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

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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 disease or pharmacological and non- pharmacological 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 behavior-education 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).

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:

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.

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.

o   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.

o   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.

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.

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.

Field Work:

The actual field work started from the first of February 2022 to the end of July 2022.

-        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 research approval was obtained from the Ethical Research Committee.

•   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.

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 percentage. Relations between different quantitative variables were tested. Data were presented in tables and figures. The statistical

analysis includes; percentage (%), standard deviation (SD), Chi-Square test (X^2), 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

Adolescents' characteristics	demographic(No.=50)	No	%
Age (years)			
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

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.

Adolescents' medical record	(No.=50)	No.	%
Smoking		6	12
Yes		44	88

No		
*Family history	14	28
Family history with multiple sclerosis Chronic disease	39	78
Neurological disease Auto immune disease	10	20
	11	22
Past history	2	4
Collagen diseases 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):	39	78
1-3	5	10
4-6	6	12
≥7		
Present History:		
Number of relapses (total attacks currently):	31	62
1-3	11	22
4-6	8	16
≥7		

Table (3): Table presented that, there was no statistically significant relation between total score level of quality of life of studied adolescents with multiple sclerosis disease and their socio- demographic characteristics as regards their age, gender, educational level, residence, ranking and occupation p-value>0.05

Adolescents' socio-demographic characteristics/Quality of life	Best (No.=3)		Fair (No.=43)		Worse (=4)	
	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
x^2			7.388			
p-value			0.286			
Ranking						
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			2.823			
p-value			0.831			
Occupation						
Employed	1	33.3	10	23.3	2	50.0
Unemployed	2	66.7	33	76.7	2	50.0
x^2			1.450			
p-value			0.484			

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 self- support, 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 (Borimnejad, 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 self- management skills, overcoming barriers to positive behavior change, and facilitating shared decision- making 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 self-management 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 QOL 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 p- value>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 Arabia" and proved 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 in preprogram p- value>0.05. On other hand this outcome 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:

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

1. 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.

2. 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.

3. Further research in children and adolescents with MS should also investigate these factors and their impact on QOL in the future.

4. Develop interventions and support systems that empower adolescents to actively participate in their disease management and improve their overall QoL.

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