## **ORIGINAL REPORT**

# IMPACT OF PAIN ON QUALITY OF LIFE IN PATIENTS WITH POST-POLIO SYNDROME

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*Objective:* Post-polio syndrome is a neurological disorder occurring several years after an acute polio infection. The main symptoms are increased muscular weakness and atrophy, fatigue and pain. Pain is present more often in younger individuals and in females and, according to the visual analogue scale (VAS), the intensity of pain is relatively high. The aim of the present study was to analyse the impact of pain on quality of life in patients with post-polio syndrome.

### Design: Transversal study.

Patients and methods: Patients with post-polio syndrome underwent a thorough neurological and general examination. They were interviewed about the presence and intensity of pain during the previous 3 months, then completed the quality of life inventory Short-Form 36 (SF-36), which included questions about pain during the previous 4 weeks, and rated their pain intensity during the previous 24 h according to the VAS.

*Results:* Seventy-seven of the patients (68%) experienced pain at the examination. Pain was found to have a significant impact on the SF-36 subdomains Vitality and General health. A correlation was found between pain during the previous 3 months, the previous 4 weeks, and the previous 24 h.

*Discussion:* Pain is common in patients with post-polio syndrome. Although patients have a high mean VAS score the pain only affects quality of life for Vitality and General Health, but not for other physical and mental domains.

*Key words:* post-polio syndrome; pain; quality of life; SF-36 health survey; visual analogue scale.

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### INTRODUCTION

Post-polio syndrome (PPS) is a neurological disorder appearing in patients who have had a prior acute poliomyelitis infection. It is characterized by increasing muscular weakness and atrophy, pain and fatigue, and has a reported prevalence of 15–80% in patients with prior polio (1–3). Ramlow et al. (4) found that the prevalence of PPS was 28.5% of all paralytic cases. The cause of PPS, at least the motor part, remains unclear, but it is most likely due to distal degeneration of enlarged postpoliomyelitis motor units (5).

Pain is a major symptom of PPS. Previous studies have shown a varying, but high, incidence of pain in PPS, with a relatively high visual analouge scale (VAS) (6–8). The pain is, in most cases, nociceptive in character, and when neuropathic pain is present it is due to a concomitant disease (9). Furthermore, women and younger patients reported pain more often, but the severity of the polio sequealae was not found to be of importance for the incidence of pain in patients with PPS (9). The cause of pain in PPS is unknown, but joint pain or overuse of muscles due to asymmetrical paresis might be a component.

In patients with both traumatic and non-traumatic spinal cord injury neuropathic pain affects quality of life to some, or to a great, extent in two-thirds of cases (10, 11). However, our clinical impression is that, in general, patients with PPS seldom report a more decreased quality of life due to pain, even if they report a high VAS score.

The aim of the present study was to analyse the impact of pain on quality of life by comparing the results of a Short Form-36 (SF-36) health survey, VAS score, and the presence of pain reported at clinical examination.

#### MATERIAL AND METHODS

The study was performed at the post-polio out-patient clinic at Danderyds University Hospital, Stockholm, Sweden, an out-patient clinic for patients with PPS from the greater Stockholm area. Computerized medical files were used to recruit patients. A total of 114 patients with PPS, who were all interviewed and examined by a physician and completed the SF-36 health survey, were included in the study. The patients underwent a neurological and general examination, including testing of muscle function, presence of muscular atrophy and tendon reflexes to confirm the diagnosis of PPS. The patients were diagnosed with PPS according to the following criteria; a history of paralytic polio, confirmed or not confirmed; partial or fairly complete functional recovery, a long period of functional stability of at least 15 years, development of new muscle dysfunction and a neurological examination compatible with prior polio, a lower motor neurone lesion; decreased or absent tendon reflexes; no sensory loss; compatible findings on electromyography (EMG) and/or magnetic resonance imaging (MRI).

The patients were interviewed by the examining physician to gather data on: (*i*) nationality; (*ii*) family situation; (*iii*) working status; (*iv*) presence of pain during the previous 3 months; and (*v*) walking capability. Nationality was divided into: (a) Swedish; (b) other Scandinavian nationality; (c) from countries outside Europe. Family status was divided into (1) married/cohabitant; (2) single. Single included divorced or widower/widow. Patients who had experienced pain during the previous 3 months were put into the group "patients with pain" and those who had

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Table I. Characteristics of 114 patients with post-polio syndrome with and without pain

	Patients with pain $n=77$	Patients without pain $n=37$	Patients without and with pair $n=114$	
Gender, <i>n</i> (%)				
Female	54 (70)	13 (35)	67 (59)	
Male	23 (30)	24 (65)	47 (41)*	
Age, years, mean (range)				
Age at polio infection	6.5 (0-35)	6.5 (0–35) 10.7 (1–37)		
Actual age at examination, years	61.9 (49–86)	64.9 (36–88)	64.6 (36-88)	
Nationality, <i>n</i> (%)				
Swedish	68 (88)	34 (91)	102 (89)	
Other Scandinavian country	1 (2)	1 (4)	2 (2)	
From a country outside Europe	8 (10)	2 (5)	10 (9)	
Social and working status, $n$ (%)				
Married/cohabitants	50 (65)	23 (62)	73 (64)	
Single, divorced, widower	27 (35)	14 (38)	41 (36)	
Working at least part-time	30 (39)	10 (27)	40 (32)	
Not working	47 (61)	27 (73)	74 (68)	
Walking capability, n (%)				
Walking without aids	37 (48)	23 (62)	60 (53)	
Walking with aids	33 (43)	11 (30)	44 (38)	
Wheelchair dependency	7 (9)	3 (8)	10 (9)	
Concomitant diseases, $n(\%)$	17 (46)	28 (36) 45 (39)		

 $\chi^{2} = 11,228. p = 0.008$ , degrees of freedom = 1.

not experienced pain were put into the group "patients without pain". When pain was present it was classified according to localization. Working status was divided into working and not working. Working means working at least 25% of fulltime hours and not working included retired patients and patients not working for other reasons. Walking capability was divided into 3 groups: (*i*) walking without aids; (*ii*) walking with aids (crutch/es, sticks, walker); and (*iii*) wheelchair dependent.

Concomitant diseases include cardiovascular diseases, cancer, arthritis, and depression. The patients were interviewed about concomitant disease at the examination by the physician.

Patients completed the SF-36 health survey after the clinical examination, or later at home. SF-36 is a multi-purpose, short-form health survey with 36 questions (12). It yields an 8-scale profile of functional health and well-being scores, as well as psychometrically-based physical and mental health summary measures and a preference-based health utility index. It is a generic measure, as opposed to one that targets a specific age, disease, or treatment group. Accordingly, SF-36 has proven useful in surveys of general and specific populations, comparing the relative burden of diseases, and in differentiating the health benefits produced by a wide range of different treatments. In the SF-36 health survey the patients were asked questions about pain and whether they had experienced pain during the previous 4 weeks. At the same time as they completed the SF-36 health survey the patients classified the intensity of their pain during the previous 24 h on the visual analogue scale (VAS) 0–100 (13).

The patients were not interviewed about the initial polio and its severity. The study was approved by the Stockholm Regional Ethics committee.

#### Data analysis

Groups and sub-groups are presented as absolute numbers and percentages. Comparisons between groups were made using  $\chi^2$  tests, or Fischer's exact test when the numbers were too small to allow a  $\chi^2$  test. Mean values and standard deviations (SD) were calculated. Mann-Whitney non-parametric statistics were used in Table II when comparing VAS and SF-36. A p < 0.05 was considered significant.

#### RESULTS

A female predominance was found among the 114 patients. Nearly all included patients were of Swedish origin and close to 60 years of age at the time of examination. A small majority was married/cohabitants, not working and was walking without aids. Most patients had their acute polio infection before the age of 10 years. For further description of gender, mean age at acute polio infection, mean age at examination, nationality, social status, walking capability and concomitant diseases, see Table I.

Pain was present in 77/114 (68%) patients at the clinical examination. The results of the SF-36 health survey and the intensity of pain according to the VAS scale in patients with and without pain are shown in Table II.

A mean VAS of 38 was found in the group reporting pain at the clinical examination. A mean VAS of 16 was found in the patients who did not report pain. These patients also had decreased quality of life according to the SF-36 sub-domain Bodily Pain compared

Table II. Reported presence of pain at clinical examination compared with Short-Form 36 (SF-36) health survey and mean visual analogue scale (VAS) results

	No pain		Pain		Pain-no pain	
	п	Mean (SD)	п	Mean (SD)	Diff. p-value	
VAS	37	16 (17)	77	38 (25)	22	< 0 001
SF-36						
Physical functioning	36	40 (28)	75	34 (21)	-6	0.369
Role-Physical	36	42 (38)	75	30 (36)	-12	0.108
Bodily pain	37	66 (25)	76	41 (20)	-25	< 0.001
General health	37	59 (22)	71	45 (23)	-14	0.005
Vitality	37	46 (20)	75	38 (21)	-9	0.032
Social functioning	37	72 (24)	76	65 (26)	-7	0.203
Role-Emotional	37	59 (42)	70	55 (42)	-3	0.744
Mental health	37	72 (16)	75	67 (23)	-6	0.316
Physical health	36	34 (9)	64	28 (8)	-6	0.002
Mental health	36	46 (11)	64	45 (14)	-1	0.682

SD: standard deviation. Diff: difference of mean between pain and no pain.

with the Swedish norm. It was, however, higher, i.e. they had a better quality of life for Bodily Pain than the patients who reported pain (Table II). Quality of life for the SF-36 sub-domains of Bodily Pain (p < 0.001), General Health, (p < 0.005), Vitality (p < 0.032), and for the Physical Compound Score (PCS) (p < 0.002) was significantly lower in patients with PPS reporting pain compared with those not reporting pain at the clinical examination.

Women had a significantly higher VAS score than males, with a median VAS of 34 compared with 19. Women with and without pain had lower scores on the SF-36 health survey than males. The difference reached statistical significance for Physical Functioning and PCS (p=0.036 and 0.005, respectively).

#### DISCUSSION

The aim of this study was to evaluate the impact of pain in patients with PPS on quality of life.

Patients with pain had a lower quality of life for the subdomains Vitality and General Health. PCS was also lower in patients with pain, indicating that the pain might be localized in tissues involved in the locomotor system, which is often reported as the location of pain by the patients with PPS. This is supported by the fact that the pain was localized to parts of the body involved in locomotion, such as the lower back, legs and upper arms. Another explanation for the decreased PCS is the fact that patients with pain had a significantly lower quality of life for the sub-domain Bodily Pain. The sub-domain Bodily Pain provides a significant contribution to the PCS. The results of this study confirmed the findings of earlier studies, i.e. that patients with PPS frequently report pain, and that the pain intensity according to the VAS scale is relatively high (a mean of 38/100 in this study). The present study underlines our impression that patients with PPS, although they have high pain intensity, seldom report decreased quality of life due to pain.

Some of the patients have had pain for many years, and therefore they are probably so used to the pain that they do not regard it as a problem. This may provide an explanation for the surprising finding that patients reporting no pain in fact had a mean VAS of 16/100. There was also a delay between the first time they answered questions about pain and the SF-36 health survey, which might have an impact on their answers, as the delay provided the opportunity for them to reflect on their pain situation. However, patients with PPS experience chronic pain with a duration of at least 3 months.

One might speculate that there is a connection between Bodily Pain, Vitality and General Health. In patients without pain the quality of life for Vitality and General Health was high, which may indicate that the latter might be secondary to pain, and the opposite was found in patients with pain. In the study by Gonzalez et al. (14) intravenous immunoglobulin (IvIg) showed an effect on quality of life for the SF-36 sub-domains Vitality and General Health. Pain was decreased and it was speculated that the IvIg effect might be secondary to a decrease in pain.

One limitation of the study was that the severity of the initial polio was not recorded, which would have provided important information about the initial motor neurone damage. The motive was that most of the patients had their polio early in life, many years ago, and their parents were, in most cases, deceased. To study medical files for the acute polio period is extremely difficult as the patients were born in different parts of Sweden.

Pain is a subjective and multifactorial symptom. As patients with PPS are older the causes of pain except PPS are many, for example arthrosis, musculoskeletal disorders, and osteoporosis. Concomitant diagnoses, such as heart failure, diabetes mellitus and hypertension, are frequently present. Furthermore, results from the study by Werhagen & Borg (9) concluded that pain in patients with PPS is nociceptive and, when pain is neuropathic, a concomitant diagnosis is present.

Symptoms such as numbness, and unpleasant feelings of warmth and cold can be interpreted as pain by some patients but not others, and may initiate a neurological examination. Many concomitant disorders also lead to difficulties in movement and may also contribute to decreased quality of life on the PCS in PPS patients. It is concluded that a clinical evaluation, including a full pain analysis and identification of concomitant disorders, should be carried out in patients with PPS who report pain.

#### REFERENCES

- Farbu E, Gilhus NE, Barnes MP, Borg K, de Visser M, Driessen A, et al. EFNS guideline on diagnosis and management of postpolio syndrome. Report of an EFNS task force. Eur J Neurol 2006; 13: 795–801.
- Farbu E. Update on current and emerging treatment options for post-polio syndrome. Ther Clin Risk Manag 2010; 6: 307–313.
- Gonzalez H, Olsson T, Borg K. Management of postpolio syndrome. Lancet Neurol 2010; 9: 634–642.
- Ramlow J, Alexander M, LaPorte R, Kaufmann C, Kuller L. Epidemiology of the post-polio syndrome. Am J Epidemiol 1992; 136: 769–786.
- Trojan DA, Cashman NR. Postpoliomyelitis syndrome. Muscle Nerve 2005; 31: 6–19.
- Widar M, Ahlström G. Pain in persons with post-polio. The Swedish version of the Multidimensional Pain Inventory (MPI). Scand J Caring Sci 1999; 13: 33–40.
- Willén C, Grimby G. Pain, physical activity, disability in individuals with late effects of polio. Arch Phys Med Rehabil 1998; 79: 915–919.
- Widar M, Ahlström G. Experiences and consequences of pain in persons with post-polio syndrome. J Adv Nurs 1998; 28: 606–613.
- Werhagen L, Borg K. Analysis of long-standing nociceptive and neuropathic pain in patients with post-polio syndrome 2010; 257: 1027–1031.
- Werhagen L, Hultling C, Molander C. The prevalence of neuropathic pain after non-traumatic spinal cord lesion. Spinal Cord 2007; 45: 609–615.
- Werhagen L, Budh CN, Hultling C, Molander C. Neuropathic pain after traumatic spinal cord injury-relations to gender, spinal level, completeness, and age at the time of injury. Spinal Cord 2004; 42: 665–673.
- Ware JE, Kosinski M, Keller SD. SF-36 Physical and mental health summary scales: a users manual. Boston, MA: New England Medical Center, The Health Institute; 1994.
- Carlsson AM Assessment of chronic pain. Aspects on reliability and validity of the visual analogue scale. Pain 1983; 16: 87–101.
- Gonzalez H, Sunnerhagen KS, Sjöberg I, Kaponidis G, Olsson T, Borg K. Intravenous immunoglobulin for post-polio patients a randomized controlled trial. Lancet Neurol 2006; 5: 493–500.