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Quality of Life for Adult Clients with Hypermobility Syndrome Attending Private Clinics in Baghdad City: A Cross-Sectional Study

جودة الحياة للبالغين المصابين بمتلازمة ارتخاء الأربطة المفصلية المراجعين للعيادات الخاصة في مدينة بغداد: دراسة مقطعية

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المستخلص:

الهدف: تقويم جودة حياة المراجعين البالغين المصابين بمتلازمة ارتخاء الأربطة المفصلية في العيادات الخاصة في مدينة بغداد.

المنهجية: استخدمت دراسة مقطعية لعينة غير عشوائية (غرضية) مكونة من (٧٥) بالغ، من كلا الجنسين ما بين (٢٥-٦٤) سنة والذين لديهم متلازمة ارتخاء الأربطة المفصلية. تم جمع البيانات من خلال استخدام استبانة منظمة الصحة العالمية القياسية المطورة الخاصة بتقويم جودة الحياة. جمعت البيانات باستخدام طريقة المقابلة المباشرة لكل مشترك والتي استغرقت حوالي (٢٠) دقيقة مع كل مشترك.

النتائج: أظهرت نتائج الدراسة أن جودة الحياة للمشتركين قد تأثرت بمتلازمة ارتخاء الأربطة المفصلية، حيث سجلت مستوى متوسط بشكل عام. كما أظهرت النتائج أن هناك تأثير واضح لمتلازمة ارتخاء الأربطة المفصلية على جودة الحياة من الناحية الجسمية والاجتماعية والنفسية.

التوصيات: توصي الدراسة بأن التشخيص المبكر ورفع مستوى المعرفة بمتلازمة ارتخاء الأربطة المفصلية مهم جدا لكل من المريض والعائلة، كما وتوصي الدراسة بتوفير الاستشارة الصحية وأعداد برامج تثقيفية حول الحالة والتي تساعد على الوقاية أو على الأقل تقليل الأعراض وتحسين جودة الحياة.

الكلمات المفتاحية: ارتخاء الأربطة المفصلية، جودة الحياة

Abstract:

Objective(s): To evaluate the quality of life for adult clients with hypermobility syndrome at private clinics in Baghdad City**.**

Methodology: A cross-sectional study used a purposive ‘’non-probability’’ sample of (75) adult clients with Hypermobility Syndrome (HMS) male and female who age (25-64) years. The data were collected through the utilization of standard developed questionnaire of the world health organization (WHO). Data collected by interview with each client who is involved in the study. Each interview takes approximately (20) minutes.

Results: The study revealed that there is an effect of hypermobility syndrome on the quality of life, which recorded fair level in general. The study also reported that there is an effect of the condition on their physical, social and psychological domains.

Recommendation: The study recommends that early diagnosis of hypermobility syndrome is essential to recognize and increase knowledge about condition for clients and their families, and that consultation and health education programs can help to prevent and minimize symptoms and raise the level of quality of life.

Key Words: Hypermobility Syndrome, Quality of Life

Introduction

Hypermobility Syndrome (HMS) is a common health complain regarding muscular skeleton system among adult people characterized by multiple joints pain, muscular pain (arthralgia), fatigue and other symptoms. These clinical feature affected on multiple aspects related health which result in problems such as physical, psychological, social, spiritual and other health- problems which effect on adult's quality of life (1).

Hypermobility syndrome is a genetic disorder of connective tissue that accrue due to a defect in matrix - proteins include fibrillin, elastin, tenascin and collagen which considered as an essential type of protein which contribute to form joint structure (2).

Pain of the joints and muscles considered as a major symptom of clients with HMS and presented as the chronic condition, which differ from acute in density, duration and location. Chronic pain of client with HMS is usually associated with movement, activity and sport. It is manifested clearer with absence of other diseases or health conditions (3)

Excessive movements of the joint, which increases stress on the joint surface, tendon and ligament, produce the mechanism of joint pain. Clients with HMS sometimes avoid doing some movements or activities to prevent pain and other symptoms that contribute to change their life style (4).

The study that conducted by Bravo and Wolff demonstrated that about 30% - 60% of clients who visited orthopedics clinics with musculoskeletal related pain usually have HMS because these clients are more susceptible to have many health problems such as bursitis, tenosynovitis, chondromalacia patellae, rotator cuff problems, and mechanical back pain (5).

Distribution of HMS in the western countries is estimated between 10-20% of the population. It is a three often-frequent incidence of the health condition among female more than male. In addition to that Asian and African origin is more prevalence in adults people which estimate between 10-30% males and 20-40% females (6).

The quality of life and hypermobility syndrome are related conditions, through the emergence of symptoms that hinder daily activities. Therefore, studying quality of life for clients with HMS is considered as a key of management to determine their limitations and problems regarding daily activity and to identify what they are suffering from, in order to prevent or minimized symptoms throughout create healthy lifestyle and daily habits according to their condition. It is very important to work together with client and family to develop an appropriate individual management plan to solve their problems and help establishing realistic expectations along the way (7).

Measurement of the quality of life for adult clients with HMS by the utilization of health domains such as physical, psychological, independency, social, environmental and spiritual domains show to which extent the client is suffering from the condition (8).

Diagnosis of HMS is conducted by utilization of Beighton score criteria, which is considered as the most common method that is used to detect HMS. It is valid and reliable measurement technique related condition (9).

Unfortunately, there are no official statistics reports of clients with HMS at the Biostatistics Department in the Ministry of Health and Environment in Iraq (10). Therefore, it is necessary to mention that there is a crucial need to estimate the existence of the problem among Iraqi adult's patients with HMS, and identify the influence of the condition on their quality of life.

Methodology

Design of the study: A cross-sectional design was used to guide this study. The study was conducted for the period from April 7th to November 25th, 2018. A purposive sample of (75) adult clients were selected; (35) male and (40) female who were diagnosed with HMS attending the orthopedic private clinics in Baghdad City.

Instrument

The study apply the standard scale for WHO as an instrument of present study World Health Organization Spirituality, Religiousness and Personal Beliefs instrument (WHOQOL-SRPB) (11). It is composed of two major parts; the first part consists of the sample's socio-demographic characteristics of age, gender, marital status and socioeconomic, and the second part consist of six domains of quality of life of clients with HMS, these are:

1. Physical domain; this domain include pain and discomfort, (9) items; energy and fatigue, (3) items, as well as sleep and rest, (4) items.

2. Independence domain; this domain include activities of daily living, (4) items and work capacity, (2) items.

3. Environmental domain; this domain consist of physical safety and security, (3) items; home environment, (3) items; opportunities for acquiring new information and skills, (2) items and participation in and opportunities for recreation / leisure activities, (2) items.

4. Spirituality domain; this domain include (3) items.

5. Social domain; this domain include personal relationships, (3) items and social support, (3) items.

6. Psychological domain; that domain consist of positive feelings, (2) items; negative feelings, (3) items and self-esteem, (3) items.

There are total of (49) items included in the instrument. These items are measured, scored, and rated on a 3 point type Likert scale with 3 for always, 2 for sometimes, and 1 for never.

Validity of the instrument is determined through a panel of (15) experts in different fields of specialty. The pilot study conducted to identify reliability of the instrument using the split-half technique of alpha Cronbach correlation coefficient. The correlation coefficient is (r=0.89) which indicates that the tool is adequately reliable measure.

Data collection

Data collection is conducted using the structured interview technique with each client after get there approval in participating in the study through a written consent. A standard-developed questionnaire is used (English version), and each interview took approximately (25) minutes.

Data Analysis

The data analysis process is conducted by using the statistical package of social science (SPSS) version (25). This includes descriptive data analysis using frequencies and percentage, as well as inferential data analysis using ANOVA, post Hoc and regression to find-out the relationships / differences between the study groups.

Results:

Table (1): Demographic Characteristics of the Study Sample (n=75)

Socio-Demographic Characteristics		
Adult Clients' Age Groups (Year)	**Freq.**	**Per.**
Early Adulthood (25-37) years	25	33.3%
Middle Adulthood (38-50) years	25	33.3%
Late Adulthood (51-64) years	25	33.3%
Total	75	100%
Adult Clients' Gender	**Freq.**	**Per.**
Male	35	46.7%
Female	40	53.3%
Adults Clients' Marital Status	**Freq.**	**Per.**

Single	8	10.7%
Married	43	57.3%
Divorced	7	9.3%
Separated	3	4.0%
Widowed	14	18.7%
Adults Clients' Family Socioeconomic Status	**Freq.**	**Per.**
Low (21-51.3)	5	3.3%
Moderate (51.4-81.7)	54	36.0%
High (81.8-112)	16	10.7%
Total	75	100%

Freq: Frequency, Per: Percentage, n: number of adult clients

Analysis of such characteristics depicts that the subjects are distributed as early adults (33.3%), middle adults (33.3%) and late adults (33.3%), most are females (53.3%), in families with moderate socioeconomic status (36.0%) and the more than half are married (57.3%).

Table (2): Overall Evaluation for the Quality of Life for Adults' Clients with Hypermobility Syndrome (n=75)

Poor (49-81)		**Fair (82-114)**		**Good (115-147)**	
F	**%**	**F**	**%**	**F**	**%**
21	**28.0%**	**39**	**52.0%**	**15**	**20.0%**

F: Frequencies; %: Percentage, n: number of Adult Clients

The overall evaluation depicts that more than a half of the adult clients with HMS have a fair level of QOL, (52.0%) from all partecipants.

Table (3): Evaluation for the Quality of Life Domains for Adult Clients with Hypermobility Syndrome (n=75)

Domains	Poor		Fair		Good		Evaluation
	F	Per.	F	Per.	F	Per.	
Physical	41	54.7	18	24.0%	16	21.3%	Poor
Independence	0	0.0%	7	9.3%	68	90.7%	Good
Environment	25	33.3%	27	36.0%	23	30.7%	Fair
Spirituality	16	21.3%	24	32.0%	35	46.7%	Good
Social Relationship	29	38.7%	19	25.3%	27	36.0%	Poor
Psychological	30	40.0%	22	29.3%	23	30.7%	Poor

Freq: Frequency, Per: Percentage, n: number of adult clients

Evaluation of the quality of life for the adult clients according to its domains reported that the majority of them have poor quality life in physical domain (54.7%), social relationship domain (38.7%), and psychological domain (40.0%), while environmental domain reported fair quality life (36.0%). Good evaluation is for independence domain (90.7%) and spirituality domain (46.7%).

Table (4): Relationship between Adults' Clients Quality of Life with Hypermobility Syndrome and their Socio-Demographic Characteristics

Adults	Unstandardized Coefficients		Standardized Coefficients	T	Sig
	B	Std. Error	Beta		
Age	-.575	.159	-.357	-3.624	.001
Gender	-2.831	3.814	-.077	-.742	.046
Marital Status	-.635	1.902	-.032	-.334	.739
Socio -Economic Status	.116	.170	.079	.683	.497

Std: standard; sig: significant; S.C: Significant Comparative; HS: High Significant; NS: Non Significant

The result of table 4 indicates a significant relationship between adults clients' age, gender and their quality of life, but there is no significant relationship between their marital status and socio- economic status with their quality of life.

Table (5): Comparative Differences among Age Groups of Adult Clients with Hypermobility Syndrome Relative to Their Quality of Life

Age groups		Sum of Squares	Df	Mean square	F	Sig	S. C.
Adult	Between Groups	18793.053	34	552.737	3.370	.000	HS
	Within Groups	6561.533	40	164.038			
	Total	25354.587	74				

Sum: summation; df: degree of freedom; sig: significant; S.C: Significant Comparative; HS: High Significant

The finding of comparing the differences in the quality of life among the three age groups of the adults' clients indicates significant differences at $P < 0.05$.

Table (6): Comparative Differences between Early, Middle and Late Adult Clients with Hypermobility Syndrome Relative to Their Quality of Life

Groups	M(SD)			Post Hoc using LSD		
	Early	Middle	Late	Early vs middle	Early vs late	Middle vs late
	103.80 (17.41)	96.56 (15.05)	86.54 (19.46)	.127	.001	.045

LSD: Least significant differences; M: mean; SD: standard deviation

This table presents the Post Hoc using Least Significant Difference (LSD) test after one-way ANOVA, which demonstrates pairwise differences in quality of life between adult clients groups. The result reported that there is a significant difference between early and late, middle and late, but there is no significant difference between early and middle groups regarding their QOL.

Discussion

Part I: Demographic Characteristics

The Summary statistics of the study sample's demographic characteristics (Table 1), depicted that the study sample distributed as early adults (33.8%), middle adults (33.8%) and late adults (32.4%), most of them are females (53.3%), and moderate socioeconomic status (36.0%) and the majority of them are married (57.3%) (Table 1).

Part II: Overall Evaluation the Quality of Life for Adult Clients with Hypermobility Syndrome

The overall evaluation for the quality of life for clients with HMS (Table 2), reported most clients have fair level of QOL (Table 2). This is evident in table 3 that depicts QOL'S domains as most of them have poor evaluation in physical domain, social domain and psychological domain; environmental domain reported fair level; while independence and spirituality domains conveyed a good evaluation of QOL.

Physical domain of the adult's QOL with HMS is related to issues of pain and discomfort during doing activities; feeling fatigue and lack of energy; difficulties in falling in sleep, which those clients are experiencing. A study for adult clients with HMS regarding joint pain and fatigue depicted those adults with this condition are suffering from pain and instability joint which produce more injuries and they need to improve their life style and receiving prevention programs (12) .

Concerning the social relationship domain, most of them do not initiate social relationships with others and slight friend's support when having problems. A study supported such result, it is reported that social relationships have long and short term effect on healthy behaviors of people with the condition which lead to negative outcome related to QOL(13) .

Regarding the psychological domain of the sample's quality of life, they depicted poor evaluation. Such a domain covered the issues that most of them believe that HMS cannot be adaptable and they have no positive view of life. They also have bad feeling since they lost some responsibilities or roles in their job or home; they may expose for joint dislocation and pain; not sure about their self-confidence for doing daily responsibilities with high quality and their family and society trust in their decision. A study supported to such finding is reported that client with HMS often, develop psychological disorder, depression and anxiety that effect on HRQOL (14).

Environmental domain of adult clients with HMS reported fair level of QOL, such a domain is about the issues of not living in a healthy neighborhood; not working in a place suitable for their health and they do not have an adequate time to participate in leisure activities. A study that conducted related physical safety at both home and work- places contributes to healthy environment by measuring location of housing and facilities, as well as measuring risks or hazards of woke place that may produce injuries or accidents (15).

Fortunately, most of the adult clients have a good evaluation in independence domain; they are capable of doing their activities of daily living, good capacity in work performance. A study that supported such a result is that adults with HMS have the ability to perform their tasks and usually can practice daily activities and providing self-care without needing a help from others (16) .

Regarding spiritual domain, most of adults believe that their suffering from their condition is wisdom from God and they accept their being ill with this condition. A study of more than (449) clients completed assessments of spiritual wellbeing had suffers from symptoms but they have positive view related their QOL (17) .

Recommendations:

1. Evaluation the QOL for adult clients with HMS is very important to determine the influence on their life to prevent or at least decrease symptoms.

2. Early diagnosis of HMS is essential to recognize and increase knowledge about condition for both clients and their families.

3. Provide consultation and health education programs for adult clients to help them change their lifestyle and enhance their activity of daily living.

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