

# Presentation and Impact of Pain in Persons with Post-Polio Syndrome: A Cross-sectional Survey Study

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## ABSTRACT

**Purpose:** It is a common and well-recognised phenomenon that functional deterioration occurs many years after people are affected by poliomyelitis infection. This study aims to determine the presentation of pain in subjects with post-polio syndrome (PPS) and also the correlation between severity of pain and interference in activities of daily living (ADL).

**Method:** A cross-sectional survey was conducted among 72 persons with PPS in Gujarat state in India. Each one was given a self-administered questionnaire which included an 11-point Numeric pain rating scale (NRS) for intensity of pain, questions about site, duration and diurnal variation of pain, and an 11-point Numeric pain rating scale for pain interference.

**Results:** The study showed that 17 persons (24%) had only joint pain, 28 (39%) had only muscular pain and 27 (37%) had both joint as well as muscular pain. The highest number of subjects or 34 persons (47%) had knee pain, followed by 24 (33%) with shoulder pain, 21% with hip and 19% with low back pain. Muscle pain was maximum in arm musculature, as reported by 33 persons (45%), followed by pain in leg and foot muscles among 25 (36%) and 17 (23%) persons, respectively. Maximum number of subjects or 31% had pain while working which was relieved by rest, while 28 % had pain which continued all day. 43% experienced more pain in winter while 57% had no seasonal variation in pain. 30 persons (42%) had severe pain, 26 had moderate pain and only 16 had mild pain. Mean pain intensity was  $5.88 \pm 1.52$ . Interference in ADL on NRS was  $4.72 \pm 2.70$ . Interference in ADL and pain intensity were found to be positively correlated with Pearson's co-efficient  $r=0.6295$  ( $p<0.0001$ ).

**Conclusion:** The majority of those who had recovered from polio experienced increased or new symptoms and problems in ADL, muscle pain, joint pain, and difficulties in walking.

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**Key words:** *muscle pain, joint pain, numeric rating scale, interference, activities of daily living.*

## INTRODUCTION

Post-Polio Syndrome (PPS) is a neurological condition which occurs in persons who have had polio. After an interval of several years of stability, people may develop increasing weakness, stamina problems, fatigue and pain (British Polio Fellowship, 2005).

Common symptoms of post-polio syndrome include fatigue, new muscle weakness in affected muscles as well as previously unaffected muscles, and atrophy of affected muscle groups. Muscle and joint pain are present, and are usually associated with muscle cramps and spasms. The joint pain is similar to arthritis, resulting in stiffness and reduced range of motion. Associated symptoms are weight gain, sleep apnoea, walking difficulties, swallowing problems, breathing problems and sensitivity to cold (British Polio Fellowship, 2005).

Results from various studies have found that the prevalence of joint pain ranges from 42% to 80% (Ramlow et al, 1992), and the prevalence of muscle pain ranges from 38% to 86% (Agre et al, 1989). In a sample of 150 polio survivors, 80% of those surveyed complained of pain (Gawne et al, 2000). Similarly, pain was the most common complaint in a sample of 875 post-polio persons, occurring in 79% of those surveyed (Yarnell, 2000). With regard to pain intensity, persons with PPS have reported levels of pain severity significantly higher than national norms on the bodily pain subscale of the SF-36 (Vasiliadis et al, 2002). They have also documented that women with PPS may be more likely to experience pain, or may experience more severe pain than men with PPS. Pain is not only common in persons with PPS, but it tends to be rated as moderate to severe, tends to occur in many locations (average of 17.3 body areas), and is related to disruptions in daily living (Thorén-Jönsson et al, 2001).

From the perspective of rehabilitation medicine and social welfare, it is important to address the need for additional information on the scope of pain, to describe pain interference in ADL, and the frequency, intensity, location and type (muscular or joint) of pain, in a community of polio survivors suffering from PPS. Despite the large number of polio-affected persons in India, studies are scarce and to date it is not known how many of them suffer from pain. Therefore, there is a need

to obtain information regarding presentation and impact of pain in persons with PPS in India, with the focus of this study being on Gujarat State.

## **Aims**

The study aimed to determine the type, site, intensity, frequency, duration and diurnal and seasonal variation of pain in subjects with Post-Polio Syndrome (PPS), and to determine the correlation between the severity of pain and interference in activities of daily living (ADL) using the pain interference scale.

## **METHOD**

A cross-sectional survey was conducted at the SBB College of Physiotherapy of VS General Hospital in Ahmedabad, Gujarat, from May 2011 up to May 2012. Ethics clearance was obtained from SBB Institutional Ethics Committee. The subjects were selected using convenience sampling. They consisted of 72 persons diagnosed with PPS according to the Halstead criteria (Gilhus, 1998) given below.

**Inclusion criteria:** A prior episode of paralytic polio, confirmed by medical history or neurological examination, with a period of neurological recovery followed by an extended interval of neurological and functional stability, usually 15 years or more, preceding the gradual or abrupt onset of new weakness or abnormal muscle fatigability, with or without generalised fatigue, muscle atrophy and pain. The symptoms that persisted for at least 1 year were considered. Subjects with confirmed PPS and with symptom of pain for more than 3 months were included.

**Exclusion criteria:** Subjects with no history of any paralytic polio, and no gradual onset of new weakness, pain or other symptoms were excluded. Other medical, orthopaedic and neurological conditions that could be the cause of the new health problem were also excluded.

Subjects were recruited from various parts of Gujarat, according to the inclusion and exclusion criteria. Persons attending as out-patients at hospitals were included, and those attending disability camps were also asked to fill out the questionnaire. The background of the study was explained, and written informed consent was obtained from them.

A questionnaire, based on the one used by Stoelb et al (2008) in their study on 'Pain in persons with post-polio syndrome: Frequency, Intensity and Impact', was developed and modified to suit the Indian community. The authors eliminated

questions regarding treatment of pain. Two senior physiotherapists in the department were asked to go through the questionnaire and suggest changes. A pilot study was conducted on 10 persons, and the study commenced after the necessary changes were made. The language in the questionnaire was changed to suit the understanding of post-polio survivors. However, statistical validity and reliability of the questionnaire were not checked by the authors. The authors of the original questionnaire have also not mentioned whether they checked their questionnaire for validity and reliability.

The questionnaire used in this study is attached in Appendix 1. It was self-administered and had questions concerning demographic information, PPS-related information, pain intensity/severity and duration, pain location and its interference in ADL, as described below.

**Demographic characteristics and PPS-related information:** Participants responded to questions pertaining to gender, age and employment status. They were also asked to provide information about their polio diagnosis, including approximate date of onset of poliomyelitis symptoms. To assess frequency of pain problems, participants were asked “Are you currently experiencing, or have you in the past 3 months experienced any pain (other than occasional headaches or menstrual cramps)?” Those who responded affirmatively to this question were then asked to provide additional information about pain intensity/severity, duration, site(s), interference, and treatments.

**Pain intensity/severity and duration:** An 11-point Numeric Rating Scale (NRS), ranging from ‘0’ (no pain) to ‘10’ (pain as bad as could be), was used to assess participants’ average pain intensity during the past week. Previous research has supported both the reliability (Daut et al, 1983) and validity (Paice et al, 1997) of NRS of pain intensity. Participants, who confirmed that they experienced pain problems associated with their PPS either currently or in the past 3 months, were also asked to provide an approximate date for when the pain began. Since pain is a characteristic symptom of PPS, they were not asked if they had ever received a separate pain-related diagnosis but were asked to report on their pain in general.

**Pain site(s), its diurnal and seasonal variation:** Participants were asked to indicate whether they had experienced persistent, bothersome pain in 1 or more of specific body sites (head, neck, shoulders, upper back, lower back, arms, elbows, wrists, hands, buttocks, hips, chest, abdomen/pelvis, legs, knees, ankles,

and feet). They were also asked about the time of day when they had pain, as well as about the seasonal variation of pain.

Pain interference with ADL: An 11-point NRS scale, ranging from '0' (does not interfere) to '10' (completely interferes), adapted from the Brief pain inventory pain interference scale, was used to measure pain interference with daily activities.

## Data Analysis

The statistical package SPSS version 16 was used to analyse the data. Descriptive statistics were used to determine the frequency, intensity, and locations of pain reported by the survey participants, and were also applied to the pain interference and pain treatment data. Pearson product moment was used to find the correlation between intensity of pain and pain interference with ADL. Level of significance was kept at 5%.

## Limitation

A limitation of this study was the use of the self-administered questionnaire, which may be less sensitive than a direct interview.

## RESULTS

There were 72 polio survivors in the study. The participants were 57 males and 15 females, ranging in age from 25 to 79 years, with the mean age of  $41.94 \pm 11.71$  years.

The prevalence of type of pain is shown in Table 1.

**Table 1: Prevalence of different Types of Pain (n=72):**

Type of Pain	Number of Subjects	%
Joint Pain	17	24 %
Muscular Pain	28	39 %
Both	27	37 %
TOTAL	72	100%

The highest number of subjects or 34 (47%) had pain in their knee joints, followed by 24 (33%) with shoulder pain, 21% with hip pain and 19% with low back pain, as shown in Table 2.

**Table 2: Prevalence of Joint Pain according to Area Involved (n=72):**

SITE	Number of Subjects		Total
	Affected side	Non-affected side	
Neck	-	-	11(15%)
Upper Back	-	-	2 (3%)
Lower Back	-	-	14(19%)
Shoulder	21(29%)	3 (4%)	24(33%)
Elbow	9(12%)	2 (3%)	11(15%)
Wrist & Hand	7(10%)	2 (3%)	9(12%)
Hip	11(16%)	4 (6%)	15(21%)
Knee	12(17%)	22(31%)	34(47%)
Ankle & Foot	1 (1%)	1 (1%)	2 (3%)

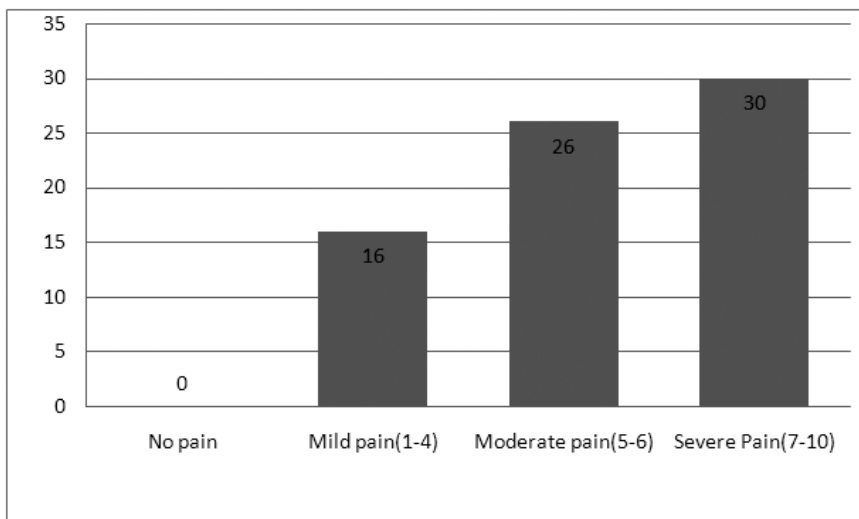
For muscle pain, the highest number or 33 participants (45%) reported pain in arm musculature, followed by 25 (36%) with pain in leg muscles and 17 (23%) with pain in foot muscles, as shown in Table 3. Maximum number of polio survivors (31%) had pain during work which was relieved by rest, while 28% had continuous pain throughout the day. 43% of the subjects had more pain in winter while 57% had no seasonal variation in pain.

**Table 3: Prevalence of Muscular Pain according to Site:**

SITE	Number of Subjects		Total
	Affected side	Non-affected side	
Neck	-	-	13(18%)
Upper Back	-	-	1 (1%)
Lower Back	-	-	9(13%)
Arm	26(36%)	7 (9%)	33(45%)
Forearm	18(25%)	6 (8%)	11(33%)
Hand	6 (8%)	2 (3%)	8(11%)
Thigh	9(13%)	6 (8%)	15(21%)
Leg	15(22%)	10(14%)	25(36%)
Foot	16(22%)	1 (1%)	17(23%)

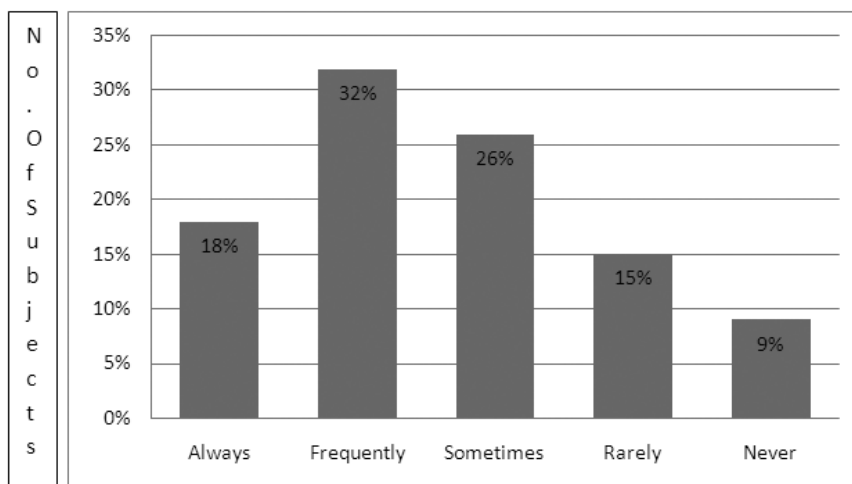
Pain intensity on NRS had mean intensity of 5.88 with  $\pm 1.52$  SD. Thirty subjects (42%) had severe pain as shown in Figure 1.

**Figure 1: Intensity of Pain**



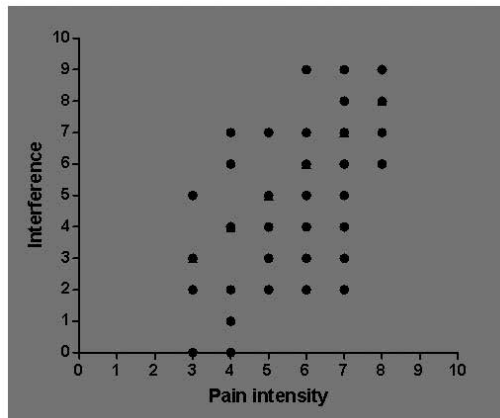
Interference in ADL was measured with the 11-point NRS pain interference scale which showed a mean of 4.72 with  $\pm 2.70$  SD. Figure 2 shows that 32% of the participants reported frequent interference in ADL due to pain, followed by 26% who had only occasional interference in ADL.

**Figure 2: Pain Interference in ADL**



Interference in ADL due to pain and intensity of pain were found to be positively correlated with Pearson's co-efficient  $r = 0.63$  ( $p < 0.0001$ ) which is shown in Figure 3.

**Figure 3: Correlation between Pain Intensity and Interference in ADL**



## DISCUSSION

This survey evaluated 72 polio survivors in Gujarat who had pain as a major symptom. The study confirmed a high level of impairment and disability among people who had earlier contracted poliomyelitis. They experienced joint or muscular or both types of pain as symptoms.

It was found that 17 polio survivors (24%) had only joint pain, 28 (39%) had only muscular pain and 27 (37%) had both joint as well as muscular pain. A survey done by Pentland et al (1999) on 221 post-polio subjects showed that common symptoms were muscle pain (64%), joint pain (61%), and joint stiffness (64%).

In the present study, subjects with pain in the shoulder joint numbered 24 or 33% (affected side 29% and non-affected side 4%). The highest number who reported muscle pain were 33 persons or 45% with pain in arm musculature, (36% on affected side and 9% on non-affected side). Koh et al (2002) in a study on upper-limb pain in long-term poliomyelitis found that among 103 valid replies the prevalence of upper limb pain was 64%. Mobility aids were used by 74% and were associated with an increased risk of upper-limb pain, while 'polio-affected' limbs were at reduced risk. However, this study found that pain in an upper extremity was more on the affected side among subjects with PPS.



Respondents in this study reported that the most common sites of muscular pain were arm, leg and foot musculature. This reflects the findings reported by other studies. The prevalence of muscle pain in arm and forearm musculature was more on the affected side. The respondents also reported that pain was greatest in the knee on the non-affected side, in the shoulder on the affected side, and in hip joints and joints of the lower back and neck. Pain was relatively widespread in the present sample, with participants reporting on an average, almost 4 different pain sites. However, this number is less than the average number of pain sites reported by participants in an earlier study done by Stoelb et al (2008), in which an average of  $9.54 \pm 3.49$  different pain sites (range, 3-17 sites) were mentioned. The pain sites most often reported were shoulder(s) (77%), lower back (75%), legs (75%), and hips (67%). Sites with the highest average pain intensity included knees ( $5.93 \pm 2.56$ ), legs ( $5.47 \pm 2.37$ ), wrists ( $5.35 \pm 2.50$ ), lower back ( $5.33 \pm 2.18$ ), and head ( $5.33 \pm 2.24$ ). On an average, participants reportedly experienced pain at an approximately earlier age in the legs ( $38.77 \pm 19.60$  years) and the chest ( $39.18 \pm 15.33$  years), compared to the other pain locations.

In the current study, the mean NRS score for pain was 5.875 with  $\pm 1.519$  SD. Willén and Grimby (1998) found that more than 50% of the individuals in their study had pain daily, most often during physical activity. The mean visual analogue scale (VAS) score for daily pain intensity was 55mm, range 0 to 93mm. In the lower limbs, cramping pain was the most common pain characteristic in both polio-affected and non-polio-affected limbs. In the upper limbs and in the trunk, aching pain was the most common pain characteristic, especially in the polio-affected areas.

The mechanisms that either cause or contribute to pain syndromes in PPS are joint instability or deterioration, muscle disuse and overuse, and abnormal biomechanics (Stoelb et al, 2008). A correlation between muscle pain and weakness is believed to be either a measure of overuse or disuse that falls into a vicious cycle (Silver and Gawne, 2004). When musculoskeletal overuse occurs, pain develops. Rest and immobilisation can relieve this pain, but this leads to decreased use of certain muscles, with development of disuse atrophy and further weakness. After this, relatively normal use of the muscle leads to pain and further disuse. Pain presents due to a degenerative joint disease (DJD), low back pain or pain from nerve compression syndromes. Weakness induced by polio-affected muscles as well as poor body mechanics, makes the joints more susceptible to the development of DJD. Survivors who can walk develop degenerative joint

disease in the lower extremities because years of ambulating on unstable joints and supporting tissue increase the likelihood of developing further pain and deformity. Those who use wheelchairs or assistive devices such as canes, crutches or walkers are prone to DJD, or overuse syndromes in their upper extremities, especially the wrists and shoulders (Gawne, 2000).

Joint pain in persons with PPS tends to be caused by overuse and postural changes due to unbalanced muscle strength, whereas muscle cramps, fasciculations, and overuse can lead to muscle pain (Stoelb et al, 2008).

The current study shows that the maximum number of PPS survivors had pain since 3 to 5 years (26%), followed by those who experienced pain for a period of 1 to 3 years (21%). Very few of the participants (4%) had pain for more than 15 years, but all of them complained of pain for more than 6 months. Most of them had pain while working which was relieved by rest, while 28% had pain which was continuous in nature. Widar and Ahlström (1999) found that polio survivors had pain for an average of 19 years. Pain from the joints of the extremities was most commonly reported, followed by lower back pain. The pain was most common in winter as compared to other seasons.

The average pain intensity among the present study sample was found to be about 5.88 with  $\pm 1.51$  SD on NRS. Pain interference in ADL was found to be a mean of 4.72 on NRS with  $\pm 2.70$  SD. This is supported by the study done by Stoelb et al (2008) in which pain was reported by a total of 91% ( $n=57$ ) of study participants ( $N=63$ ). Their respondents reported moderate pain intensity during the previous week of  $5.32 \pm 2.21$  on the '0 - 10' NRS, with 20 (35%) of the 63 participants reporting mild pain (1- 4 on the NRS), 20 (35%) reporting moderate pain (5 - 6 on the NRS), and 17 (30%) reporting severe pain (7- 10 on the NRS). None of their respondents reporting pain endorsed an average pain intensity of '0' during the previous week. The majority of those with pain or 68% ( $n=38$ ) indicated having had intermittent pain in the past 4 weeks, whereas 32% ( $n=18$ ) indicated that they had constant pain during that period. None of them reported having been pain-free in the previous 4 weeks. In that study, respondents reported that they had experienced PPS-related pain for a mean of  $20.22 \pm 12.79$  years. Pain interfered the most with sleep (mean 4.60 on the '0 -10' NRS), followed by recreational activities (4.46), mobility (4.42), and normal work (4.42). However, in their sample the average pain intensity was strongly related to interference with life activities particularly for sleep and those activities requiring a high level of musculoskeletal involvement. In the present study, 42% of the respondents had

very severe pain (7-10 on the '0 to 10' NRS) and 36% had moderate pain (4 - 5 on the NRS). The present study found moderate positive correlation between pain intensity and interference in ADL.

## CONCLUSION

This cross-sectional survey of polio survivors in Gujarat state, India, evaluated 72 subjects with PPS. The majority experienced increased or new symptoms and problems in ADL, muscle pain, joint pain, fatigue, atrophy, and difficulties in walking. Prevalence of muscle pain was reported by 39%, joint pain by 24%, and 37% had both muscle and joint pain. The most common sites of muscular pain were arm, leg and foot musculature, and pain was most in the knee, shoulder and hip joints and joints of lower back and neck. Most of the polio survivors had experienced pain since the past 3 -5 years, and some complained of pain since 7 -10 years. The maximum number had pain during work but got relief by resting, while some had continuous pain. Some respondents had more pain in winter but very few reported pain in summer, and more than half of them had no seasonal variation in pain. There is a positive correlation between interference in ADL due to pain and intensity of pain. Therefore, intervention strategies to reduce the pain and problems related to pain need to be implemented for persons with post-polio syndrome.

Future research could be done on the relationship between fatigue, muscle weakness, and pain in PPS. Very few studies have explored exercise as a means to reduce pain or pain-related interference in PPS populations, so research should also attempt to find an effective treatment for pain.

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## Appendix 1

### PROFORMA

No: .....

Date: .....

1) NAME:

2) AGE / GENDER:

3) ADDRESS:

4) OCCUPATION:

5) MOBILE NO:

A) Age at the time of onset of polio:

☐ 0-6 months☐ 6-12 months☐ 1-3 years☐ 3-6 years☐ 6-10 years☐ 10-15 years☐ 15-25 years

B) Limb affected:

RIGHT

LEFT

☐ Upper limb☐ Upper limb☐ Lower limb☐ Lower limb

C) Are you having any pain now?

☐ Yes☐ No

D) Site of Pain: (If Joint Pain is present)

a. Neck ☐b. Upper back ☐c. Lower back ☐

RIGHT

LEFT

d. Shoulder ☐☐e. Elbow ☐☐f. Wrist & Hand ☐☐

- |          |        |        |
|----------|--------|--------|
| g. Hip   | (    ) | (    ) |
| h. Knee  | (    ) | (    ) |
| i. Ankle | (    ) | (    ) |

E) Site of pain : ( If Muscular pain is present)

- |                |        |        |
|----------------|--------|--------|
| a. Neck        | (    ) |        |
| b. Upper back  | (    ) |        |
| c. Lower Back  | (    ) |        |
|                | Right  | Left   |
| d. Arm         | (    ) | (    ) |
| e. Forearm     | (    ) | (    ) |
| f. Hand        | (    ) | (    ) |
| g. Ant. Thigh  | (    ) | (    ) |
| h. Post. Thigh | (    ) | (    ) |
| i. Leg         | (    ) | (    ) |
| j. Foot        | (    ) | (    ) |

F) Duration of pain:

- (    ) 0-6 months  
 (    ) 6-12 months  
 (    ) 1-3 years  
 (    ) 3-5 years  
 (    ) 7-10 years  
 (    ) 10-15 years  
 (    ) more than 15 years

G) Diurnal distribution of pain:

- (    ) Morning  
 (    ) At night  
 (    ) After work  
 (    ) During work, relieved after rest  
 (    ) At rest (also)  
 (    ) Continuous

## H) Seasonal variation of pain:

- ( ) Winter  
 ( ) Summer  
 ( ) Monsoon  
 ( ) All seasons

## I) Relieving Factors of pain:

- ( ) Rest  
 ( ) Medication  
 ( ) Other

## J) Severity of pain:

## 11- point Numeric pain rating scale:

0	0	0	0	0	0	0	0	0	0	0
0	1	2	3	4	5	6	7	8	9	10

No pain

Non-bearable pain

## K) Is pain interfering with your daily activities(self-care like bathing and dressing, mobility and working) :

- ( ) Always  
 ( ) Frequently  
 ( ) Sometimes  
 ( ) Rarely  
 ( ) Never

## L) Pain interference scale:

## 11- point Numeric pain interference scale

0	0	0	0	0	0	0	0	0	0	0
0	1	2	3	4	5	6	7	8	9	10

No interference

No work possible