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Original article

Health related quality of life in Turkish polio survivors: impact of post-polio on the health related quality of life in terms of functional status, severity of pain, fatigue, and social, and emotional functioning☆

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ABSTRACT

Objective: To determine the impact of postpolio-syndrome on quality of life in polio survivors.

Methods: Forty polio survivors were included in the study. Twenty-one patients fulfilling the Halstead's postpolio-syndrome criteria participated in postpolio-syndrome group. The remaining nineteen patients formed non-postpolio-syndrome group. Control group was composed of forty healthy subjects. Quality of life was evaluated by Nottingham Health Profile, depression by Beck Depression Scale and fatigue by Fatigue Symptom Inventory. Isometric muscle strength was measured by manual muscle testing.

Results: Total manual muscle testing score was 26.19 ± 13.24 (median: 29) in postpolio-syndrome group and 30.08 ± 8.9 (median: 32) in non-postpolio-syndrome group. Total manual muscle testing scores of non-postpolio-syndrome group were significantly higher than that of postpolio-syndrome group. Patients with postpolio-syndrome reported significantly higher levels of fatigue and reduced quality of life in terms of physical mobility, pain and energy when compared with patients without postpolio-syndrome and control group. It was not reported a statistically significant difference in social and emotional functioning and sleep quality between postpolio-syndrome, non-postpolio-syndrome and control groups. Also it was not found any statistically significant difference in Beck Depression Scale scores among the groups.

☆ This study originated from the Department of Physical Medicine and Rehabilitation, Ankara Numune Training and Research Hospital, Ankara, Turkey.

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Conclusions: Postpolio-syndrome has a negative impact on quality of life in terms of functional status, severity of pain and energy. The identification, early recognition and rehabilitation of postpolio-syndrome patients may result in an improvement in their quality of life.

Qualidade de vida relacionada com a saúde em sobreviventes turcos da pólio: impacto pós-pólio na saúde relacionada com a qualidade de vida em termos de estado funcional, gravidade da dor, fadiga e funcionamento social e emocional

Palavras-chave:
Síndrome pós-pólio
Qualidade de vida
Fadiga
Reabilitação

RESUMO

Objetivo: Determinar o impacto da síndrome pós-pólio na qualidade de vida nos sobreviventes da pólio.
Métodos: Quarenta sobreviventes da pólio foram incluídos no estudo. Participaram do grupo de síndrome pós-pólio 21 pacientes que atenderam aos critérios de síndrome pós-pólio de Halstead. Os 19 restantes formaram o grupo não síndrome pós-pólio. O grupo controle foi composto por 40 indivíduos saudáveis. A qualidade de vida foi avaliada pelo Nottingham Health Profile, a depressão pela Escala de Depressão de Beck e a fadiga pelo Inventário de Sintomas de Fadiga. A força muscular isométrica foi medida por teste muscular manual.
Resultados: O escore total do teste muscular manual foi 26,19 ± 13,24 (mediana: 29) no grupo de síndrome pós-pólio e 30,08 ± 8,9 (mediana: 32) no grupo não síndrome pós-pólio. Escores totais de teste muscular manual de grupo não síndrome pós-pólio foram significativamente maiores do que os do grupo de síndrome pós-pólio. Os pacientes com síndrome pós-pólio relataram níveis significativamente maiores de fadiga e qualidade de vida reduzida em termos de mobilidade física, dor e energia quando comparados com pacientes sem síndrome pós-pólio e grupo controle. Não se relatou uma diferença estatisticamente significativa no funcionamento social e emocional e na qualidade do sono entre grupos de síndrome pós-pólio, não síndrome pós-pólio e controle. Além disso, não se encontrou diferença estatisticamente significativa nos escores da Escala de Depressão de Beck entre os grupos.
Conclusões: A síndrome pós-pólio tem um impacto negativo na qualidade de vida em termos de estado funcional, gravidade da dor e energia. A identificação, o reconhecimento precoce e a reabilitação dos pacientes com síndrome pós-pólio podem resultar em uma melhoria da qualidade de vida.

Introduction

Postpolio-syndrome (PPS) is a neurologic disorder characterized by a collection of late manifestations occurring many years after the initial poliomyelitis infection. New or increased muscle weakness is the hallmark. The other clinical features are fatigue, pain in joints, bones and muscles, cold intolerance and bulbar symptoms (swallow, speech, respiratory symptoms). Fatigue has been described as the most common symptom. PPS symptoms affect the ability to perform the activities of daily living, mobility, upper limb function, and respiratory capacity. PPS has a negative effect on quality of life (QoL).[1–3]

The present study aimed to investigate QoL in polio survivors in Turkey, to assess the impact of PPS on various QoL domains in terms of functional status, severity of pain, social and emotional functioning.

Material and methods

The study included a total of 40 polio survivors (21 men, 19 women) who were followed at the outpatient clinic of physical medicine and rehabilitation department of a training and research Hospital which is a major referral center under Ministry of Health, located in Ankara, capital city of Turkey, between December 2012 and September 2013. Study was conducted in accordance with the principles set forth in the Helsinki Declaration 2008.

67.5% of polio survivors (21 patients) fulfilling the Halstead's PPS criteria[4] participated in PPS group, and the remaining 19 polio survivors without PPS formed non-PPS group. Halstead's PPS criteria are: (1) a confirmed history of acute poliomyelitis affecting lower limbs; (2) partial or complete neurological and functional recovery after acute poliomyelitis; (3) new symptoms (extensive fatigue, muscle

pain and/or joint pain, new muscle weakness in the muscles previously affected or unaffected) after a stable period of at least 15 years; (4) exclusion of other medical conditions that may explain these symptoms.[4]

Isometric muscle strength was measured by manual muscle testing (MMT) according to Medical Research Council (MRC) Scale.[5] Hip flexors, knee extensors, knee flexors, ankle dorsal flexor and ankle plantar flexors were evaluated bilaterally, then total score was obtained (maximum score: 50).

Control group consisted of 40 age and sex matched healthy subjects (20 men, 20 women) whose total MMT scores were 50. Inclusion criteria for all subjects were no other disorders including fibromyalgia, hypertension, diabetes mellitus, hepatic and renal diseases, inflammatory arthritis, other neurological or psychiatric disorders that may cause fatigue.

Symptoms including muscle pain, fatigue, joint pain, sleep disorders, respiratory disorders and dysphagia were analyzed in PPS and non-PPS groups. QoL was assessed by Nottingham Health Profile (NHP)[6] and depression by using Beck Depression Scale (BDS).[7]

Fatigue was evaluated by using Turkish version of Fatigue Symptom Inventory (FSI).[8] FSI, first published in 1998, is a 14-item self-report measure designed to assess fatigue intensity (four items), duration (two items), its interference with quality of life (7 items), and the daily pattern of fatigue. Intensity is measured on separate 11-point scales (0 = not at all fatigued; 10 = extreme fatigue) that assess most, least, current fatigue and average fatigue in the previous week. Each of these is scored as an individual item. The interference items assess the extent to which fatigue interfered with a respondent's general activity level, ability to bathe and dress, work activity, ability to concentrate, relations with others, enjoyment of life and mood during the previous week using an 11 point rating scale (0 = no interference and 10 = extreme interference). These 7 items are averaged to obtain an interference scale score. Duration items (number of days fatigued, amount of time fatigued) assess fatigue frequency. It is measured as the number of the days (from 0 to 7 days) in the past week that respondents felt fatigued and the amount of each day on average respondents felt fatigued (0 = none of the day, 10 = the entire day). Each of these is scored as an individual item. The final item asks respondents to indicate their daily pattern of fatigue and so provides descriptive information about possible diurnal variation in the daily experience of fatigue (0 = not at all fatigued, 1 = worse in the morning, 2 = worse in the afternoon, 3 = worse in the evening, 4 = no consistent daily pattern of fatigue). Final item provides information only and is not intended to be used as a quantitative scale.[9–11] The items included in the FSI are shown in Appendix 1.

Statistical analyses

Data were presented by descriptive analysis with means ± standard deviation (SD) and median scores. Because variables were not normally distributed, Kruskal–Wallis and Mann–Whitney *U* tests were performed to assess statistically significant differences in MMT, BDS, FSI and NHP scores of the groups. Categorical variables were evaluated by Chi-square test. A value of $p < 0.05$ was considered statistically significant. All analyses were performed using Statistical Package for the Social Sciences – 13.0 (SPSS-13.0) software.

Results

Demographic and clinical characteristics of the patients and control subjects are summarized in Table 1. Mean age was 38.15 ± 7.17 in PPS group, 37 ± 4.86 in non-PPS group and 35 ± 8.42 in the control group. At the time of acute polio, polio survivors were 19.2 ± 12.23 months old on average (3 months to 4 years, median: 18 months).

Of the patients in PPS group, 12 had paralyses of one limb, 5 had paralyses of two limbs, 2 had paralyses of three limbs, and 2 had paralyses of four limbs. One of them reported that the disease affected the respiratory system. Of the patients in non-PPS group, 15 had paralyses of one limb, 3 had paralyses of two limbs, and 1 had paralyses of three limbs. None of them had paralyses of four limbs. Also none of them reported that the respiratory system was affected (Table 1).

The most common symptoms were fatigue (16 patients, 76.2%), and muscle pain (15 patients, 71.4%) in PPS group. These were followed by sleep disorders (12 patients, 57.14%) and joint pain (11 patients, 52.38%), respectively. Dysphagia and respiratory disorders were noted in one patient (4.76%). In non-PPS group, the most frequent symptoms were muscle pain, fatigue, sleep disorders and joint pain, which were reported in 42.1%, 36.8%, 31.58%, 15.79% of the patients, respectively. Fatigue, joint pain and muscle pain were significantly higher in PPS group ($p < 0.05$). Total MMT score was 26.19 ± 13.24 (median: 29) in PPS group and 30.08 ± 8.9 (median: 32) in non-PPS group. According to the Mann–Whitney *U* test,

Table 1 – Demographic and clinical data.

	PPS group ($n = 21$)	Non-PPS group ($n = 19$)	Control group ($n = 40$)
Age, mean ± SD	38.15 ± 7.17	37 ± 4.86	35 ± 8.42
Gender (men/women)	11/10	13/6	20/20
Age of acute polio (months)	19.85 ± 13.79	17.84 ± 8.45	
Paralyses of one limb (number of patients)	12	15	
Paralyses of two limbs (number of patients)	5	3	
Paralyses of three limbs (number of patients)	2	1	
Paralyses of four limbs (number of patients)	2	0	
Total MMT score (0–50), mean ± SD	26.19 ± 13.24	30.08 ± 8.9	

MMT, manual muscle testing.

Table 2 – Comparison of total MMT scores and symptoms between the PPS and non-PPS groups.

	PPS group ($n=21$)	Non-PPS group ($n=19$)	p value
Total MMT score (0–50), mean ± SD/median	26.19 ± 13.24/29	30.08 ± 8.9/32	0.04*
Presence of muscle pain, n (%)	15 (71.4%)	8 (42.1%)	0.04*
Presence of fatigue, n (%)	16 (76.2%)	7 (36.8%)	0.01*
Presence of joint pain, n (%)	11 (52.38%)	3 (15.79%)	0.022*
Presence of sleep disorders, n (%)	12 (57.14%)	6 (31.58%)	0.125
Presence of respiratory disorders, n (%)	1 (4.76%)	0	0.48
Presence of dysphagia, n (%)	1 (4.76%)	0	0.48

MMT, manual muscle testing.
* $p<0.05$ (significant).

total MMT scores of non-PPS group were significantly higher than that of PPS group ($p<0.05$) (Table 2).

Kruskal–Wallis test revealed that differences among groups were significant in all FSI subgroups ($p<0.05$). According to the Mann–Whitney U test, FSI scores of PPS group were significantly higher than that of both non-PPS group and the control group ($p<0.05$) (Table 3). It was not found any statistically significant difference in BDS scores between PPS, non-PPS and control groups ($p>0.05$). Median values of BDS and FSI in patients and the control group are given in Table 3.

Kruskal–Wallis test showed that differences among groups were significant in all NHP subgroups except social isolation, emotional reaction and sleep ($p<0.05$). According to the Mann–Whitney U test, PPS group scored significantly higher in pain, physical mobility and energy subgroups of NHP than non-PPS and the control group ($p<0.05$). It was not reported a statistically significant difference in social isolation, emotional reaction and sleep subgroups. Also non-PPS group reported poorer levels in all NHP groups except social isolation, emotional reaction and sleep subgroups, when compared to the control group (Table 4). Median values of NHP scores in patients and the control group are given in Table 4.

Discussion

The aim of this study was to investigate QoL in polio survivors in Turkey in order to assess the impact of PPS on QoL in terms of functional status, severity of pain, social and emotional functioning.

The results showed that PPS impaired QoL including physical mobility, pain and energy, but did not affect emotional and social health. Furthermore it was not found any statistically significant difference in BDS scores between PPS, non-PPS and control groups. This finding confirmed that PPS did not have a negative impact on emotional status. Our results support the previous studies in the literature. It was reported lower scores in physical functioning in 38 post-polio patients in the study of McNaughton et al. where QoL was measured by using Short Form-36 (SF-36).[12] Similarly, Jacob investigated QoL in 101 polio survivors from two post-polio clinics in Israel and reported low physical scores and normal mental scores including emotional and social functioning in post-polio patients.[13] Tate et al. confirmed that polio survivors did not differ from the general population in levels of depression.[14] By contrast, Schanke,[15] Conrady[16] and Hazendonk[17] reported that PPS patients had higher levels of depressive symptoms as compared to control groups. Also On et al. found lower physical, social and emotional scores in PPS group where QoL was evaluated by using NHP.[18]

Patients with PPS experienced significantly higher levels of fatigue when compared to non-PPS and control group. This finding supports the previous studies.[18–20] To our knowledge, this is the first study to evaluate fatigue in polio survivors by using FSI. Fatigue is a complex symptom and it must be assessed by a multidimensional questionnaire which identifies different aspects of fatigue in detail. FSI deals with various characteristics of fatigue and its perceived interference with quality of life in terms of general work activities, ability to concentrate, and enjoyment of life and mood. Furthermore, it states daily patterns of Fatigue.[10,11] It was suggested as a useful instrument in assessment of fatigue by the reviewers.[21] In previous studies, no significant differences were found in total MMT scores between PPS and non-PPS groups.[18,22] Contrarily, in our study, total MMT scores of PPS group were significantly lower than that of non-PPS group.

In the present study, the most common symptoms were fatigue (76.2%), and muscle pain (71.4%) in PPS group. This result is in accordance with other clinical studies. In a study by Nollet on disability and functional status in Dutch patients with PPS, 78% of the patients selected fatigue as their major problem.[22] In Conde's study, the most frequent complaints were fatigue (87.1%), muscle pain (82.4%), and joint pain (72%).[23] We found that prevalence of fatigue, joint pain and muscle pain was significantly higher in PPS group than non-PPS group. Prevalence of sleep disorders was similar in both of the groups. 57% of PPS patients had sleep disorders. In the study of van Kralingen, prevalence of sleep disorders was found as 50%.[24] Östlund reported that post polio related fatigue had a negative effect on sleep quality.[25] Contrarily, in our study, fatigue did not influence NHP sleep scores.

The small sample size deemed our main limitation. It is due to the exclusion of concomitant medical and psychiatric diseases that may cause fatigue.

As a conclusion, PPS has a negative impact on QoL in terms of functional status, severity of pain and energy. Thus, early recognition and complex rehabilitation in the beginning of PPS may result in an increase in QoL in polio survivors. Also identifying postpolio-related fatigue and then reducing it may be an additional strategy in improving QoL. Since FSI is a multidimensional questionnaire that presents different aspects of fatigue, it should take place in clinical practice.

Table 3 – Comparison of fatigue and depression between the groups.

	PPS group ($n = 21$) Median values	Non-PPS group ($n = 19$) Median values	Control group ($n = 40$) Median values	Chi-square (Kruskal–Wallis)	p value X (Mann–Whitney U)	p value Y (Mann–Whitney U)	p value Z (Mann–Whitney U)
Beck Depression Scale	16	13	12	5.43	0.125	0.06	0.83
Most fatigue	9	5	3	53.29*	0.00*	0.00*	0.001*
Least fatigue	7	2	0	62.58*	0.00*	0.00*	0.00*
Current fatigue	7	4	2	53.68*	0.00*	0.00*	0.00*
Average fatigue	7	4	2	53.88*	0.00*	0.00*	0.00*
Interference scale	7	3	1	52.29*	0.00*	0.00*	0.002*
Number of days fatigued	7	3	2	52.46*	0.00*	0.00*	0.002*
Amount of time fatigued	8	4	2	57.23*	0.00*	0.00*	0.00*

p value X: p value between PPS and non-PPS group.
p value Y: p value between PPS and control group.
p value Z: p value between non-PPS and control group.
* $p < 0.05$ (significant).

Table 4 – Comparison of QoL between the groups.

	PPS group ($n = 21$) Median values	Non-PPS group ($n = 19$) Median values	Control group ($n = 40$) Median values	Chi-square (Kruskal–Wallis)	p value X	p value Y	p value Z
NHP physical mobility	87.5	50	0.0	54.04*	0.00*	0.00*	0.00*
NHP pain	85.71	42.86	0.0	61.20*	0.00*	0.00*	0.00*
NHP energy	100	50	0.0	31.66*	0.00*	0.00*	0.00*
NHP social isolation	25	25	25	0.55	0.56	0.72	0.55
NHP emotional reaction	37.5	25	25	2.38	0.79	0.10	0.43
NHP sleep	20	20	20	3.03	0.27	0.08	0.76

NHP, Nottingham Health Profile.
p value X: p value between PPS and non-PPS group.
p value Y: p value between PPS and control group.
p value Z: p value between non-PPS and control group.
* $p < 0.05$ (significant).

Conflicts of interest

The authors declare no conflicts of interest.

Appendix 1. The Fatigue Symptom Inventory (FSI)

1-Rate your level of fatigue on the day you felt **most** fatigued during the past week.
0 1 2 3 4 5 6 7 8 9 10
Not at all fatigued *Extreme fatigue*
2-Rate your level of fatigue on the day you felt **least** fatigued during the past week.
0 1 2 3 4 5 6 7 8 9 10
Not at all fatigued *Extreme fatigue*
3- Rate your level of fatigue on the **average** during the last week.
0 1 2 3 4 5 6 7 8 9 10
Not at all fatigued *Extreme fatigue*
4- Rate your level of fatigue **right now**.
0 1 2 3 4 5 6 7 8 9 10
Not at all fatigued *Extreme fatigue*
5-Rate how much in the past week, fatigue interfered with your **level of activity**.
0 1 2 3 4 5 6 7 8 9 10
No interference *Extreme interference*
6-Rate how much, in the past week fatigue interfered with your **ability to bathe and dress yourself**.
0 1 2 3 4 5 6 7 8 9 10
No interference *Extreme interference*
7- Rate how much, in the past week fatigue interfered with your **normal activity (includes both work outside the home and housework)**.
0 1 2 3 4 5 6 7 8 9 10
No interference *Extreme interference*
8-Rate how much, in the past week fatigue interfered with your **ability to concentrate**.
0 1 2 3 4 5 6 7 8 9 10
No interference *Extreme interference*
9- Rate how much, in the past week fatigue interfered with your **relations with other people**.
0 1 2 3 4 5 6 7 8 9 10
No interference *Extreme interference*
10- Rate how much, in the past week fatigue interfered with your **enjoyment of life**.
0 1 2 3 4 5 6 7 8 9 10
No interference *Extreme interference*
11- Rate how much, in the past week fatigue interfered with your **mood**.
0 1 2 3 4 5 6 7 8 9 10
No interference *Extreme interference*
12-Indicate **how many days**, in the past week, you felt fatigued for any part of the day.
0 1 2 3 4 5 6 7 *days*
13- Rate **how much of the day**, on average, you felt fatigued in the past week.
0 1 2 3 4 5 6 7 8 9 10
None of the day *The entire day*
14-Indicate which of the following best describes the **daily pattern** of your fatigue in the past week
0 1 2 3 4

0 = *not at all fatigued*, 1 = *worse in the morning*, 2 = *worse in the afternoon*, 3 = *worse in the evening*, 4 = *no consistent daily pattern of fatigue*.

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