

# Quality of life and associated factors in tunisian postpoliomyelitis syndrome patients

## Qualité de vie et facteurs associés chez les patients Tunisiens atteints du syndrome Post-Polio

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### ABSTRACT

**Introduction:** Postpoliomyelitis syndrome (PPS) is defined as secondary onset of new neuromuscular symptoms, following recovery from an initial episode of Acute Anterior Poliomyelitis with no other possible causes, which may lead to altered quality of life.

**Objective:** To assess the quality of life (QoL) of Tunisian PPS patients and determine its associated factors.

**Methods:** A cross-sectional study conducted over a 24 month period. Sociodemographic variables as well as clinical data evaluating the severity of PPS and QoL were collected using SF-36 scale. Associations between different clinical variables and QoL were studied.

**Results:** We included 45 patients with a mean age of  $52.4 \pm 7.5$  years. All aspects of QoL were affected. The most affected domain was PF with an average score of  $32.5 \pm 11.8$ . QoL was better for the mental component (MCS) compared to the physical component (PCS) with mean scores of  $43.7 \pm 7$  and  $35.6 \pm 12.1$  respectively. The alteration of the PF and MH domains was significantly associated with MCS score ( $p = 0.01$  and  $r = -0.38$ ) and increased BMI ( $p = 0.04$ ;  $r = -0.31$ ). Pain intensity was associated with an alteration of all the domains of QoL except for the RP domain. QoL was significantly associated with Functional capacity ( $p = 0.018$  and  $r = 0.35$ ) and vitality ( $p = 0.038$ ;  $r = 0.31$ ).

**Conclusion:** All aspects of QoL were affected in PPS patients. The general PCS component was the most affected and the PF domain was the most affected.

**Key words:** Poliomyelitis, Postpoliomyelitis Syndrome, Quality of life

### RÉSUMÉ

**Introduction:** Le syndrome post-polio (SPP) est défini comme l'apparition secondaire de nouveaux symptômes neuromusculaires pouvant altérer la qualité de vie.

**Objectif:** Cette étude visait à évaluer la qualité de vie (QDV) des patients Tunisiens atteints de SPP et à identifier ses facteurs associés.

**Méthodes:** Etude transversale sur une période de 24 mois. Les variables sociodémographiques et les données cliniques du SPP ainsi que la QDV ont été recueillies. Les associations entre différentes variables cliniques et la QDV ont été étudiées.

**Résultats:** Nous avons inclus 45 patients. Tous les aspects de la QDV étaient altérés. Le domaine le plus affecté était la PF avec un score moyen de  $32,5 \pm 11,8$ . La QDV était meilleure pour la composante mentale comparée à la composante physique avec des scores moyens de  $43,7 \pm 7$  et  $35,6 \pm 12,1$ . L'altération des domaines PF et MH était significativement associée au domaine mental ( $p = 0,01$  et  $r = -0,38$ ) et à un IMC accru ( $p = 0,04$ ;  $r = -0,31$ ). La douleur était associée à une altération de tous les domaines de la QDV, sauf pour le domaine RP. La QDV était significativement associée à la capacité fonctionnelle ( $p = 0,018$  et  $r = 0,35$ ) et à la vitalité ( $p = 0,038$ ;  $r = 0,31$ ).

**Conclusion:** Tous les aspects de la QDV étaient altérés chez les patients atteints de SPP. La composante générale PCS était la plus affectée, tandis que le domaine PF était le plus affecté.

**Mots clés:** Poliomyélite, Syndrome post-poliomyélite, Qualité de vie

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## INTRODUCTION

Acute anterior poliomyelitis (AAP) is a highly contagious infectious disease mainly affecting children which has been eradicated thanks to a global efforts(1). In Tunisia, AAP was a major health problem, but vaccination rate against this disease had reached 90% in 1990 and no case of AAP has been reported since 1993. Besides the neuro-orthopedic sequelae left by the initial episode, additional symptoms have been reported in patients with a history of AAP(2). In fact, 30 to 65% of these patients report an aggravation, which is often related to medical or surgical complications, to age and to postpoliomyelitis syndrome (PPS) (3–5). PPS is defined as the secondary and late onset of new neuromuscular symptoms, following recovery from an initial acute episode of AAP with no other possible causes. Symptoms such as muscle weakness, musculoskeletal pain during physical activity, general fatigue, and cold intolerance may occur (6,7). Sleep disorders, difficulty concentrating and remembering, as well as mood disorders have also been reported (8,9). In addition, PPS can have a significant impact on daily living activities with an alteration in quality of life (QoL) (10,11). QoL related data in North African PPS patients is lacking. The aim of this study was to assess the QoL of PPS patients and determine its associated factors.

## METHODS

This was a cross-sectional analytical study that was conducted over a 24 month period.

Patients with PPS, referred to the Physical Medicine and Rehabilitation (PMR) Department at X University Hospital were assessed for eligibility.

Patients were included if they presented a history of AAP followed by sudden or progressive and persistent onset of weakness or abnormal muscle fatigue, with or without general fatigue, muscle atrophy, or muscle and joint pain. Symptoms had to persist for a minimum of one year, demonstrating a chronic pattern.

Patients with pathologies that could significantly influence QoL and / or lead to fatigue (major depression, systemic illnesses, central nervous system disorders) and rheumatic diseases (rheumatoid arthritis, ankylosing spondylitis ...) were not included in the study.

The study has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans.

Informed consent was obtained from all participants in the study.

### Outcome measures

Data were collected by a single investigator through clinical examination and results were recorded on individual report cards.

These cards contained sociodemographic information (age, gender, origin, marital status, profession) an evaluation of PPS symptoms, as well as an assessment of the patients' QoL.

### The multidimensional fatigue inventory 20 (MFI-20)

This is a self-administered questionnaire validated in PPS patients, consisting of 20 items that explore 5 dimensions of fatigue: general fatigue, physical fatigue, mental fatigue, reduced motivation and reduced activity (12). The dimensions include 4 questions or items with 5 response methods rated from 1 to 5 each. A score is calculated for each dimension corresponding to the weighted sum of the items and varying from 4 to 20. The total MFI-20 score varies from 20 to 100. The higher the score, the greater the fatigue.

### The Borg rating of perceived exertion (RPE) scale

The Borg RPE scale is based on the perception of fatigue as a function of the intensity of physical activity. This scale is used mainly for an overall rating of the perception of exertion but also for dyspnea and muscle fatigue. It is based on physical sensations and personal experiences during physical activity, such as increased heart rate and respiratory rate, sweating and muscle fatigue (13). Different aspects of effort and fatigue were measured by placing "light, medium, difficult and painful," verbal anchors on a numbered scale from 6 to 20 so that correspondence in meaning was obtained between the numbers and the anchors. (14).Therefore, physical activity was rated as mild from 6 to 11, average from 12 to 15 and difficult to strenuous from 16 to 20.

### The visual analogue scale (VAS) for pain

This is a sensitive, reproducible, reliable and validated self-rated scale in both acute pain and chronic pain situations (15). The VAS comes in the form of a 10 cm plastic strip which provides a cursor moved by the patient along a straight line. One corresponds to "No pain" and the other to "Maximum pain imaginable". On the other side of the ruler are millimeter graduations read by the examiner where 0 corresponds to "No pain" and 10 to "Maximum imaginable pain" (16).

### The six-minute walk test (SMWT)

The SMWT is a well-recognized test. Its validity, reproducibility and sensitivity have been verified for multiple musculoskeletal conditions.

This test measures the distance that a patient can quickly walk on level, hard ground for 6 minutes. It assesses the functional capacity of patients in daily living activity, taking into account all the systems involved in exercise: pulmonary, cardiovascular, systemic and peripheral circulation, neuromuscular units and muscle metabolism. Patients are asked to walk as far as possible for 6 minutes at a self-selected pace and are allowed to rest during the exercise (17).

### The functional independence measurement (FIM) Scale

The FIM is a widely used generic scale because of its simplicity, allowing to measure disabilities and functional impact of a pathology (18). The FIM scale consists of 18 items assessing 6 functional areas: personal care, sphincter control, mobility and transfers, locomotion,

communication and awareness of the outside world. The items are separated into 2 categories: motor (13 items) and cognitive (5 items). These categories are referred to as FIM-motor and FIM-cognitive. Each FIM item is rated on a 7-point Likert scale, and a score indicates the amount of assistance required to complete each item (1 = full assistance, 7 = full independence). The overall result is between 18 (full dependence / full assistance) and 126 (full independence).

#### The hospital anxiety and depression scale (HAD)

The HAD scale is an instrument used to screen for anxiety and depressive disorders. It is translated and validated in Arabic. It has 14 items scored from 0 to 3, with seven questions relating to anxiety (total A) and seven other questions relating to the depressive dimension (total D). We therefore obtain two scores: HAD-A and HAD-D. The maximum for each score being equal to 21. For a score less than or equal to 7, the symptoms are considered to be absent. If the score is between 8 and 10, the symptomatology is considered doubtful and it is certain if the score is greater than 10 (19).

#### The medical outcome study "Short form 36" questionnaire (SF-36)

The SF-36 is one of the most commonly used generic QoL measuring instruments. It is a scale that is translated and validated in Arabic (20). It includes 36 questions each rated from 0 to 100. The answers are used to calculate the scores for 8 areas: Physical function (PF), limitation related to physical condition (RP), Bodily Pain (BP), perceived health (GH), Vitality (VT), social function (SF), Mental health (MH) and limitation related to mental health (RE). These domains make it possible to calculate two scores: the physical composite score (PCS) associating the domains GH, PF, RP, BP and the composite mental score (MCS) associating the domains SF, RE, VT and MH. The higher the score, the better the QoL (21).

#### The life satisfaction questionnaire: LiSat 11

This is a self-administered questionnaire that measures life satisfaction. It determines the overall life satisfaction for one of the items. It is then domain specific for the other ten items.

The six response levels are: "very satisfied", "satisfied", "Moderately satisfied", "not very satisfied", "not satisfied" and "not at all satisfied".

The responses are grouped into "Satisfied" (Very satisfied and satisfied) and "Not satisfied" (moderately satisfied to not satisfied at all) for each item according to the recommendations of the author of the questionnaire to facilitate statistical analyzes (22).

#### Statistical analysis

Data analysis was performed using SPSS version 21.0 statistical software. Qualitative variables are presented in the form of frequencies and percentages. Quantitative variables are presented as mean and standard deviation or medians and quartiles depending on the distribution of the variable.

The tests for the analytical study were chosen based on the nature of the variables to be compared. We used the Mann Whitney and Kuskal Wallis nonparametric test for the comparison of quantitative variables. Likewise, Spearman's correlation coefficient and simple linear regression were used to assess the relationship between two quantitative variables. The statistical significance level was set at 0.05.

## RESULTS

### Demographic and clinical data of the population

We included 45 patients with a mean age of  $52.4 \pm 7.5$  years. We noted a slight female predominance (57.8%) with a sex ratio of 0.7. Forty percent of patients had moderate pain. In our patients, fatigue was present in all domains of MFI-20 with predominance of general fatigue and physical fatigue. Fifty tree percent of our patients perceived the exertion as "a little difficult" to "Difficult". Fatigue and dyspnea at the end of the SMWT were reported by 41 (91%) of the patients.. the most affected domains of the FIM were 'Self-care' and "Transfers". Twelve of our patients (26.7%) had definite depression with HAD-D. and 16 had both anxiety and depressive disorders. Patients were mainly dissatisfied with the area of somatic health and psychological health (Table 1).

**Table 1.** Demographic and clinical characteristics of the study population

Variable		Value (mean $\pm$ SD)
Age (years)		52.4 $\pm$ 7.5
BMI		28.7 $\pm$ 6.5
Pain VAS		4.4 $\pm$ 1.9
MFI-20	General fatigue	12.8 $\pm$ 4
	Physical fatigue	13.5 $\pm$ 4.9
	Mental fatigue	10 $\pm$ 4.5
	Activity restriction	12.6 $\pm$ 4
	Motivation reduction	11.8 $\pm$ 4.1
	Total score	60.4 $\pm$ 4.1
Borg RPE		14.9 $\pm$ 2.5
SMWT (m)		226.8 $\pm$ 120.6
FIM		119 $\pm$ 15.1
HAD	HAD-A	9.3 $\pm$ 2.3
	HAD-D	8.2 $\pm$ 3.2

VAS: Visual analogue scale; BMI: Body mass index; MFI-20 Multidimensional Fatigue Inventory; Borg RPE: Borg rating of perceived exertion; HAD: Hospital Anxiety and Depression Scale; SD: Standard deviation

All aspects of QoL were altered with PF being the most affected area ( $32.5 \pm 11.8$ ). On the other hand, VT and BP were the least affected areas with mean scores of  $44.8 \pm 23.4$  and  $43.7 \pm 27.3$  respectively. Regarding the general dimensions, the QoL was better for the mental component (MCS) compared to the physical component (PCS) with mean scores of  $43.7 \pm 7$  and  $35.6 \pm 12.1$  respectively (Figure1).

### Analytical study

The PCS component was negatively correlated with Borg RPE scale and all domains of the MFI-20 except for mental fatigue. There was no significant association

between gender and quality of life. The MCS component was negatively correlated with increased fatigue and psychological distress. A significant association between alteration of the PF and MH domains and advanced age and increased BMI was found. All the domains of QoL were significantly altered with the increase in pain intensity except for the RP domain. We noted that QoL was significantly and positively correlated with FIM only for the PF and VT domains. In addition, PF, GH, VT, MH domains and the MCS component of SF 36 were significantly and positively correlated with SMWT. We found a statistically significant and positive correlation between the MCS mental component and the VT domain of QoL and satisfaction (Table 2).



**Figure 1.** Graph illustrating the average quality of life scores according to the SF-36 questionnaire

PF: physical function, RP: limitation related to physical state, BP: pain, GH: perceived health, VT: vitality, SF: social function, RE: limitation related to mental state, MH: mental health, PCS: the composite physical score and MCS: the composite mental score

**Table 2.** Associations between quality of life and other clinical parameters

SF-36 domain	Pain VAS p (r)	Borg RPE p (r)	MFI-20 p (r)	FIM p (r)	SMWT p (r)	HAD-D p (r)	HAD-A p (r)
PCS	<0.01 (-0.44)	<0.01(-0.45)	<0.01(-0.39)	0.7(0.14)	0.74(0.24)	0.4(-0.02)	0.7(-0.13)
MCS	<0.01(-0.43)	<0.01(-0.59)	<0.01(-0.76)	0.8(0.22)	0.04(0.34)	<0.01(-0.66)	<0.01(-0.68)
PF	<0.01(-0.43)	<0.0(-0.58)1	<0.01(-0.45)	0.018(0.35)	0.02(0.38)	0.81(-0.16)	0.66(-0.2)
RP	0.07(-0.26)	<0.01(-0.51)	<0.01(-0.54)	0.5(0.15)	0.5(0.2)	0.021(-0.3)	0.77(-0.26)
BP	<0.01(-0.51)	0.1(-0.22)	0.09(-0.17)	0.33(-0.04)	0.37(0.05)	0.69(0.11)	0.31(-0.1)
GH	<0.01(-0.43)	<0.01(-0.46)	<0.01(-0.72)	0.5(0.15)	0.04(0.27)	<0.01(-0.45)	<0.01(-0.49)
VT	0.033(-0.38)	<0.01(-0.39)	<0.01(-0.66)	0.038(0.31)	0.04(0.36)	<0.01(-0.53)	<0.01(-0.63)
SF	0.034(-0.31)	0.001(-0.38)	0.022(-0.38)	0.5(0.22)	0.5(0.22)	0.42(-0.27)	<0.01(-0.39)
RE	<0.01(-0.4)	<0.01(-0.65)	<0.01 (-0.56)	0.67(0.28)	0.66(0.27)	<0.01(-0.4)	0.66(-0.29)
MH	<0.01(-0.39)	<0.01(-0.45)	<0.01(-0.73)	0.81(0.11)	0.04(0.34)	<0.01(-0.56)	<0.01(-0.7)

VAS: visual analogue scale, MFI-20: multidimensional fatigue inventory, Borg RPE: Borg rating of perceived exertion; HAD: hospital anxiety and depression scale, A: anxiety, D: depression; FIM: functional independence measure; PF: physical function, RP: limitation linked to physical state, BP: pain, GH: perceived health, VT: vitality, SF: social function, RE: limitation linked to mental state, HD: mental health, PCS: the physical composite score and MCS: the mental composite score, r: correlation coefficient, p: significance

## DISCUSSION

Through this cross-sectional study involving 45 patients we aimed to assess the QoL of Tunisian PPS patients and determine its associated factors.

All areas of SF-36 QoL were altered with the PCS and PF domains being the most affected.

We noted that better QoL was associated to several factors. In fact, the subjects who had better QoL felt less pain and fatigue, better functional capacity and life satisfaction. Altered QoL was negatively associated with BMI and anxiety-depressive disorders and older age especially for the PF and MH.

These results are in agreement with previous studies (9,23,24) which have assessed QoL in PPS patients using the SF-36 scale. In fact, the study by Jung et al (25), including 364 patients, concluded that PCS was the most impaired component with an average score of 30.8 and that the PF score was the least altered with an average of 38.1.

Other studies (26–28), using the Nottingham Health Profil scale to assess QoL, reported that the most altered domains were energy and mobility. In contrast, Ivanyi's (29) study conducted in the Netherlands on a cohort of 233 polio survivors, 53% of patients reported an impairment in their social life.

We found that QoL was significantly correlated with several factors. In fact, patients who had better QoL

had less pain and fatigue. In addition, the MCS mental component was positively correlated with functional capacity and life satisfaction, and negatively with BMI and anxiety-depressive disorders. Additionally, physical function and mental health were negatively correlated with age.

Our findings are in agreement with previous studies reporting an alteration in the QoL of patients with PPS (23,28,30). Klein et al (31) found a decrease in QoL with age. In addition, Jung et al (25) and Willén et al (32) noted a negative association between physical function of QoL and age.

While we noted worse QoL in women than in men, gender was not statistically associated with QoL. This is in contrast with the studies of Zorgati et al (33) and Jung et al (25) who found a gender influence on QoL. This difference with our study can be explained by cultural influences and the complex multidimensional nature of QoL.

Our results support findings from previous studies (6,9,28) reporting an association between decreased QoL in patients with PPS and higher levels of fatigue. An alteration in the MCS mental component of the SF-36 scale was negatively associated with fatigue in both polio patients and the general population (34–36).



We found that pain negatively affected both general components of SF-36 (MCS and PCS) as well as all SF\_36 subdomains except RP. On the other hand, Murray et al (24) only reported a negative correlation with the MCS mental component. Whereas Werhagen and Borg (37) found an alteration of the physical PCS component and the VT and GH domains depending on the intensity of the pain. These different results can be explained by the multidimensional and subjective nature of the pain which can affect the physical and / or mental component. Tate's study (38), noted that postpoliomyelitis patients with depression reported more QoL alterations and feelings of loneliness. In addition, according to Azru (28) and Murray (24), depression in patients with polio sequelae had a negative impact on fatigue as well as on QoL. In addition, according to Yelnik (39), depressed patients showed greater physical deterioration, more pain with a higher rate of somatic complaints, lower combativeness, poorer quality of life and frequent loneliness. This is consistent with our results.

In the series by Garip et al (27), it was reported that patients with PPS had an impaired QoL with limited functional capacity. These patients also noted significant fatigue, and very severe pain. Which is in agreement with our study.

In addition, according to Shiri et al (23), patients with PPS had altered QoL. These authors noted a positive association between QoL and status professional, functional limitation and life satisfaction.

### Limitations

The limits of this work are mainly represented by:

The small sample size resulting from the rigid exclusion criteria of the PPS and the fact that Tunisian postpoliomyelitis survivors have become accustomed to their disability and so they rarely consult.

Our study only included patients who consulted at our PMR department at Monastir university hospital. Therefore, our work may not be representative of all Tunisian postpoliomyelitis patients.

## CONCLUSION

PPS seems to affect all aspects of QoL and especially the physical component which is related to fatigue induced by this syndrome. Increased BMI and pain intensity seem to further deteriorate QoL in these patients.

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