Coping Patterns and Quality of Life among Children with Multiple Sclerosis Disease: Educational Intervention Based on Health Belief Model

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Abstract

Background: Multiple Sclerosis (MS) is a chronic disease occurred in the central nervous system which may be developed under 18 years old. Children with MS have lower Quality of Life (QOL) compared with other chronically ill patients. Health Belief Model (HBM) used to perceive and predict promotion for coping patterns and QOL practices. **Aim:** The aim was to evaluate the effect of implementing educational intervention program which based on HBM regarding coping patterns and QOL among children with MS disease. **Research design:** A quasi-experimental design was utilized. **Sampling:** A purposive sample involved 50 children suffering from MS. **Setting:** MS outpatient clinics in Medical Psychiatric Center, Ain Shams University Hospital. **Tools:** Data collected through using the following tools (pre/post) including an interviewing questionnaire, Jalowiec and Power's Coping Scale, Stress Tolerance Test, and Pediatrics Quality of Life Inventory Fourth Version (PedsQL4.0**)** for MS. **Results:** After implementing the educational intervention program based on HBM, most of the studied children had satisfactory level of knowledge regarding MS disease, as well most of them had positive total coping patterns. In addition, the majority of children had high stress tolerance and good total QOL. **Conclusion:** Educational intervention program based on HBM had a positive effect on children with MS disease in relation to improving their knowledge, enhancing coping patterns and improving stress tolerance and promoting their QOL. There were positive correlations between the total levels of studied children knowledge, coping patterns, stress tolerance and QOL pre and post the program. **Recommendations:** Further studies needed to assess factors affecting QOL among children with MS, and using health belief model in planning of health-centered interventions based on empowerment of children with MS in self-care activities.

Keywords: Coping Patterns, stress tolerance, Quality of life, Children, Multiple Sclerosis Disease, Educational Intervention, Health Belief Model.

Introduction

Multiple Sclerosis (MS) is a chronic disease occurred in the central nervous system which may be developed under 18 years old. Pediatric MS makes up approximately 4–5% of the total populations with MS and commonly occurs before age of 16 years, but less than 1% of all the children with MS had onset before age of 10 years. Worldwide, approximately 30,000 of children and teenagers suffering from MS **(Flemmen, et al., 2020 and Salime, et al., 2022)**

The incidence of pediatric MS is increasing worldwide; it ranged from 0.05 - 2.85/ 100.000 children, and from 0.69 - 26.92/ 100.000 children prevalence. The increase in the MS disease incidence is mainly because of the advance and accessible diagnostic measures as a result for increasing autoimmune diseases. However, fewer than 5.000 children and teens are living with it in the United States, and fewer than 10.000 worldwide **(Coghe, et al., 2019 and Brola, and Steinborn, 2020).**

The etiology of MS is still unknown, and many factors are involved in the pathogenesis of the disease. MS characterized by two main processes; inflammation and neuro-degeneration. Symptoms of MS disease vary and depends on which area affected in the nervous system. Typical signs of MS include loss of motor and sensory functions, imbalance, and the problem with bladder or bowel control, fatigue, blindness, diplopia, cognitive impairment, and emotional changes **(Alroughani, and Boyko, 2018 and Courtney, 2019).**

There are four types of MS disease including primary progressive MS; Relapsing-Remitting MS (RRMS). Whereas, research's results reported that, up to 98% of children with MS had RRMS. It consists of exaggerated periods then recovery periods, in which there is partial or

complete recovery from the symptoms (**Alroughani, and Boyko, 2018).** Benign MS is often a mild RRMS, and secondary progressive MS occurs in children who initially had RRMS but with the progression of the disease and the disability increases gradually over time with or without relapses (**De Meo, et al., 2022).**

Coping is defined as cognitive and behavioral efforts used to overcome stressful events. Hence, stress is common among children with MS. It could be a risk factor for relapsing of the disease **(Benedict, et al., 2020)**

Quality of life (QOL) is the different characteristics, which are required from the children to maintain their own abilities to perform life activities. The World Health Organization (WHO) defined QOL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (**Shawkat, et al., 2019).** The QOL is an important aspect of health in caring and treating of children with MS as chronic patients, whereas their survival and QOL are important and influenced by psychosocial restraints **(Amato, et al., 2021).**

Multiple sclerosis is a progressive disease with an unpredictable sequence on children and negatively effects on their QOL **(Brola, and Steinborn, 2020).** Therefore, it is necessary to assess health related quality of life (HRQOL) among children with MS. Researches' findings showed that QOL among children with MS is poorer than other children weather healthy or with chronic illness **(Taheri, et al., 2020).** Since, the majority of children with MS are in the energetic age, and the disease effects on several features of their QOL that are risky and damaging (**Mrosková, et al., 2021**).

Therefore, educational intervention which emphasis on; improving knowledge, enhancing coping patterns, and promoting QOL among the children with MS is very important. As this could increase child's ability in dealing with the problems related to the disease independently and competently. It also affects the child' physical condition through teaching about diet, exercise, and energy that well be reflecting on promoting the child's QOL **(Brola, and Steinborn, 2020 and Salime, et al., 2022).**

However, effectiveness of teaching intervention depends mainly on the appropriate use of models, concepts, and theories. One of these models is Health Belief Model (HBM) that mainly used to investigate the predictors related to health behavior among children with MS. HBM is utilizing widely to maintain the child's health behaviors, as well as its using as a frame for health treatment (**Penwell-Waines, et al., 2017)**. The HBM could increase children perceived susceptibility, severity of the MS disease, benefits, barriers and action cues that leading the child to health-centered behaviors **(Bhuvaneswari, et al., 2020).**

Significance of the study:

Multiple sclerosis is one of the most common neurological disorders and cause of disability among children. In Egypt, the result of survey both in Alexandria, Alkosier, Alkharga Oasis and Assuit, showed approximately 25/100,000 at the age of 15 years old among the Egyptians children with MS beside positive familial history **(Hamdy, et al., 2017 and Ibrahim, et al., 2020).**

Adequate stress management for children with MS may worth the benefits of both physical and psychological well-being that reflects on their coping and QOL. The HBM represents a great challenge for children with MS disease that promote their level of functioning, improve their QOL for long time and coping patterns toward stress that caused by the disease process **(Cameron, & Nilsagard, 2018, Hashem, 2020 and Salime, et al., 2022)**.

Researches about pediatric MS issues are raised within the years, including those studies assessing the children QOL. There is a lack in review and studies that evaluating the coping patterns and stress tolerance among children with MS and factors' analysis which determine the negative or positive QOL **(Carroll, et al., 2019 and Vargas, et al., 2020)**.

From the researchers' clinical experience, children with MS disease have several cognitive, physical, social, behavioral and emotional problems that reflected negatively on their coping abilities and QOL regarding process of MS disease. Accordingly, the study aim was to evaluate the effect of educational intervention program based on HBM regarding coping patterns and QOL among children with MS disease.

Therefore, this study results could be beneficial in equipping children with knowledge in relation to MS disease that enhancing their coping patterns as well as, promoting QOL

among those children. In addition to, attract attentions & motivations for further researches in this area.

Aim of the Study:

The study aim was to evaluate the effect of implementing educational intervention program which based on HBM regarding coping patterns and QOL among children with MS disease through:

1. Assessing children knowledge, coping patterns, stress tolerance and QOL regarding MS disease.
2. Designing and conducting the educational intervention program for children with MS disease.
3. Evaluating the effect of educational intervention program on knowledge level, coping patterns, stress tolerance and QOL among children with MS disease.

Research Hypotheses:

H1. Children knowledge about MS disease will improve after implementation of the educational intervention program which based on HBM.

H2. Implementation of the educational intervention program based on HBM will enhance coping patterns, improve stress tolerance, and promote QOL among children with MS disease.

H3. There will be positive correlations between children knowledge regarding MS disease and their coping patterns, stress tolerance and QOL pre and post implementation of the educational intervention program which based on HBM.

Subject and Methods:

Research design:

A quasi-experimental study design was used (pre/post).

Setting:

The study conducted at MS outpatient clinics in Medical Psychiatric Center, Ain Shams University Hospital; whereas a large number of children with MS disease were coming for examination and follow up.

Subject:

A purposive sample involved 50 children suffering from MS. The sample size was estimated through using this equation:

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

N x p(1-p)	=[60*(0.5*(1-0.5))]
N-1	=(60-1)
d^2/z^2	=0.0025 / 2.8561
p(1-p)	=0.5*(1-0.5)
N	= 49.3 = 50

N = The community size / Month

Z = The class standard corresponding to level of significance = 0.95 and 1.96

d = The rate of error = 0.05

p = The ratio provides a neutral property = 0.50

The inclusion criteria are:

- Children aged 9-18 years old who were willing to participate in the study.
- Children who diagnosed with any type of MS by a neurologist since at least one year and receiving treatment for MS.

Exclusive criteria:

- Children with any congenital malformations, psychiatric diseases, or chronic illnesses as hypertension, cardiac diseases, and diabetes mellitus.

Tools of data collection:

Data collected through four tools as follows:

Tool I: An Interviewing Questionnaire:

It used to assess children knowledge regarding MS disease. It designed by researchers according to the current related literatures. It was written in an Arabic. It contained 40 questions in the form of closed-open ended and Multiple-Choice Questions (MCQs). It involved three parts:

Part 1: Characteristics of the studied children such as; age, sex, level of education and child's birth order. It contains four questions in the form of MCQs.

Part 2: Child's medical history: It was used to assess child's medical history from medical records as regards; child's diagnosis with MS, child's history such as age at first attack, and chief complain at diagnosis and number of attacks in the last six months, duration of the disease, previous hospitalization. The present history related to the number of attacks, disabilities and family history of MS.

Laboratories investigations and tests such as analysis of the Cerebro-Spinal Fluid (CSF), Visual Evoked Potential (VEP), Spinal test, and Magnetic Resonance Imaging (MRI) in addition to, neurological examination.

Part 3: Children knowledge assessment questionnaire (Pre/post educational intervention based on HBM): It was designed based on the relevant literatures **(Mohamadirizi et. al., 2017 and Alroughani & Boyko 2018).** It was used to assess the children' level of knowledge regarding definition, types, predisposing factors, causes, incidence, age of MS onset, signs & symptoms, diagnosis, plan of treatment, complications and prevention of MS. It included 28 MCQs. The interviewing questionnaire filled in by the children with help from the researchers and took from 10 to 15 minutes to fill in.

Scoring system:

The model answer was prepared by the researchers and correct responses were checked through the following:

- One degree for correct answer meanwhile, zero for incorrect.

- The total score was 40. The children' responses summed up, then converted into a percentage to be classified into two categories of knowledge:

- Satisfactory ≥ 60% (≥ 24 scores).

- Unsatisfactory <60% (<24scores).

Tool II: Jalowiec and Power's Coping Scale (Pre/post educational intervention based on HBM): It was adapted from **Dempster, et al., (2015)**. It used to assess the coping patterns among children toward stress from MS disease. This scale is using for children with chronic disease that filled by children themselves and took 5 - 10 minutes to be completed.

Scoring System:

The scale consists of 40 items for evaluating the coping behaviors according to 5 points Likert scale, (never do=1; seldom do=2; sometimes do=; 3, often do=4, always do=5). The scale categorized into two domains; problem-oriented (15 items =75 scores) & emotion-oriented (25 items =125 scores). The total score of each domain summed up, then converted into a percentage to be categorized into two levels as positive ≥75% and negative < 75%.

The total score of coping scale items was 200; children responses summed up then converted into percentage. The total scores categorized as:

- **Positive coping patterns ≥75% (≥ 150).**
- **Negative coping patters <75% (<150).**

Tool III: Stress Tolerance Test (Pre/post educational intervention based on HBM): It was adapted from **Devy, et al. (2015)**. It used to assess the stress tolerance level of children with MS disease. The researchers carried out the required modifications to suit the nature of the current study.

Scoring System:

The scale consists of 20 items. It was a 4 points Likert scale, (rarely=1, sometimes=2, often=3, always=4). The total score was 80. Responses summed up then converted into percentage and categorized as:

- **High stress tolerance ≥ 60% (≥ 48).**
- **Low stress tolerance < 60% (< 48).**

Tool IV: The Paediatric Quality of Life Inventory Fourth Version (PedsQL4.0) (Pre/post educational intervention based on HBM): It was adapted from **Desai, et al., (2014).** It used to measure the Health-Related Quality of Life (HRQOL) of children aged 5-18 years old. PedsQL 4.0 is brief version and child self-report. It translated firstly into Arabic and then into English. It used to assess the QOL among children with MS disease. However, the items focuses on functioning and what the child could do, it also focuses on how much it difficult for a child to do something. If a child had many difficulties, the self-esteem and QOL might be threatened. It contains 23 items for children through four subscale of child's functioning related to; physical (8 items), emotional (5 items), social (5 items) and school (5 items). From these four subscales, three standardized scores were calculated; total QOL score, physical health score based on the physical items, and psychosocial health score contains; emotional, social & school items). The child asked to determine the problems that had been suffered regarding those items in the last month, with response options to each item in

the scale. The PedsQL4.0 filled in by children and took 5 - 10 minutes.

Scoring System:

Responses for each item was rated into a five- points Likert scale ranged (0-4), where, (never = 0, almost never= 1, sometimes= 2, often= 3, almost always= 4". There were two negative phrased items (No.2 and No.5) in the emotional functioning subscale, which reversely scored and subsequent transform the negative phrased items into positive phrased items.

The total score of each subscale was summed up and converted into a percentage and categorized into 'good' if total score ≥60% and 'poor' if total score < 60%.

The total score for this scale was 92 that represent 100%. Then the score of QOL was categorized into:

- **Good quality of life: ≥ 60% (≥ 55).**
- **Poor quality of life: <60% (< 55).**

Content validity:

The study tools reviewed by a panel of five experts (three professors from Pediatric Nursing and two professors from community health nursing departments) from Faculty of Nursing, Ain Shams University. They tested the face and content validity. All experts reviewed tools for clarity, relevancy, comprehensiveness, appropriateness, and applicability and according to their opinions, modifications through addition or omission for some items according to experts' recommendations.

Reliability:

Testing reliability of the study tools was done by using Cronbach's alpha test. It was (0.879, 0.877, 0.987 and 0.967) for the interviewing questionnaire, Jalowiec and Power's coping scale, stress tolerance test and paediatric QOL inventory respectively.

Ethical considerations:

- The research ethical approval was granted from the ethical research committee of the Faculty of Nursing, Modern University for Technology, and Information (MTI), Egypt with a formal approval code (FAN/30/2021).
- The researchers clarified the aim and objectives of the study to the children and their parents included in the study.
- Oral and written consents were taken from children and their parents before their participation in the study.
- The researchers assured anonymity and data confidentiality of children.
- Children informed that they have the right for withdrawing at any time from the study without clarifying any reasons.

Pilot study:

The pilot study was carried out on 10% from the study sample (5 children) with MS to evaluate the applicability, clarity and time needed for filling in each tool. In addition, it helps in overcoming problems and barriers that may face the researchers during data collection. The required modifications were done through adding, omitting or rephrasing some items or questions based on the pilot study results. The five children in the pilot study were excluded from the study subjects.

Fieldwork:

The actual fieldwork carried out within six months from September 2021 to February 2022 through the following phases:

A. Assessment phase:

Researchers at this phase were available three days/week (Saturday, Tuesday, Thursday), in the morning shift (9 am - 2pm) in previous mentioned MS outpatient clinics. The total number of children interviewed per week ranged from 5 to 10 child. The aim study and steps were clarified for the studied children. The studied children filled the study tools with help of the researchers through average time for each tool around 10 -15 minutes.

Children with MS interviewed individually for one-hour duration to assess their knowledge, coping patterns and stress tolerance in addition to QOL through using the study tools as pre assessment prior to implementation of the educational intervention of HBM.

B. Planning phase:

The researchers designing the educational intervention program's sessions based on HBM through assessing the actual needs of studied children with MS in order to improve their knowledge, coping patterns, stress tolerance and QOL through using a guiding booklet

prepared by the researchers. It designed in simple and clear Arabic language based on the needs assessment of the children and including figures. It used to provide children with MS by the important knowledge about the disease as regards; meaning of MS; causes; signs and symptoms, complications, prevention and follow up. In addition, quality of life regarding lifestyle and daily living activities like exercises, medications compliance, nutrition, school performance, sleep, pain relief measures and importance of medical follow up.

C. Implementation phase:

The children classified into 10 groups; each group 5 children. The researchers started the program sessions based on HBM at outpatients' clinics in the medical Psychiatric MS Unit which affiliated to Ain Shams University Hospital. Two sessions per week were heled for the children, each session lasted for one hour in total 6 sessions (4 theoretical sessions and 2 practical sessions) for each group. Therefore, the number of studied children was 50 children in 10 groups, each group took 6 hours and the total hours equal 60 hours.

The first session included an introduction and the aim of the HBM sessions, performing the pre-test by using the study tools and distributing the booklet.

The second session included the meaning of health; and HBM components (perceived susceptibility, severity, barriers, benefits, cues to action and action related to MS disease).

The third session included definition of MS, causes, signs and symptoms, factors contributing to MS, types, diagnostic tests, preventive measures, management and treatment plan, and complications and related treatment.

The fourth session included discussion about QOL and its importance regarding physical, emotional, social, and school functioning for children with MS. In addition, demonstration, and re-demonstration of their daily life activities such as exercises, sleeping, nutrition, recreations, play, scholastic achievement, medications compliance, non-pharmacological intervention for pain relief as breathing exercises and importance of medical follow up.

The fifth session included demonstration of the coping mechanisms for children with MS and how to cope with the disease and the activities required to attract their attention to decrease their stress tolerance. In addition to, the role of parents and families to help children for positive coping.

The sixth session the researchers thanks all children and performing reassessment for their knowledge level coping patterns , stress tolerance and QOL through post assessment (post the educational intervention program implementation).

At the beginning of each session, the researchers performing feedback for previous session and explained objectives of this session and at the end of every session, answering all children questions.

Different teaching strategies used such as modified lectures, role-play, small group discussion, and demonstration. Suitable and attractive teaching aids as booklet, colored pictures, posters, videos, doll, and real objects. In addition, motivations by simple rewards and encouragement provided for children as positive feedbacks during the sessions.

D. Evaluation phase:

At completion of the sessions, the post-test done for each child by using the same study tools to evaluate the effect of the HBM through comparing the results of the pre and post-tests (Post educational intervention based on HBM implementation).

Statistical design:

Study data collected, organized, coded and then analyzed by using the software version 25 of Statistical Package of Social Science (SPSS). Data were presented in tables and figures. Data checked for normality and equality of distribution, data presented as number and percentage, mean, standard deviation (SD). Relations between different quantitative variables tested. The Chi-Square (X^2) test was used to find the differences between different variables of the qualitative data. Also Spearman correlation coefficient test was used to assess the degree of association between two sets of different qualitative variables.

Results:

Table 1: showed that, nearly three quarters (74%) of the studied children in the age group from15-18 years old and 22% of them their age from 12- <15 years with mean age 15.8± 1.39 years, as well 70% of the study sample were girls and 66 % of them in the secondary school

in addition to, 30% & 28% their birth order was first and second respectively.

Table 2: illustrated that, half (50%) of children, their first attack occurs at the mean age 13.90±2.65, and diagnosed at the mean age 13.20±2.47. Also, the mean of disease duration for children was 1.90±0.71. More than one third (36%) of children their chief complaint was vision problems, 14%, 22% and 18% of them their chief complaint was motor problems, dizziness and difficulty in concentration and memory, in addition to fatigue, weakness and tremors respectively. In addition, the mean of disease attacks number during the last six months was 7.80±3.28, 60% and 30% of them hospitalized previously and had positive family history with MS disease respectively. Moreover, 24 % of the studied children had motor disability; meanwhile 86% and 72% of them had abnormal CSF and VEP tests respectively.

Table 3: demonstrated that, most of children (96%, 94%, 90%, &96%) had unsatisfactory knowledge regarding definition, types, causes and prevention of MS disease pre-educational intervention which based on HBM respectively; meanwhile 86%, 98%, 98% and 98% of the studied children had satisfactory knowledge regarding MS disease post implementation of the educational intervention which based on HBM respectively.

Figure 1: displayed that, 84% of children had unsatisfactory level of knowledge regarding MS disease and 16% of them had satisfactory knowledge pre implementation of the educational intervention which based on HBM. While, 90% of children had satisfactory knowledge regarding MS disease and 10% of them had unsatisfactory level of knowledge post implementation of the educational intervention which based on HBM respectively.

Table 4: detected that most (90% % 98%) of the studied children had negative problem and emotion-oriented types respectively pre implementation of the educational intervention which based on HBM compared with 92% & 90% respectively of them who showed positive reaction post implementation of the educational intervention which based on HBM. Also, 80% of children had positive total coping patterns post implementation of the educational intervention which based on HBM.

Table 5: revealed that 12 % of the studied children had high stress tolerance pre the educational intervention which based on HBM compared with 90% of them post the educational intervention which based on HBM. In addition, there was statistically significant difference pre and post implementation of the educational intervention which based on HBM.

Table 6: showed that, 20%, 6%, 16% and 6% of children had good QOL regarding their physical, emotional, social and school functioning pre the educational intervention which based on HBM respectively; compared with 88%, 90%, 74% and 76 of them post the educational intervention which based on HBM respectively. While 20% of children had good total QOL compared with 70% of them post implementation of the educational intervention which based on HBM respectively.

Table 7: illustrated that there was statistically significance difference between total level of knowledge and children sex, level of education and birth order while, the lower score for children was among illiterate and the higher score was among girls who have university education and in the third or fourth birth orders at (p= 0.001) pre the educational intervention which based on HBM. Also, there was statistically significance difference between total level of coping patterns and children age and sex at p-value 0.001, while the positive coping patterns was among children at 15 - 18 years old pre implementation of the educational intervention which based on HBM.

Table 8: clarified that there was statistically significance difference between total level of stress tolerance and studied children age, sex and level of education at p-value $\leq$ 0.05, where high stress tolerance showed among girls' children whose age was 15-18 years old and at secondary school or university. In addition, there was statistically significance difference between total level of stress tolerance and child's birth orders at p-value $\leq$ 0.001 pre implementation of the educational intervention which based on HBM. Moreover, there was statistically significance difference between total level of QOL and children age and Sex; where, the lower score for children aged 9 - <12 years old and the higher score was for girls at p= 0.001. Also, there was no statistically significance difference between total level of QOL and children educational level at p-value >0.05 pre implementation of the educational intervention which based on HBM.

Table 9: revealed that, there was positive correlations between the total levels of studied children knowledge, coping patterns, stress tolerance and QOL pre implementation of the educational intervention which based on HBM (r = 0.117, 0.219 and 0.218) at p-value <0.05.

Table 10: proved that, there was positive correlations between the total levels of studied children knowledge, coping patterns, stress tolerance and QOL post implementation of the educational intervention which based on HBM (r = 0.339, 0.579 and 0.577) at p-value <0.001.

Table (1): Distribution of the studied children with multiple sclerosis disease according to their characteristics (n=50)

Children characteristics	(No.=50)	
	No.	%
Age in Years:		
9 - <12	2	4
12 - <15	11	22
15-18	37	74
Mean ± SD (15.8±1.39)		
Sex:		
Boy	15	30
Girl	35	70
Level of education:		
Illiterate	2	4
Primary School	5	10
Secondary School	33	66
University	10	20
Child's birth order:		
First	15	30
Second	14	28
Third	11	22
Fourth and more	10	20

Table (2): Distribution of the studied children with multiple sclerosis disease according to their history and examination (n=50)

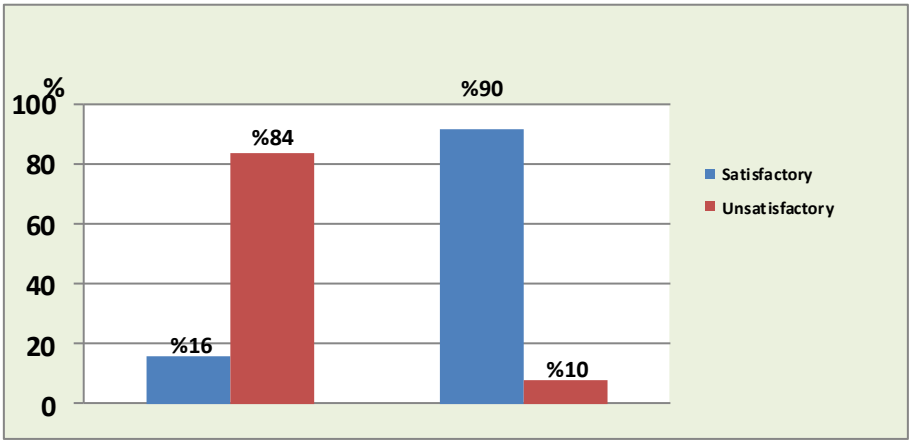
Children History		
Past History:	**Mean ± SD**	
Child's age at first attack (years):	13.90±2.65	
Child's age at diagnosis of MS (years):	13.20±2.47	
Duration of the disease (years):	1.90±0.71	
Number of attacks (Last 6 months):	7.80±3.28	
Chief child's complaint at diagnosis:	**No.**	**%**
Vision problems (blurred vision, trouble seeing or double vision)	18	36
Motor problem (difficult walking and keeping balance).	7	14
Dizziness, difficulty in concentration and memory.	11	22
Fatigue, weakness, and tremors.	9	18
Numbness, tingling and pin needles feeling or pain.	5	10
Previous hospitalization.	30	60
Positive family history with MS disease.	15	30
Presence of motor disability.	12	24
Abnormal clinical tests:		
Cerebro- Spinal Fluid (CSF)	43	86
Visual Evoked Potential (VEP)	40	80
Spinal Test	40	80
Magnetic Resonance Imaging (MRI)	36	72

Table (3): Percentage distribution of the studied children according to their knowledge regarding multiple sclerosis disease pre and post educational intervention which based on Health Belief Model (n=50)

Children knowledge	Pre HBM		Post HBM		X^2	P - Value
	Satisfactory	Unsatisfactory	Satisfactory	Unsatisfactory		
	%	%	%	%		
Definition of MS.	4	96	86	14	71.591	0.001**
Types of MS.	6	94	98	2	81.293	0.001**
Predisposing factors of MS	10	90	94	6	63.934	0.001**
Causes of MS.	10	90	98	2	96.078	0.001**
Incidence of MS.	12	88	90	10	81.818	0.001**
Age of onset of MS.	44	56	98	2	42.857	0.001**
Signs & symptoms of MS.	36	74	96	4	53.846	0.001**
Diagnosis of MS.	10	90	96	4	81.818	0.001**
Treatment of MS.	14	86	98	2	78.571	0.001**
Complications of MS.	20	80	98	2	63.934	0.001**
Prevention of MS.	4	96	98	2	85.185	0.001**

*p>0.05 Not Significant; *p ≤ 0.05 Statistically Significant; **p ≤ 0.001 Statistically Significant*

Figure (1): Distribution of the studied children according to their total level of knowledge regarding multiple sclerosis disease pre and post educational intervention which based on Health Belief Model



***p-value <0.001 Significant*

Table (4): Distribution of the studied children with multiple sclerosis disease according to their coping patterns pre and post educational intervention which based on Health Belief Model (n=50)

Children Coping Patterns	Pre HBM		Post HBM		X^2	P-Value
	Positive	Negative	Positive	Negative		
	%	%	%	%		
Problem-oriented type	10	90	92	8	47.500	0.001**
Emotion-oriented type	2	98	90	10	78.653	0.001**
Total Coping Patterns	**8**	**92**	**80**	**20**	**27.535**	**0.001****

*p>0.05 Not Significant; *p ≤ 0.05 Statistically Significant; **p ≤ 0.001 Statistically Significant*

Table (5): Distribution of the studied children with multiple sclerosis disease according to their stress tolerance pre and post educational intervention which based on Health Belief Model (n=50)

Children Stress Tolerance	Pre HBM		Post HBM		X^2	P-Value
	No.	%	No.	%		
High Stress Tolerance	6	12	45	90	77.507	0.001**
Low Stress Tolerance	44	88	5	10	73.373	0.001**

*p>0.05 Not Significant; *p ≤ 0.05 Statistically Significant; **p ≤ 0.001 High Statistically Significant*

Table (6): Distribution of the studied children with multiple sclerosis disease according to their quality-of-life pre and post educational intervention based on Health Belief Model (n=50)

Children QOL	Pre HBM		Post HBM		X^2	P-Value
	Good	Poor	Good	Poor		
	%	%	%	%		
I. Physical Health:						
- Physical Functioning.	20	80	88	12	46.538	0.001**
II. Psychosocial Health:	**8**	**92**	**86**	**14**	**56.753**	**0.001****
- Emotional Functioning.	6	94	90	10	70.673	0.001**
- Social Functioning.	16	84	74	26	37.527	0.001**
- School Functioning.	6	94	76	24	34.219	0.001**
Total quality of life	**20**	**80**	**70**	**30**	**29.636**	**0.001****

*p>0.05 Not Significant; *p ≤ 0.05 Statistically Significant; **p ≤ 0.001 Statistically Significant*

Table (7): Relation between the studied children characteristics and their total score level of knowledge and total coping patterns with multiple sclerosis disease pre-educational intervention which based on Health Belief Model (n=50)

Children characteristic	Pre HBM			
	Total Score Level of Knowledge		Total Coping Patterns	
	x^2	p-value	x^2	p-value
Age (years)				
9 - <12	0.832	0.660	2.517	0.001**
12 - <15				
15-18				
Sex				
Boy	2.535	0.001**	2.513	0.001**
Girl				
Level of education				
Illiterate	2.810	0.001**	1.711	0.051*
Primary School				
Secondary School				
University				
Child's birth order				
First	2.629	0.001**	2.719	0.050*
Second				
Third				
Fourth and more				

*p>0.05 Not Significant; *p ≤ 0.05 Statistically Significant; **p ≤ 0.001 Statistically Significant*

Table (8): Relation between the studied children characteristics and their stress tolerance and total quality of life with multiple sclerosis disease pre-educational intervention which based on Health Belief Model (n=50)

Children characteristics	Pre HBM			
	Stress Tolerance		Total Quality of Life	
	x2	p-value	x2	p-value
Age (years)				
9 - <12	2.517	0.050 *	2.813	0.001**
12 - <15				
15-18				
Sex				
Boy	2.511	0.041*	2.005	0.001**
Girl				
Level of education				
Illiterate	1.711	0.051*	0.811	0.847
Primary School				
Secondary School				
University				
Child's birth order				
First	2.719	0.001**	1.629	0.051*
Second				
Third				
Fourth and more				

*p>0.05 Not Significant; *p ≤ 0.05 Statistically Significant; **p ≤ 0.001 Statistically Significant*

Table (9): Correlation between the studied children total levels of knowledge, coping patterns, stress tolerance and quality of life pre-educational intervention which based on Health Belief Model

Mean Scores Levels	Pre HBM				
	r- test P. value	Knowledge	Coping Patterns	Stress Tolerance	Quality of Life
Coping Patterns	**r- test**	0.117		0.179	0.189
	P. value	0.051*		0.050*	0.589*
Stress tolerance	**r- test**	0.219	0.231		0.091
	P. value	0.533*	0.511*		0.567*
Quality of Life	**r- test**	0.218	0.757	0.111	
	P. value	0.071	0.001**	0.051*	

**Correlation is significant at p ≤ 0.05 level (2-tailed)*
*** Correlation is significant at p ≤ 0.001 level (2-tailed)*

Table (10): Correlation between the studied children total levels of knowledge, coping patterns, stress tolerance and quality of life post educational intervention which based on Health Belief Model (n=50)

Mean Scores Levels	Post HBM				
	r- test P. value	Knowledge	Coping Patterns	Stress Tolerance	Quality of Life
Coping Patterns	**r- test**	0.339		0.479	0.389
	P. value	0.001**		0.001**	0.001**
Stress tolerance	**r- test**	0.579	0.231		0.589
	P. value	0.001**	0.001**		0.001**
Quality of Life	**r- test**	0.577	0.757	0.775	
	P. value	0.001**	0.001**	0.001**	

**Correlation is significant at p ≤ 0.05 level (2-tailed).*
*** Correlation is significant at p ≤ 0.001 level (2-tailed).*

Discussion:

Multiple sclerosis is a chronic disease that causes both physical and psychosocial limitations. Children with MS must live and accommodate with the disease that requires facing the stressful situations adequately to have a good QOL. The adaptation to MS disease depends on the effectiveness of coping, which regulates the adaptation process & psychosocial safety and comfort **(Macaron, et al., 2019 and Harvie, 2021).**

The interventional structure of the current study consists of the HBM, that is one of the most common educational models used in the health programs. So, this study aimed to evaluate the effect of implementingeducational intervention program which based on health belief model regarding coping patterns and quality of life among children with multiple sclerosis disease.

On studying the studied children characteristics concerning their age, the present study results showed that, closely three quarters of the children age between 15-18 years old and less than one quarter of them from 12- <15 years old with X± SD 15.8± 1.39 years. In addition, more than one quarter of the studied children their birth order was as first and second. These results are constant with **Khodashenas, et al., (2021)** who pointed out that children diagnosed with MS before their 18th birthday, and most of them get the condition during their teens years. Also, in a study done by **Jeong, et al., (2019)** who found that most children who developed clinical symptoms of MS aged from 13 to 16 years old. While only 10 - 15 % who diagnosed with MS were among children who under 12 years old.

As regards to the sex of the studied children with MS, the results of this study revealed that more than two thirds were girls. The finding is consistent **Wallin, et al., (2019)** about the "Global, regional, and national burden of multiple sclerosis" who mentioned that girls affected twice time than boys.

Concerning the level of education of children with MS, two thirds of them were in the secondary school. This result disagreed with the finding of a study done by **Tremlett, and Marrie, (2021)** who conducted a study about " The multiple sclerosis prodrome: Emerging evidence, challenges, and opportunities" and pointed out that half of the children with MS possess higher educational degree.

In addition, the mean age for half of children about first attack of MS was 13.90±2.65 years, and half of them diagnosed at the mean age of 13.20±2.47 years. Also the mean duration of disease was 1.90±0.71. More than one third of children their chief complaint was vision problems, less than one quarter of the children their chief complaint was motor problems, dizziness and difficulty in concentration and memory, in addition to fatigue, weakness and tremors.

Regarding previous hospitalization of the studied children and family history with MS, the current study showed that more than half of children were hospitalize and approximately one third of them had family history with MS disease. This result supported by **Hamidreza, et al., (2013)** who examined "The impact of a HBM-based intervention program on quality of life in patients with MS" and found that the majority of patients were previously hospitalized, while less than one quarter of them reported presence of MS disease in one member of the family. **Khedr, et al., (2022)** studied the "Perceived stress in multiple sclerosis patients: Relationship with mood states and pain experience" and mentioned more than one fourth of the patients had positive history of MS disease.

According to the duration of disease and number of attacks during last six months among children, the current study found 7.80±3.28 years was the mean duration of disease, and two thirds of them had ≥7 attacks in the last six months. The result of the present study was in accordance with the finding of **Abd Elsalam, and Ali, (2022)** study concerning "Self-Management Guidelines: Effect on Knowledge, Fatigue, Self-Efficacy and Medications Adherence among Patients with Multiple Sclerosis" who stated that approximately four fifths of the patients had 1-3 attacks in the last 2 years.

The existing study findings showed that, more than one fifth of children have motor disability and the majority of them had abnormal CSF. Meanwhile, more than three-fourths of children their VEP and spinal testes were

abnormal respectively. These findings are similar to **Šehanović, et al., (2021)** about "Cognitive performance and quality of life in patients with multiple sclerosis" and found that most of patients had degree of disability and their spinal test was abnormal. **Waubant, et al., (2019) and Maguire, (2020)** emphasized that, MS disease cause vision, balance and mobility problems**.** Early detection and diagnosis of such disabilities in childhood may be due using of advanced diagnostic tools.

On evaluating the level of children knowledge regarding MS, result of this study revealed that, most of the children had unsatisfactory knowledge concerning definition, types, causes and preventive measures of MS disease pre implementation of the educational intervention which based on HBM. Meanwhile, the majority of them had satisfactory knowledge regarding MS disease post implementation of the educational intervention which based on HBM. This result could be due to that the main reference of the studied children knowledge regarding MS disease through groups of social media like Facebook and communication with other children with MS and their family. This result was similar to study results that carried out by **Mohamadirizi, et al., (2017)** entitled "The effect of electronic education on knowledge of patients with multiple sclerosis" illustrated increased patient's knowledge about MS post education compared with pre education.

As regards the total knowledge level of children with MS, the result of the current study revealed that, majority of children had unsatisfactory knowledge level regarding MS disease pre the educational intervention implementation which based on HBM. While, most of children had satisfactory knowledge regarding MS disease, post the educational intervention implementation which based on HBM. This result supported by **Saad, and Abo Elfetoh, (2021)** who studied " Self-Management Program to Adapt with Multiple Sclerosis Problems and Enhance Quality of Life" and illustrated that, less than half of children had poor knowledge preprogram compared with more than half of them had good knowledge post program implementation.

Regarding coping patterns of children with MS, the findings of the present study showed that most children had negative problem and emotion-oriented type pre implementation of the educational intervention compared with the majority of them become positive emotional-oriented post implementation. Additionally, more than three fourths of children had positive total coping patterns post implementation of the educational intervention which based on HBM. The current study results agree with **Momenabadi, et al., (2019)** when assessing the effect of "Educational Intervention Based on Health-Promoting Self-Care Behaviors Model on Quality of Life, Resilience, and Sense of Coherence in Patients with Multiple Sclerosis" and reported positive effect of self- care model on coping approaches of patients with MS.

On evaluating the children stress tolerance, the current study results illustrated that very little of children had high stress tolerance pre the educational intervention implementation which based on HBM compared with most of them post implementation. In addition, there was statistically significant difference pre & post. This finding was in agreement with **Habibi et al., (2021)** who studied "Self-care practices and related factors in patients with MS based on the health belief model" and pointed out that there was an enhancement in stress tolerance, coping strategies in addition to change in health of patients with MS post intervention.

As regards QOL concerning physical functioning of the studied children, the results represented; more than one fifth of children had good QOL regarding their physical functioning compared with the majority of them pre &post implementation of the educational intervention respectively. These findings were similar with study results of **Mohammad**, **et al., (2021)** about "Effect of Family-centered Empowerment Model on Self-care Behaviors of Patients with Multiple sclerosis" and mentioned there was statistically significant difference pre & post empowerment model regarding patients' health energy.

In contrast, these findings were disagreed with **Fasczewski et al., (2017)** who "Assessing self-report physical activity behavior and quality of life of children with multiple sclerosis" and showed that more than half of the patients their QOL was poor and recommend performing educational program to improve patient's HRQOL.

As regards QOL concerning emotional functioning of the studied children, the results represented that, very few of children had good QOL regarding their emotional functioning compared with most of them pre & post implementation of the educational intervention which based on HBM respectively. These results could be due to their limitation as their peer in health. According to **Bessing et al., (2022)** who "Evaluating the impact of the Understanding Multiple Sclerosis online course on participant MS knowledge, health literacy, resilience, self-efficacy, quality of life, and MS symptom severity" and found that patients' limitation was enhanced due to their emotional problems post the intervention.

Concerning QOL in relation to social functioning of children, the result pointed out that, less than one quarter of the children had good QOL regarding their social functioning compared with nearly three quarters of them pre & post implementation of the educational intervention which based on HBM respectively. This could be due to increase the social relation between children during medical follow up with others through group discussion.

This result was agree with the study finding of **Faraji et al., (2018)** entitled "Effect of self-care education on social adaptability in patients with multiple sclerosis" and pointed out there was positive impact regarding improving the social relations among patients with MS post the educational program with statistically significant difference pre and post intervention.

Regarding QOL in relation to school functioning children, the results of the current study reported that, very few of children had good quality of life regarding their school functioning compared with slightly more than three quarters of them pre & post implementation of the educational intervention respectively. This could be due to school absenteeism which repeated by the children as a result of pain and fatigue pre implementation of the intervention compared with post implementation of the intervention. The current study findings were in the same line with **Shawli et al., (2019)** about "Fatigue and Self-management among Multiple Sclerosis Patients" and emphasized that, more than half of patient with MS their total score QOL was best in relation to their cognitive function post intervention with statistical significant difference pre & post intervention.

As regards the total score level for QOL of children with MS, the current study results showed that less than one quarter of the children had good total QOL compared with the majority of them pre and post implementation of the educational intervention which based on HBM respectively. From the researchers' point of view, due to the nature of MS disease, it is expected that the QOL of children to be lower than other children in the same age without the disease. These findings indicated the positive effect of the educational intervention which based on HBM in improving the QOL among children with MS.

The current study results were consistent with a study done by **HamidReza et al., (2013)** who examined "the impact of a HBM-based intervention program on quality of life in patients with MS" and reported a significant difference after the intervention program implementation regarding all aspects of QOL compared to before the intervention. Also in a study done by **Penwell-Waines et al., (2017)** about "Testing the health promotion model for adherence and quality of life in individuals with multiple sclerosis" and found that, QOL among patients improved post implementation of the intervention health promotion program. **Salime et al., (2022)** showed that the QOL among patients with MS lower level than the healthy individuals, whereas more than two thirds of the patients evaluated their QOL as "fair" pre the intervention program.

Additionally, **Abdallah et al., (2022)** conducted a study about "Assessment of health-related quality of life among patients with multiple sclerosis at Minia University Hospital" and stated most of patients with MS their QOL was poor and recommended performing nursing intervention program to upgrade perception of health for patients with MS.

Concerning the total level of the children knowledge about MS in relation to their characteristics such as; age, sex, level of education and birth order. The results of study illustrated that there was statistically significance difference between total level of knowledge and children sex, level of education and birth order whereas, the lower score for children who was

illiterate, meanwhile the higher was for girls who have university education and in the third or fourth birth orders. In addition, there was no statistical significance difference between total level of knowledge & children age pre implementation. This could be due to increased incidence of MS among girls.

The result of the present study was similar with **Claflin, et al., (2022)** who "Assessing the Impact of Online Health Education Interventions from 2010-2020" and concluded there was statistical significant difference regarding total knowledge of studied patients with MS and their level of education.

On studying the relation between children coping patterns and their level of education and birth order, the result of the present study pointed out that there was statistically significant difference regarding coping patterns of children and their level of education & birth order pre implementation of the educational intervention. This may be attributed to that with increasing the educational level of children increase their awareness & knowledge regarding disease and how to cope with it.

The current study result revealed that there was statistically significance difference between total level of coping patterns and children age, where the positive coping patterns with children whose age was 15 - 18 years old. Additionally, there was statistical significant difference between coping patterns of children and their level of education and birth order pre implementation of the educational intervention. This could be due to that with increase children age and educational level, this reflected positively on their coping due to awareness and increase their abilities to communicate with others about disease through social media. This study result was consistent with **Momenabadi, et al., (2019)** who reported positive outcome of the educational program on patients' QOL and their resilience regarding MS disease.

In addition, the present study results clarified there was statistical significance difference between total level of stress tolerance of children and their age, sex & level of education, where the high stress tolerance with girls' children whose age was 15 - 18 years old and at the secondary school or university. Furthermore, there was statistical significance difference between children total level of stress tolerance and their birth orders at p-value ≤ 0.001pre HBM implementation. This could be due to that girls had the abilities to accommodate on the disease more than boys do, because they express their feeling by crying that reflects positively on their stress tolerance.

As regards the relation between the children QOL and their characteristics, the results of the current study revealed that, there was statistical significance difference between total level of QOL in relation to children age & sex. Whereas, the lower level of QOL was among children whose age was 9 -<12 years old and the higher score was among girls at p= 0.001 pre implementation of the educational intervention which based on HBM. These results approved with **Hainsworth, (2019) and Debska, et al., (2020)** who stated that QOL is related to multiple factors, including socio-demographic, psychosocial and clinical correlates. Also, **Kolokoltsev, et al., (2021)** studied "Girls with different volumes and intensity of physical activity constitution types" and emphasized that the HROPL among children with MS is lower than children without the disease or with other chronically ill. Child's gender, disability status, social & economic level and stress linked to suppress HRQOL in children with MS.

In contrast, **Zadeh, et al., (2022)** studied " Sense of coherence among patients with multiple sclerosis and its relevant factors" and reported that there was no statistical significant relation for QoL of patients with MS & their level of education. In the same context, **Abdulla, et al., (2021)** studied "Factors that influence QOL in patients with MS in Saudi Arabia" and concluded there was no statistically significant relation between QoL of children with MS and demographic characteristics regarding age, sex, ranking, residence and their level of education preprogram. Meanwhile, **Sharafi, and Seydi, (2021)** "Investigating the effect of evidence-based education on self–care in patients with multiple sclerosis" & found significant difference between age, education & self-esteem; but not significant with patient's gender.

The current study results revealed that**, t**here was positive correlations between the total levels of the studied children knowledge, coping patterns, stress tolerance and quality of life pre

implementation of the educational intervention which based on HBM with r.= 0.117, 0.219 and 0.218 at p-value <0.05, compared with positive correlations post implementation of the intervention with r.= 0.339, 0.579 and 0.577, at p-value <0.001 respectively. These were in accordance with **El-Kattan, and El-Zayat, (2019)** who studied "Effects of Self-Care Educational Program on QOL of Patients with MS," and mentioned that there was positive correlation between patients' knowledge & their QOL after implementation.

However, **Kidd, et al., (2017)** carried out "A systematic review of the effectiveness of self-management interventions in people with MS at improving depression, anxiety and quality of life", & concluded there was significant improvement in QOL post intervention. While, **Mitchell, et al., (2020)** investigated " Quality of life and its assessment in multiple sclerosis: integrating physical and psychological components of wellbeing" & pointed out there was no statistical correlation regarding knowledge level of children with MS and their QOL before intervention compared with positive correlation after intervention.

Conclusion

Educational intervention program which based on health belief model had a positive effect on children with MS in relation to improve their knowledge regarding multiple sclerosis disease, enhancing coping patterns, improve their stress tolerance as well as, promoting their quality of life. There were positive statistical significant correlations between the studied children total knowledge level, coping patterns, stress tolerance and quality of life pre and post implementation of the educational intervention which based on health belief model.

Recommendations:

- Using health belief model in planning of health interventions which based on empowerment of children with MS in a self-care activity.
- Increase awareness of teachers in children school that help in early detection and prompt intervention for children with MS cases as early as possible.
- Regular follow up for children with MS to evaluate their health conditions and to detect complications as early as possible.
- Performing educational program for parents of newly diagnosed children with MS to increase their awareness regarding psychosocial care and support for their children with MS.
- Further studies needed to assess factors affecting QOL of children with MS.

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