Assessment of Quality of Life for Multiple Sclerosis among Adolescents

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Abstract

Background: Adolescents with multiple sclerosis (MS) report lower health-related quality of life (HRQoL) as compared to general and other chronic disease populations. **The aim** of the study was to assess quality of life for multiple sclerosis among Adolescents. **Research design**: Descriptive design. **Settings:** This study was conducted in MS unit at Ain Shams University Hospital whereas; this unit has a large number of adolescences with MS. **Subjects**: A Purposive sample of 50 adolescents suffered from MS. **Tools**: 1st tool; Structure interview questionnaire included demographic characteristics. 2nd tool: medical record and 3rd tool was Multiple Sclerosis Quality of Life for Adolescents (MSQOL)-54. **Results:** the study revealed that (74.0%) were female, more than one quarter (28%) of them their families had history of multiple sclerosis disease and majority (86.0%) of them total score level of their quality of life was fair. **Conclusion:** the majority of studied adolescents had had fair quality of life. **Recommendation:** Provide continuous education training program and illustrative booklet for adolescents with MS. Further investigation is required to examine the impact of MS on the quality of life for caregivers within the families of adolescents affected by the disease.

Key words: Quality life, Multiple Sclerosis, Adolescents.

Introduction:

Multiple sclerosis (MS) is a chronic inflammatory disease of the central nervous system. The term childhood MS is used in patients whose first clinical signs occur before 18 years of age. The incidence of MS in children is rare, compared to MS in adulthood. The MS International Federation estimates that there are at least 30,000 children and teenagers with MS living in the world. A recent systematic review reported an overall range of incidences from 0.05 to 2.85 per 100,000 children, and an overall prevalence from 0.69 to 26.92 per 100,000 children (**Bessing et al., 2022**).

The slight increase in the incidence of the disease in recent years is mainly due to better and more accessible diagnostic methods but can also be attributed to a higher incidence of autoimmune diseases in developed countries. Pediatric MS most commonly occurs during adolescence, and the incidence rises dramatically after puberty. Less than 1% of all pediatric MS patients have an onset before the age of 10 years. Gender ratio varies with age at onset (**Bijani et al., 2022**).

Adolescence is the phase of life between childhood and adulthood, from ages 10 to 19. It is a unique stage of human development and an important time for laying the foundations of good health. Adolescents experience rapid physical, cognitive and psychosocial growth. This affects how they feel, think, make decisions, and interact with the world around them. Despite being thought of as a healthy stage of life, there is significant death, illness and injury in the adolescent years. Much of this is preventable or treatable. During this phase, adolescents establish patterns of behavior – for instance, related to diet, physical activity, substance use, and sexual activity – that can protect their health and the health of others around them, or put their health at risk now and in the future (**Odgers & Jensen, 2022**).

Although there are different definitions or models of health-related quality of life (HRQOL), four main dimensions are incorporated: physical, mental, social, and functional health. HRQOL is a subjective and multidimensional concept that makes it possible to assess the impact of the pharmacological and disease or nonpharmacological treatment on these four dimensions and on well-being. Identification of purpose in life and personal growth, particularly in light of a diagnosis of a progressive, chronic illness, provides a much fuller picture of an individual and their well-being and is complicated and intertwined with HRQOL (Goverover et al., 2022).

Many organizations, e.g., the European Medicines Agency, emphasize the need to assess HRQOL in patients with chronic diseases. The effect of the disease on the quality of life (QoL) of children has been demonstrated in various chronic diseases such as cancer, rheumatic diseases, asthma, diabetes mellitus, neurological diseases including neurosurgical patients, fibromyalgia, demyelinating diseases, spinal muscular atrophy, cerebral palsy, or epilepsy (**Ow et al., 2021**).

Persons with multiple sclerosis (MS) report lower health-related quality of life (HRQoL) as compared to general and other chronic disease populations. Factors such as age, sex, socioeconomic status, disability status, depression, and fatigue have been associated with HRQoL in MS. Comorbidity is high in MS and the most prevalent comorbidities include mental health conditions, such as depression and anxiety, and physical conditions, such as hypertension, hyperlipidemia, and chronic lung disease. While comorbidity is associated with reduced HRQoL for other chronic diseases, little is known about its influence in MS (Stephens et al., 2021).

Considering the increasing prevalence of MS at young ages, initiating self-care behavioreducation can prevent balance and motor function disorders in these patients, in the future. On the other hand, few research studies have addressed the effectiveness of nursing intervention on the balance and motor function in patients with MS using Orem's self-care model. Based on the proposed nursing systems in Orem's self-care model, nurses can play different roles in patient care regarding empowerment through methods of helping such as acting, teaching, and supporting to improve patients' balance and motor function. In particular, empowering patients with MS reduces the costs of treatment, prevents early disabilities, improves their quality of life, and improves their individual and social performance (Stephens et al., 2021).

Significance of the study:

According to the statistical report of Ain Shams MS unit that, the total number of patients admitted to multiple sclerosis unit were 3300 patients within the last ten months (1/12/2018-30/9/ 2019), and approximately 400 patients per month and 40 of them were adolescents that representing 10% of them.

There is a scarcity of research focusing specifically on the quality of life of adolescents with MS. Most studies on MS have predominantly focused on adult populations, neglecting the unique needs and experiences of adolescents.

Aim of the Study:

This study aimed to assess quality of life for multiple sclerosis among Adolescents.

Research Question:

-What is the level of quality of life among adolescents suffered from multiple sclerosis?

Subjects and Methods

I. Technical Design:

The technical design for the study entails the research design, setting, subjects, and tools of data collection.

Research Design:

Descriptive design was used in this study.

Research Setting:

This study was conducted in Multiple Sclerosis (MS) Unit at Medical Psychiatric Center affiliated to Ain Shams University Hospital whereas; this unit has a large number of adolescence suffering from multiple sclerosis.

Research Subjects:

A purposive sample composed of 50 adolescents suffering from MS and was selected under the following inclusion and exclusion criteria:

The inclusion criteria are:

• Age: adolescence age (12-21years).

- Have a definite diagnosis of MS of any type, confirmed by a neurologist.
- Diagnosed with MS for at least one year.

Exclusive criteria:

- Adolescents have other co-morbid serious chronic illnesses as hypertension, diabetes mellitus and coronary artery disease
- Adolescents who receiving other therapies (e.g psychological therapy).

A purposive sample, the estimated sample size is 50 adolescents at confidence level 90% and precision rate at 0.05 by using Steven equation (Steven, 2012). Since the total number was 193 adolescents.

$$n = \frac{N \times p(1-p)}{\left[N - 1 \times \left(d^2 \div z^2\right)\right] + p(1-p)}$$

While; P= 0.5, N= Total population, Z= Z value "1.96", D= Standard Error, n= sample size.

Tools of data collection:

Three tools were used for data collection as the following:

Tool (1): A structured Interviewing Questionnaire Sheet (AIQS): This tool was designed by the researcher. It was written in simple Arabic Language. Demographic characteristics of studied adolescents; age, gender, level of education, ranking, and occupation.

Tool (2): Medical Records: smoking, family history, diagnosis, onset of the disease, age at first attack, duration, investigations, number of attacks.

Tool (3): Multiple Sclerosis Quality of Life for Adolescents (MSQOL)-54: It was adopted from Acquadro et al. (2003). MSQOL -54 is a standardized scale in an English language; it used to assess/evaluate a quality of life specifically tailored to MS. The MSQOL-54 form is a comprehensive but relatively brief assessment package consisting of 54 items organized into the 12 sub items and it translated into an Arabic language and was used to assess quality of life for adolescents with multiple sclerosis.

***** Scoring system:

There are 12 subscales including., physical health, physical -limitations, emotional -limitations, health perception, pain, emotional well-being, health energy, social relationship, cognitive function, health distress, changes in health, and overall quality of life.

 \circ The total score for each subscale was 10 marks categorized into three levels, and answers was coded as follow: best = 8-10, fair = 5-7, worse = 1-4.

 \circ The total score for 12 subscales was 120, and was categorized into three levels as follow: best = 81-120, fair = 41-80, worse = 1-40.

II-Operational Design:

The operational design was included preparatory phase, content validity and reliability, pilot study and field work

A-Preparatory Phase:

This phase included reviewing of recent updating, current, national and international related literature to cover the various aspects of research problem by the using nursing textbooks, articles, magazines and websites. This was necessary for the researcher to be aquatinted with, and oriented about all aspects of the study problems, as well as to assist in development of data collection tools.

B-Content Validity and Reliability:

• Content Validity:

The study tools were reviewed by a panel of 3 experts in the field of pediatric to test the face and content validity. Modifications of the tools were done according to the panel judgment in clarity of same questions, appropriateness of few content and sequence of some items.

• Reliability:

The reliability was tested by using a Cronbach's Alpha test that was used to measure the internal consistency of the tool (reliability of the used tool or instrument). Where, r = 0.86 and 0.87 for questionnaire and MSQOL-54 respectively. These show high reliability scores for the tools.

$$\alpha = \frac{N \cdot \bar{c}}{\bar{v} + (N - 1) \cdot \bar{c}}$$

Where:

N = the number of items.

 \overline{c} = average covariance between item-pairs.

 $\overline{\mathbf{v}}$ = average variance.

-Reliability of adolescent's MSQOL -54 tool = 0.87.

C-Pilot Study:

A pilot study was conducted on 10% (5 adolescents with MS) of the study subjects to evaluate the clarity and applicability of the study tools and to estimate the time needed for its completion. After obtaining the results of the pilot study, the ambiguous items were omitted. Other items were added or modified. Then the final form was developed. The adolescents who participated in the pilot study were excluded from the actual study subjects later.

D-Field Work:

The actual field work started from the first of February 2020 to the end of July 2020.

- The researcher attended for three days per week (Saturday, Tuesday and Thursday) from 9 am to 2pm in MS Unit at Medical Psychiatric Center affiliated to Ain Shams University Hospital. The aim of the study \was clarified for the adolescence with MS.

- The structured interviewing questionnaire was distributed for adolescents with MS. Each adolescent took about 20 minutes to fill in the questionnaire. In relation to studied adolescents with the MS the characteristics and medical data were filled in by the researcher from the medical record of the studied adolescents. The time needed to fulfill the medical record was 10 minutes.

- Multiple Sclerosis Quality of Life for Adolescents tool time needed to fulfill was 15 minutes.

Ethical considerations:

The ethical research considerations in this study included the following:

• The research approval was obtained from the Ethical Research Committee in Faculty of Nursing Ain Shams University before conduction of the study.

• The aim of the study was explained to the study subjects to obtain their cooperation.

• An oral consent was also obtained from the studied adolescents with multiple sclerosis. Confidentiality was secured for each participant, where all the gathered data were used for the research purpose only.

• Study tools were not including any immoral statements that touch adolescents with multiple sclerosis beliefs, dignity, religion, culture or any other personal issues.

• Participants were informed to choose to participate or not and they were informed that they have the right to withdraw from participation in the study at any time without giving any reason.

IV- Statistical design:

The collected data were organized; tabulated and analyzed using software. The appropriate statistical tests were used for data handling and graphical presentation, and Statistical Package for Social Sciences (SPSS) version 25. Data were checked for normality and equality of distribution, data was presented as number and Relations percentage. between different quantitative variables were tested. Data were presented in tables and figures. The statistical analysis includes; percentage (%), standard deviation (SD), Chi-Square test (X²), Proportion probability (P- values), and Cronbach's Alpha coefficient test which revealed that tool consisted of relatively homogenous items as indicated by the moderate to high reliability of each tool.

Results:

Table (1): Table showed that, the mean age of the studied adolescents was 18.8 ± 1.89 years, and half of them (50 %) studied adolescents in the university, as regards their ranking, 60% of studied adolescents ranked as first and second. Concerning their occupation, approximately three quarters (74%) of them were unemployed.

Figure (1): showed that 74% of studied adolescents were females, and 26% of them were males.

Table (2): Table displayed that, the majority (88%) of studied adolescents were not smokers, regarding their family history, more than one quarter (28%) of them their families had history of multiple sclerosis disease, more than three quarters (78%) had chronic disease, 20% and 22% of them had neurological and auto immune diseases respectively. Concerning past history of studied adolescents with multiple sclerosis disease, very

few (4%) of them had collagen diseases, and 8% had Covid-19. Regarding current number of total relapses attacks, this table clarified that 62% had one to three attacks, more than three quarters (78%) of them had relapses of one to three attacks in the previous two years.

Table (3): Table presented that, there wasno statistically significant relation between totalscore level of quality of life of studied adolescentswith multiple sclerosis disease and their socio-demographic characteristics as regards their age,gender, educational level, residence, ranking andoccupationp-value>0.05.

 Table (1):Distribution of Studied Adolescents with Multiple Sclerosis Disease according to their Demographic Characteristics.

Adolescents' demographic characteristics	(No.: No	=50) %
Age (vears)	110.	/0
12-<15	3	6
15-<18	9	18
18-21	38	76
Mean±SD	18.8±	1.89
Educational level		
Illiterate	1	2
Primary	6	12
Secondary	18	36
University	25	50
Ranking		
First	15	30
Second	15	30
Third	10	20
Fourth and more	10	20
Occupation		
Unemployed	37	74
Employed 13	2	6
Gender 26% 74%		

Figure (1): Distribution of Studied Adolescents with Multiple Sclerosis Disease according to their Gender.

■ Male ■ Female

	(No.=50)			
Adolescents' medical record	No.	%		
Smoking				
Yes	6	12		
No	44	88		
*Family history				
Family history with multiple sclerosis	14	28		
Chronic disease	39	78		
Neurological disease	10	20		
Auto immune disease	11	22		
Past history				
Collagen diseases	2	4		
Covid-19	4	8		
Adolescents age at first attack (years):	14	28		
12- < 15	20	40		
15 - < 18	16	32		
18 - 21	8	16		
Adolescents age at diagnosis by multiple sclerosis (years)	12	24		
12 - < 15	30	60		
15 - < 18				
18 - 21				
Number of relapses attacks (previous 2 years):				
1-3	39	78		
4-6	5	10		
≥7	6	12		
Present History:				
Number of relapses (total attacks currently):				
1-3	31	62		
4-6	11	22		
≥7	8	16		

Table (2): Distribution of Studied Adolescents with Multiple Sclerosis Disease according to Family and post, present History.

*Numbers are not mutually exclusive

Adolescents' socio-demographic	Best (No.=3) Fai		Fair	Fair (No.=43)		Worse (=4)		
characteristics/Quality of life	No.	%	No.	%	No.	%		
Age (years)								
12-<15	0	0.0	2	4.7	1	25.0		
15-<18	0	0.0	8	18.6	1	25.0		
18-21	3	100.0	33	76.7	2	50.0		
x^2	3.961							
p-value	0.411							
Gender								
Male	1	33.3	11	25.6	1	25.0		
Female	2	66.7	32	74.4	3	75.0		
x^2	0.090							
p-value			0.956					
Education level								
Illiterate	0	0.0	1	2.3	0	0.0		
Primary	0	0.0	5	11.6	1	25.0		
Secondary	0	0.0	15	34.9	3	75.0		
University	3	100.0	22	51.2	0	0.0		
<i>x</i> ²		7.388						
<i>p-value</i>			0.286					
Ranking	•		10	27.0		25.0		
First	2	66.7	12	27.9	1	25.0		
Second	1	33.3	13	30.2	1	25.0		
Third	0	0.0	9	20.9	1	25.0		
Fourth and more	0	0.0	9	20.9	1	25.0		
x		2.823						
<i>p-value</i>			l	0.831				
Occupation	1	22.2	10	22.2	2	50.0		
Employed	1	33.3	10	23.3	2	50.0		
Unemployed	2	66.7	55	/6./	2	50.0		
<i>x</i> -			1	.450				
p-value			l).484				

Table (3): Relation between Studied Adolescent's Total Score Level regarding their Quality
 of life with Multiple Sclerosis Disease and their Socio-Demographic Characteristics.

p >0.05 Not Significant *p<0.05 Statistical Significant** p <0.001 High Statistical Significant

Discussion:

MS is a progressive and degenerative disease of the myelin sheath for cover cells in the CNS that required to evidence based self-care includes inferring and wisely using the best available scientific in combination with the patient's condition. Many adolescents with chronic conditions experience reduced selfsupport, independent living, communication skills, and quality of life. Nursing intervention program can be a predictor of an adolescent's ability to change his/her behavior and decision to increase quality of life (**Borinnejad, et al., 2018, and Sharafi, & Seydi, 2021**).

MS is a chronic neurodegenerative disease that gradually impairs CNS function, leading to a wide range of symptoms. MS disease the condition can result in severe disability and reduced quality of life for adolescents living with MS. Consequently, MS requires effective disease management, including pharmacological interventions and/or non-pharmacological symptom management approaches. Health education interventions aim to increase knowledge, understanding and selfmanagement skills, overcoming barriers to positive behavior change, and facilitating shared decisionmaking and improve quality of life (Harvie, 2021). So, this study aimed to assess quality of life for multiple sclerosis among Adolescents.

On studying sociodemographic characteristics of the studied adolescents, concerning on their age, the present study illustrated that the mean age of the studied adolescents was 18.8 ± 1.89 years. this finding disagreement with **Ibrahim et al.**, (2020) who

conducted study "Effect of Nursing Guidelines Regarding Safety Measures on Occurrence of Injuries among Adolescents with Multiple Sclerosis" and reported that majority of studied adolescents with MS were 16 < 18 years and the mean age of selected adolescents with MS was 15.1 ± 0.6 years.

As regard to education level, the current study displayed that half of the studied adolescents with MS had university education. This result in the same line with study by **Torpil, & Pekçetin (2022)** who conducted study about " Effectiveness of Client-Centered Training on Percieved Occupational Performance and Satisfaction in People with Multiple Sclerosis" and reported that half of the studied patients with multiple sclerosis had university education

Regarding gender of the studied adolescents, the present study showed that less than three quarters of the studied adolescents with multiple sclerosis were females. this might be due to the immune system may be stimulated by sex steroid hormones during puberty. This finding was consistent with study by **Wallin et al.**, (2019) who conducted study about " Global, regional, and national burden of multiple sclerosis 1990–2016" and reported that females more than twice as likely to be affected than males.

Regarding family history, the current study showed that more than one quarter of the studied adolescents had history of MS. This result matched with study by **Khedr et al.**, (2022) who conducted study about "Perceived stress in multiple sclerosis patients: Relationship with mood states and pain experience" and reported that less than one third of the studied patients had history of multiple sclerosis disease.

As regards to types of MS, the finding of present study revealed that about two thirds of the studied adolescents had relapsing remitting MS, this result was in agreement with study by **Bijani et al.**, (2022) who conducted study about " The effect of peer education based on Pender's health promotion model on quality of life, stress management and self-efficacy of patients with multiple sclerosis" and reported that two thirds of the studied adolescents had relapsing remitting MS.

According to number of relapses during previous 2 years, the current study illustrated that less than two thirds of the studied adolescents had one to three attacks, this result in the same line with study by **Abd Elsalam, & Ali, (2022)** who conducted study about " Self-Management Guidelines: Effect on Knowledge, Fatigue, Self-Efficacy and Medications Adherence among Patients with Multiple Sclerosis" and showed that less than three quarters of the studied sample had one to three attacks at previous 2 years

On investigating adolescents' medical record, the present study revealed that more than half of the studied adolescents had mild of expanded disability status according to their neurological examination. meanwhile regarding para-clinical tests, the present study revealed that all studied adolescents their magnetic resonance imaging was abnormal, more than half of them their spinal test was abnormal, as well as half of them had abnormal visual evoked potential test, and the majority of them had abnormal cerebro spinal fluid test. These findings were consistent with Omer, & PaÅ, (2022) who conducted study about "Cognitive performance and quality of life in patients with multiple sclerosis" and founded that the majority of the studied sample had mild disability status and abnormal spinal test.

Pertaining to total score level of the studied adolescents ' QOL, the present study demonstrated that majority of studied adolescents total score level of their quality of life was fair while very few percentage of them was best. These results may be due to wide range of physical symptoms, MS can have a significant emotional impact on adolescents, and MS may face social limitations due to their condition. This outcome supported with study by Penwell-Waines et al., (2017) entitled "Testing the health promotion model for adherence and quality of life in individuals with multiple sclerosis" and founded that most of the studied sample had fair quality of life. Conversely, this finding was in disagreement with a study by Kidd et al., (2017) about "A systematic review of the effectiveness of selfmanagement interventions in people with multiple sclerosis at improving depression, anxiety and quality of life", and demonstrated that most of the studied sample had poor quality of life in individuals with multiple sclerosis

Regarding to relation between studied adolescents' level of total score level OOL about MS and their socio-demographic characteristics, the present study showed that there was no statistically significant relation regarding total QOL of studied adolescents with MS and their socio-demographic characteristics regarding age, gender, educational level, residence, ranking and occupation at pvalue>0.05. This result was congruent with study by Abdulla et al., (2021) who conducted study about "Factors that influence quality of life in patients with multiple sclerosis in Saudi and proved that there was no Arabia" statistically significant relation regarding total QOL of studied adolescents with MS and their socio-demographic characteristics regarding age, gender, educational level, residence, ranking and occupation in preprogram p-On other hand this outcome value>0.05. disagreement with study by Zadeh et al., (2022) who conducted study about " Sense of coherence among patients with multiple sclerosis and its relevant factors" and showed that there is no statistically significant relation regarding total quality of life of studied adolescents with multiple sclerosis disease and educational level at p-value>0.05

Conclusion:

In light of the current study, it can be concluded that, the majority of studied adolescents had had fair quality of life. Also, mentioned that family history for Multiple sclerosis is major risk factors for Multiple sclerosis (MS) and the majority of studied adolescents had had fair quality of life.

Recommendations:

Based on the findings of the current study results, the following recommendations were suggested:

1. Provide continuous education training program and illustrative booklet for adolescents with MS.

- 2. Collaboration between healthcare professionals, researchers, and policymakers is essential to ensure the implementation of comprehensive care strategies and policies that address the unique needs of adolescents with MS.
- 3. Further investigation is required to examine the impact of MS on the quality of life for caregivers within the families of adolescents affected by the disease.
- 4. Further research in children and adolescents with MS should also investigate these factors and their impact on QOL in the future.
- 5. Develop interventions and support systems that empower adolescents to actively participate in their disease management and improve their overall QoL.

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