campaigns should be conducted to increase parent's awareness toward their children disease regarding emergency and maintenance management.
- Develop systematic guidance programs and counseling to increase positive coping strategies that contribute to reducing burdens and stressors for parents.
- Future study in another setting for generalization



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