

The effects of the COVID-19 pandemic on quality of life: a survey of mildly disabled multiple sclerosis patients

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Abstract

Background: Almost everyone's health-related quality of life (HQoL) can be affected by a huge health problem like the COVID-19 pandemic.

Aims: We assessed the short-term impact of the COVID-19 pandemic on HQoL in multiple sclerosis (MS) patients in Tabriz, Islamic Republic of Iran.

Methods: A printed version of the MS-specific HQoL questionnaire was completed by patients at the neurology department at the university hospital in Tabriz and the scores before and during the pandemic (2019 and 2020) were compared.

Results: We recruited 50 patients for this study. Although the overall physical (69.29 + SD 16.59, to 68.40 + SD 20.95) and mental health (67.36 + SD 19.02 to 66.76 + SD 22.70) composite scores decreased slightly in the second stage, however, this change was not statistically significant ($P = 0.67$, $P = 0.83$). The severity of MS was associated with changes in mental and physical health composites.

Conclusions: The effect of the pandemic on the HQoL of mildly disabled MS patients was not statistically significant.

Keywords: multiple sclerosis, quality of life, COVID-19 pandemic, health-related quality of life

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Introduction

The coronavirus disease 2019 (COVID-19) pandemic, as the greatest challenge since World War II (1), is a major concern globally in 2020. Multiple sclerosis (MS) itself, is not a risk factor for contracting severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) (2), but some disease-modifying drugs may reduce the ability of the immune system to respond to an infection, which can make MS patients more susceptible to the disease (3,4).

A study of the evaluation of health-related quality of life (HQoL) reported a significant increase in pain/discomfort and anxiety/depression factors of the EuroQol-5D instrument in a general Chinese population (5). Another study assessing quality of life (QoL) in cancer patients during the COVID-19 pandemic found that QoL was distinctly affected (6). A QoL survey among 158 Italian patients confirmed the impact of the COVID-19 pandemic on the risk of anxiety/depression in patients with primary antibody deficiencies (7).

Previous studies have indicated that social and family circumstances and physical disability of disease can impact patients' QoL (8–11). Adding other stressors such as disease outbreaks may affect patients' QoL due to fear of the effects of infectious disease on the existing illness and fear of the consequences of changing treatment. The goal of this study was to evaluate the short-term impact of COVID-19 pandemic on HQoL in a sample of MS patients.

Methods

Study design and ethical issues

This cross-sectional study was carried out during October 2019–June 2020. Patients were recruited via the neurology department at the university hospital in Tabriz, Islamic Republic of Iran. All of the patients involved in the study gave detailed informed consent before each stage of completing the questionnaire and the study did not impose a financial burden on patients. Adult patients with a definitive diagnosis of relapsing–remitting MS (RRMS) according to the revised 2017 McDonald diagnostic criteria and a lower degree of disability on the Expanded Disability Status Scale (EDSS), score ≤ 4 , were selected for this study. Patients with a history of COVID-19 or any other infectious disease, patients with COVID-19 underlying medical conditions, history of alcohol abuse, changing medication between 2 stages of the study, having corticosteroid pulse or MS relapse within 8 weeks of the assessments, systemic diseases or severe disabilities, and presence of physical impairments that could interfere with HQoL testing were excluded from our sample. At both stages, patients were examined by a neurologist and where there was any change in the EDSS score, they were excluded from our sample.

Ethical considerations

The ethics committee of Tabriz University of Medical Sciences reviewed and approved the study protocol (Ethics Code: IR.TBZMED.REC.1399.385).

Data collection

The first stage of collecting data was carried out between October 2019 and February 2020, before the COVID-19 pandemic as a part of another published study (12); 92 patients were involved in this stage. The second stage was during the COVID-19 pandemic in May and June 2020; in total, 50 patients were involved in this stage. All of the patients who had participated in the first stage of the study and had attended the medical centre for their routine medical visit were involved in this study apart from those who were ruled out according to the exclusion criteria. To reduce the risk of infection, all the hygiene protocols were followed strictly by both the healthcare providers and the patients, during the examination. We used the Farsi version of the MS quality of life-54 (MSQOL-54) questionnaire designed by Vickrey et al. (10,11,13) for measuring HQoL. The validity and reliability of the Farsi translated version of the questionnaire were approved by Ghaem et al. (14). A printed version of the questionnaire was completed by the patients (in the case of disability, a trained colleague helped in reading and completing it). We divided patients into 3 groups according to drug usage: oral, injection and infusion medications. The oral drug group included dimethyl fumarate and fingolid. The injection group included high-dose high-frequency

Table 1 Demographic and clinical characteristics of relapsing–remitting MS patients (n = 50: 17 males, 33 females), Tabriz, 2019–2020

Characteristic	Mean (SD)
Age (years)	33.14 (9.08)
Education (years)	12.54 (3.86)
EDSS score	1.34 (1.24)
Disease duration (months)	88.46 (72.91)
No. of relapses	2.36 (2.53)
Medication (no. of patients using oral; injection; infusion)	20; 17; 13

SD = standard deviation.

EDSS = Expanded Disability Status Scale.

drugs (interferon beta-1a), glatiramer acetate and low-dose low-frequency drugs (interferon beta-1a) and infusion drugs, including natalizumab and rituximab.

Statistical analysis

The results of the first and the second stages of study were compared by patients themselves using SPSS, version 26.0, with significance level 0.05 and 95% confidence interval. Values are given as mean and standard deviation (SD) rounded to 2 decimal places and the paired samples *t*-test was used to compare results before and during the pandemic. The HQoL changes were calculated and the Pearson correlation was used to find the correlation coefficients between demographic factors and absolute values of HQoL changes. For assessment of differences

Table 2 Scores on the MSQOL-54 questionnaire health-related quality of life subscales assessed before and during the COVID-19 pandemic for 50 relapsing–remitting MS patients in Tabriz (October 2019–June 2020)

HQoL subscales	Score		P-value ^a
	Before Mean (SD)	During Mean (SD)	
Physical			
Physical function	80.15 (22.83)	80.10 (24.85)	0.98
Health perceptions	62.70 (19.27)	66.80 (20.64)	0.11
Energy/fatigue	57.12 (18.16)	57.44 (21.97)	0.91
Physical role limitations	71.50 (37.46)	66.00 (40.01)	0.25
Pain	71.96 (20.05)	69.69 (26.23)	0.47
Sexual function	71.98 (31.37)	70.83 (35.66)	0.83
Social function	71.50 (20.48)	70.99 (20.28)	0.86
Health distress	67.70 (25.75)	67.90 (28.99)	0.95
Mental			
Overall quality of life	71.63 (20.33)	70.93 (21.86)	0.81
Emotional well-being	59.35 (19.19)	59.51 (21.42)	0.95
Mental role limitations	67.99 (38.07)	67.33 (39.54)	0.92
Cognitive function	76.30 (17.43)	72.70 (25.39)	0.23
Health distress	67.70 (25.75)	67.90 (28.99)	0.95
Overall			
Physical health composite	69.29 (16.59)	68.40 (20.95)	0.67
Mental health composite	67.36 (19.02)	66.76 (22.70)	0.83

HQoL = health-related quality of life; SD = standard deviation.

^aDifference was not statistically significant in any subscale in our sample.

related to sex and medications, the independent samples *t*-test and one-way ANOVA were used for both demographic factors and HQoL score changes.

Results

We recruited 50 RRMS patients, 17 males and 33 females. Table 1 gives a summary of the demographic characteristics. Mean age of the participants was 33.14 (SD 9.08; range 19–54) years. Mean duration of illness was 88.46 (SD 72.92) months.

Table 2 gives a summary of the scores on the MSQOL-54 questionnaire subscales before and during

the pandemic. Although the overall physical (69.29, SD 16.59, to 68.40, SD 20.95) and mental health (67.36 SD 19.02 to 66.76 SD 22.70) composite scores decreased slightly in the second stage, however, this change was not statistically significant ($P = 0.67$, $P = 0.83$). Some subscales such as physical role limitations ($P = 0.25$), pain ($P = 0.24$) and cognitive function ($P = 0.23$) showed a decline, while health perception ($P = 0.11$) showed an improvement during the COVID-19 pandemic. Generally, none of these changes were statistically significant. Physical function and emotional well-being were the subscales that were the most similar between the first and second stages of the study ($P = 0.98$, $P = 0.95$). The decrease in mental ($P =$

Table 3 Correlation coefficients for demographic factors and clinical characteristics among relapsing–remitting MS patients in Tabriz (October 2019–June 2020) and absolute values of the health-related quality of life (HQoL) subscale changes (Pearson correlation)

HQoL subscale	Statistic	Component			
		Age	Education	Duration of disease	EDSS score
Physical					
Physical function	r	0.20	-0.03	0.46	0.48
	P-value	0.15	0.78	< 0.01	< 0.01
Health perceptions	r	0.05	-0.27	0.13	0.06
	P-value	0.70	0.05	0.33	0.66
Energy/fatigue	r	0.01	-0.01	0.00	0.20
	P-value	0.93	0.93	0.98	0.15
Physical role limitation	r	0.17	-0.06	0.18	0.34
	P-value	0.21	0.64	0.18	0.01
Pain	r	0.28	0.64	0.29	0.25
	P-value	0.04	0.43	0.03	0.07
Sexual function	r	-0.05	0.02	-0.19	0.03
	P-value	0.75	0.87	0.24	0.84
Social function	r	-0.16	-0.15	-0.03	-0.00
	P-value	0.26	0.27	0.81	0.96
Health distress	r	0.07	-0.08	0.01	0.26
	P-value	0.59	0.55	0.89	0.06
Mental					
Overall quality of life	r	0.10	-0.22	0.28	0.33
	P-value	0.48	0.11	0.04	0.01
Emotional well-being	r	-0.04	-0.26	-0.02	0.28
	P-value	0.74	0.06	0.85	0.04
Mental role limitations	r	-0.12	0.10	0.02	0.26
	P-value	0.38	0.44	0.86	0.06
Cognitive function	r	0.42	-0.27	0.30	0.21
	P-value	< 0.01	0.05	0.03	0.13
Health distress	r	0.07	-0.08	0.01	0.26
	P-value	0.59	0.55	0.89	0.06
Overall					
Physical health composite	r	0.06	-0.09	0.26	0.35
	P-value	0.64	0.50	0.06	0.01
Mental health composite	r	0.03	-0.13	0.23	0.29
	P-value	0.81	0.34	0.09	0.03

EDSS = Expanded Disability Status Scale.

0.83) and physical health ($P = 0.67$) composites were not significant either.

A summary of the correlation coefficients for the demographic factors and clinical characteristics of patients with absolute values of changes in the HQoL subscales is presented in Table 3. Age was associated with the pain ($P = 0.04$) and cognitive function ($P < 0.01$) subscale changes. Education did not affect changes in any subscale of HQoL but duration of the disease influenced the physical function ($P < 0.01$), pain ($P = 0.03$), overall QoL ($P = 0.04$) and cognitive function ($P = 0.03$) subscales. Severity of MS according to the EDSS score had an association with physical function ($P < 0.01$), physical role limitation ($P = 0.01$), overall quality of life ($P = 0.01$), emotional well-being ($P = 0.04$), and physical ($P = 0.01$) and mental ($P = 0.03$) health composites changes. Without any significant difference between the demographic characteristics of the female and male participants, the changes in HQoL subscales were not statistically significant in any HQoL subscale (overall score P -values 0.41 and 0.46). Also, comparing types of medication, there was no significant difference in any HQoL subscale between users of oral, injection and infusion disease-modifying drugs (overall score P -values 0.18 and 0.24).

Discussion

The COVID-19 pandemic had negative effects on patients' HQoL but the differences were not statistically significant in our sample. The effects of the COVID-19 pandemic on mental and physical health composites were greater in patients with a higher EDSS score.

A 2020 cross-sectional study in an Iranian setting found that 90% of MS patients knew that COVID-19 was in the pandemic stage but 27% did not follow quarantine guidelines strictly (15). It is essential to take the risk seriously, but feelings of anxiety can make people more susceptible to infection. This could be more worrying when we consider the higher rate of anxiety and depression among MS patients (16,17). Nevertheless, the pandemic did not significantly worsen the mental health of the patients in our sample.

MS is not one of conditions that increase the risk of severe illness from COVID-19 (3,18) so health perception showed improvement during the pandemic in MS patients based on the HQoL questionnaire. The United

Kingdom MS society advises patients just to practice social distancing and keep washing their hands (19). Italy, the first European country to encounter the effects of COVID-19 pandemic (20), has set up a programme for a compressive response to COVID-19 in patients with MS and achieved reassuring results in the time of the pandemic (21). According to their reports, only 5 of 238 MS patients with symptomatic COVID-19 infection died. All of them had an EDSS score ≥ 6.5 (22). Also, all 3 cases of COVID-19-positive MS patients in a study in Chile required hospitalization but after a course of treatment they were discharged home and none of them died (23). In our sample, the EDSS score was associated with mental and physical health composites. To keep patients safe and also minimize disease severity, we did not include patients with an EDSS score > 4 in our study.

A study in Saudi Arabia found 32% missing hospital appointments and 35.2% missing drug infusions in MS patients (24). As over 40% of the COVID-19 infections are hospital-acquired (25), the World Health Organization recommends doctors use telehealth services (26) but there are still some doubts in regard to efficacy (27).

Another concern is medications; the Association of British Neurologists has issued a guideline to assess the safety of using drugs during this pandemic (28). Immunosuppressive drugs can make patients more susceptible to getting infected by SARS-CoV-2 and their use should be reduced as much as possible during the COVID-19 pandemic. In our study, however, differences in type of medication were not associated with any effect of the pandemic on HQoL.

Conclusion

In conclusion, the COVID-19 pandemic can worsen the HQoL of MS patients but not statistically significantly. The changes in HQoL mental health and physical health composites are associated with severity of MS, but age, education, duration of the disease, sex and type of disease-modifying drugs did not affect these changes.

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Competing interests: None declared.

Effets de la pandémie de COVID-19 sur la qualité de vie : enquête auprès de patients légèrement handicapés atteints de sclérose en plaques

Résumé

Contexte : La qualité de vie liée à la santé (QVLS) de la plupart des personnes peut être affectée par un problème sanitaire de grande ampleur tel que la pandémie de COVID-19.

Objectifs : Nous avons évalué l'impact à court terme de la pandémie de COVID-19 sur la QVLS des patients atteints de sclérose en plaques (SEP) à Tabriz, en République islamique d'Iran.

Méthodes : Une version imprimée du questionnaire sur la QVLS spécifique à la SEP a été remplie par les patients du service de neurologie de l'hôpital universitaire de Tabriz et les scores avant et pendant la pandémie (2019 et 2020) ont été comparés.

Résultats : Nous avons recruté 50 patients pour cette étude. Même si les scores composites globaux pour la santé physique [69,29, écart type (\pm ET) 16,59 à 68,40, \pm ET 20,95] et mentale (67,36, \pm ET 19,02 à 66,76, \pm ET 22,70) ont légèrement diminué au cours de la deuxième phase, ce changement n'était pas significatif ($p = 0,67$, $p = 0,83$). La gravité de la SEP est associée à des changements dans les composites de santé mentale et physique.

Conclusions : L'effet de la pandémie sur la qualité de vie liée à la santé des patients légèrement handicapés atteints de SEP n'est pas statistiquement significatif.

آثار جائحة كوفيد-19 على نوعية الحياة؛ دراسة استقصائية لمرضى التصلب المتعدد ذوي الإعاقات الخفيفة

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الخلاصة

الخلفية: يمكن أن تؤثر مشكلة صحية كبيرة مثل جائحة كوفيد-19 في نوعية الحياة الصحية للجميع.

الأهداف: هدفت هذه الدراسة الى تقييم الأثر قصير الأجل لجائحة كوفيد-19 على نوعية الحياة الصحية لمرضى التصلب المتعدد في تبريز، جمهورية إيران الإسلامية.

طرق البحث: استكمل المرضى في قسم الأعصاب بالمستشفى الجامعي في تبريز نسخة مطبوعة من استبيان نوعية الحياة الصحية لمرضى التصلب المتعدد، وقورنت الدرجات قبل الجائحة وأثناءها (2019 و 2020).

النتائج: اخترنا 50 مريضاً للمشاركة في هذه الدراسة. على الرغم من أن الدرجات المجمعة الكلية ($69.29 + SD 16.59$)، إلى $68.40 + SD 20.95$ والصحة العقلية ($67.36 + SD 19.02$ إلى $66.76 + SD 22.70$) انخفضت بشكل طفيف في المرحلة الثانية، إلا أن هذا التغيير لم يكن ذا دلالة إحصائية ($P = 0.67$, $P = 0.83$) وكانت شدة التصلب المتعدد مرتبطة بتغيرات في الدرجات المجمعة للصحة النفسية والبدنية.

الاستنتاجات: لم يكن لتأثير الجائحة في نوعية الحياة الصحية لمرضى التصلب المتعدد ذوي الإعاقات الخفيفة دلالة إحصائية.

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