ORIGINAL ARTICLE

Pain after paraplegia: a survey in India

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Study design: A postal survey.

Objective: To ascertain the incidence of pain in individuals with paraplegia in India and to associate it with demographic characteristics.

Setting: India.

Method: The study was done by means of a questionnaire. This questionnaire was mailed to the identified individuals ($n = 600$) on the addresses obtained from the medical records section of hospitals and from various organizations. Data analysis was done by using non-parametric tests of association.

Results: The return rate was 46% (276/600). Fifty-seven percent of individuals complained of pain. Of this, pain in the back and chest ranked the highest (30.1%), followed by pain below the level of lesion (6.9%), pain in the shoulder and upper limb (4.7%) and neck (0.4%). Fifteen percent of individuals complained of pain at multiple sites. We found a significant association of pain with age, duration since injury and ambulation.

Conclusion: More than half of the subjects complained of pain in the study. Pain was found to be associated with age, duration since injury and ambulation. As pain has a dramatic effect on a subjects' quality of life, there is a need to evaluate it in detail and treat accordingly with preventive, rehabilitative or surgical procedures.

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Introduction

Pain is a significant problem encountered in individuals with spinal cord injury (SCI). This pain often starts within 6 months of SCI and continues throughout life.¹ Incidence of acute pain is 96%.² The estimated prevalence of chronic pain varies from 11 to 94%¹ and in a recent study, it was found to be 76%.³ Studies have shown that almost all of the patients (96%) experienced pain at some stage during their inpatient rehabilitation.² There is a relationship between pain reported in the acute phase (6 weeks after injury), and pain reported 1 year after hospital discharge. A study by Kennedy, Frankel, Gardener and Nuseibeh (1997) in UK showed that within the acute category, 24% of respondents (6 weeks after injury) reported very intense pain, whereas the prevalence of chronic pain (at 1 year after hospital discharge) was found to be 41%. A similar prevalence was also reported by UmLauf (1987) and Britell and Mariano.⁴

The most common locations of pain reported in literature are the back (61%), hips and buttocks (61%) and legs and feet

(58%). Upper extremity pain was experienced by 76% of subjects after the initial injury.¹ In the upper extremity, 71% had shoulder pain, 53% wrist pain, 43% hand pain and 35% elbow pain. Pain interfered with transfers in 65% of the patients who were doing them. Pain was more likely to be associated with pressure relief, transfers and wheelchair mobility.⁵

Wheelchair use has been a contributing factor to pain. Curtis *et al.*⁶ had reported a self-report survey where it was found that more than two thirds of the sample reported shoulder pain since beginning wheelchair use. In India, ambulation is usually deferred in favour of wheelchair due to reasons of accessibility and cost. Individuals with paraplegia either spend most of their time on a wheelchair or in a recumbent position because of environmental constraints like inaccessible or small houses, uneven terrain and so on. The type of wheelchair normally used by the spinal cord injured population in India is a basic transport wheelchair, which requires undue forces to be exerted for self-propulsion.

Pain was significantly more common in less-educated persons and individuals not employed or in school.¹ It was found to be associated with age,¹ time since injury (linear relationship)^{3,7} but reports about association between pain and the neurologic level of the SCI were contradictory.¹

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The existing literature suggests that pain, whether acute or chronic, leads to loss of function, interferes with activities of daily living and demands for assistance.¹ It sometimes had such an impact that individuals with SCI were ready to trade pain relief for loss of bladder, bowel or sexual function.⁸

Pain hinders community reintegration of individuals with SCI⁹ and their productive life. A prospective co-relational study, by Donnelly and Eng, in 2005, had shown that 86% of individuals with an SCI reported pain at 6 months after discharge, with 27% of these individuals reporting pain that impacted on many or most activities. Pain impact and pain intensity were related to community reintegration.¹⁰

As there has been no structured nationwide study reporting this aspect in India, the prevalence of this problem in India is unclear. There is a need to understand the effect of demographics on pain, so that preventive measures can be taken before its occurrence.

Thus, this study was an initial attempt to ascertain the incidence of pain in individuals with paraplegia in India and to associate it with demographic characteristics.

Materials and methods

A postal survey by means of a questionnaire was done from 1 August 2004 to 31 May 2006. Subjects included in the study were individuals with paraplegia of any cause, either gender with evidence of complete cord lesion and who were 18 years or older. Subjects included were community dwelling as well as institutionalized individuals.

Procedure

Part I: Development of questionnaire and validation. We developed a questionnaire in English, which was constructed at the language level of third grade education. The questionnaire was evaluated for face validity by five physiotherapists. Each of the physiotherapists had a minimum of 5 years working experience with SCI, including community-based work with this population. The suggestions put forth by the evaluators were incorporated, and the revised questionnaire was pilot tested on 10 SCI individuals for comprehensibility. Changes suggested were incorporated and this version was again pilot tested on five patients who had not participated in the first pilot testing. The final version was translated into Indian languages by means of parallel back translation ensuring that the language level was maintained at the third grade level in all languages.

The final versions of the questionnaire consisted of the following three sections:

The first section included demographic and disease characteristics namely age, gender, education, occupation, level of lesion, duration since injury and ambulation status. The expected responses to this section were open ended except ambulation status, which was dichotomous (walking/not walking).

The second section consisted of questions regarding pain. The instructions pertaining to pain consisted of presence/absence as well as site of pain. The patient was asked to mark pain if it was 'bothersome' or 'frequently occurring'

or 'periodic'. Intensity was not queried because of the inherent problems associated with the use of visual analogue scale, in terms of understandability.¹¹ It was assumed that if a subject reported pain, it was a significant factor in the subjects' perception.

The third section consisted of details of employment following the SCI. The responses to this section were open ended.

Part II: Administration of questionnaire. Because of the absence of a national database on SCI, addresses of potential subjects were collected from hospitals and organizations and associations dedicated to the SCI population. Addresses of individuals living in 20 of 28 states in India were collected. The questionnaire in English and the relevant regional language was mailed to the identified individuals ($n = 600$). The mail packet included a covering letter in English and the regional language, clearly outlining the purpose of the questionnaire, the subject's option to participate or not and the expected return date; the questionnaire itself with instructions for completion and a reply paid self-addressed envelope. One reminder was sent a week after the expected date of reply had passed. Those subjects who did not respond to the reminder were not contacted again.

Data analysis

Data were analysed using descriptives. Pain and its association with demographic details were analysed using co-efficient of association—Goodman Kruskal Tau.

Results

Return rate

Of the 600 individuals, 276 responded to the mailed questionnaire, with a return rate of 46%.

Demographics

Demographic characteristics included in the study were age, gender, education, etiology, level of lesion and duration since injury.

Age (in years) was categorized into 9: 18–<25, 25–<30, 30–<35, 35–<40, 40–<50, 50–<60, 60–<70, 70–<80, >80. Of the 276 participants, 53 (19.2%) were in the age group of 18–<25 years, 53 (19.2%) in 40–<50 years, 49 (17.8%) in 25–<30 years, 41 (14.9%) in 35–<40 years, 38 (13.8%) in 30–<35 years, 30 (10.9%) in 50–<60 years and one each (0.4%) in 70–<80 and more than 80 years. In total, 233 subjects were men and 43 were women.

Education was categorized into seven categories: no education, primary, secondary, higher secondary, graduation, post-graduation and professional. In all, 148 subjects (53.6%) belonged to secondary education category, 40 (14.5%) subjects had higher secondary education, 23 (8.3%) subjects were illiterate, 22 (8%) subjects were graduates, 19 (6.9%) subjects were professionals, 19 subjects (6.9%) had primary education and 5 (1.8%) subjects were post-graduates.

Etiology was categorized into six categories: fall from a height, fall of an object, road traffic accident, sports

Figure 1 Incidence of pain relative to site. UL, upper limb.

related, gun-shot injury and non-traumatic insult. Falls from height was the leading cause for spinal cord insult (25%), followed by road traffic accidents (17.4%), non-traumatic insult (8.3%), fall of an object (6.5%), gun shot injuries (4.3%) and sports related cause of an insult (0.7%). Thirty-eight percent of individuals did not mention the cause for injury.

Level of lesion was categorized into four categories: not mentioned, upper thoracic, lower thoracic and lumbar. In all, 166 subjects (60.1%) had the lesion at the lumbar level, 39 subjects (14.1%) at the upper thoracic level, 31 subjects (11.2%) at the lower thoracic level and 40 subjects (14.5%) did not mention about the level.

Duration since injury was categorized into 11 categories: 1–<7 months, 7–<12 months, 1–<2 years, 2–<3 years, 3–<4 years, 4–<5 years, 5–<10 years, 10–<15 years, 15–<20 years, 20–<25 years and >25 years. Of the 276 participants, most of the subjects (57, 20.7%) were 1–<6 months after injury and the least (6, 2.2%) were in 15–<20 years after injury period.

Pain characteristics

Incidence of pain. Fifty-seven percent of individuals complained of pain. All subjects complained of 'bothersome' 'frequently occurring' pain.

Site of pain. Out of the 57% of individuals who complained of pain, pain in the back and chest ranked the highest (30.1%), followed by pain below the level of lesion (6.9%), pain in the shoulder and upper limb (4.7%) and neck (0.4%). Fifteen percent of individuals complained of pain at multiple sites. The incidence of pain relative to site is depicted in Figure 1.

Site of pain relative to different levels of lesion. Site of pain relative to different levels of lesions is shown in Figure 2.

Significant association of pain with demographics

The associations of pain with demographics that were significant are shown in Table 1. We found significant

Figure 2 Distribution of pain at different levels of injury. Level of lesion categories: 0, not mentioned; 1, upper thoracic; 2, lower thoracic and 3, lumbar. Distribution of pain at different levels of injury: upper thoracic: back and chest>others>below level of lesion>shoulder and upper limb; lower thoracic: back and chest>below level of lesion>others>shoulder and upper limb; lumbar: back and chest>others>below level of lesion>shoulder and upper limb>neck.

Table 1 Association of pain with demographics

Morbidity	Demographics	Tau	Significance
Pain	Age	0.063	0.000
	Duration since injury	0.071	0.000
	Ambulation	0.028	0.000

association of pain with age, duration since injury and ambulation (Figures 3–5).

Discussion

Pain is one of the leading causes of morbidity in individuals with paraplegia. More than half of the individuals in our study complained of pain at various sites. Pain in the back and chest were more common in the subjects with lumbar lesion, which could be explained as the majority of the subjects in our study had sustained lumbar lesions. However, association between pain and neurological level of lesion is contradictory. We did not find any significant association between pain and level of lesion. Pain in the back and chest was the leading site of pain at all levels. The most common location for pain reported by Turner, Cardenas, Warms and McClellan, in 2001, was the back. The reasons cited by them were mechanical factors. They stated that such pain problems may be helped by treatments such as activity pacing, avoidance of prolonged activity in one position and regular stretching, range of motion and exercise regimens, tailored to individuals who use wheelchairs. Subjects with paraplegia may experience shoulder and upper extremity pain associated with overuse related to weight bearing during wheelchair transfers and the demands of wheelchair

Figure 3 Distribution of pain at different age groups. Age categories (in years): (1) 18–<25, (2) 25–<30, (3) 30–<35, (4) 35–<40, (5) 40–<50, (6) 50–<60, (7) 60–<70, (8) 70–<80 and (9) >80. Distribution of pain at different age groups: (1) back and chest>others>below level of lesion>shoulder and upper limb; (2) back and chest>others>below level of lesion>shoulder and upper limb; (3) back and chest>others>below level of lesion>shoulder and upper limb; (4) back and chest>below level of lesion>others>shoulder and upper limb; (5) others>back and chest>below level of lesion>shoulder and upper limb and neck; (6) back and chest>below level of lesion>others>shoulder and upper limb; (7) others>back and chest; (8) others; (9) back and chest.

propulsion. Neck pain is more likely to be common in subjects with cervical injuries than with that of lumbar injuries.¹

We found a significant association of pain with age, duration since injury and ambulation. Pain was common in the age group of 40–<50 years followed by 18–<25 years, which could be explained as it followed the trend of age distribution of subjects in the study. Pain in the back and chest was seen in almost all the age groups, with it being the most common among subjects in the age groups of 40–<50 years, 18–<25 years and 25–<30 years. Shoulder and upper limb pain were more prevalent in the age group of 50–<60 years, which could be due to the ageing process and due to the higher perception of pain by older individuals.^{2,7,12,13} The existing literature supports the finding of association of pain and age, with greater pain intensity being found to be associated with older age.^{7,12,13} The reason could be the decrease in plasticity of the central nervous system with age, as far as neurogenic pain is concerned, as well as overuse of supra-lesional joints leading to osteo-articular pains.¹⁴ Another factor could be psycho-social stresses.¹⁰

Pain in the back and chest was seen in all the groups especially in the group that were 1–<6 months after injury. As stated earlier, the majority of subjects in the study fell into this age group. Pain in the shoulder, which was common in the group that were 1–<2 years after injury, could be due to the reason that the majority of the subjects in this group were ambulators. Ambulation in these patients involved use of walking aids, which may have contributed to increase in shoulder pain. This was also seen in the groups that were 10–<15 years and 20–<25 years after injury. The existing literature supports the fact that there is an association

Figure 4 Distribution of pain based on duration since injury. Duration since injury: 0, not mentioned; (1) 1–<6 months; (2) 7–<12 months; (3) 1–<2 years; (4) 2–<3 years; (5) 3–<4 years; (6) 4–<5 years; (7) 5–<10 years; (8) 10–<15 years; (9) 15–<20 years; (10) 20–<25 years and (11) >25 years. Pain distribution in descending order in all the groups: (1) back and chest>others>below level of lesion>shoulder and upper limb; (2) back and chest>others>below level of lesion, shoulder and upper limb; (3) back and chest>below level of lesion>others>shoulder and upper limb; (4) back and chest>others>below level of lesion; (5) back and chest>others; (6) back and chest, others>shoulder and upper limb; (7) back and chest, others and below level of lesion>shoulder and upper limb; (8) others, below level of lesion>back and chest>shoulder and upper limb; (9) others>below level of lesion, back and chest; (10) others>shoulder and upper limb>back and chest>neck; (11) back and chest>below level of lesion, shoulder and upper limb.

Figure 5 Distribution of pain based on ambulatory status. Non-ambulators: back and chest>others>below level of lesion>shoulder and upper limb. Ambulators: back and chest, below level of lesion>others, shoulder and upper limb.

between age and pain, with pain often starting within the first 6 months after injury and continuing throughout life. Ambulators experienced less pain compared with non-ambulators, though the frequency of shoulder pain was more among the ambulators.

In our study, there were three groups of subjects: (1) subjects who were living in the community, (2) subjects who were living in the centers run by armed forces and

(3) subjects who were living in the specialized centers or non-governmental organizations. Pain was the leading cause of morbidity in all the groups, with the frequency being the highest among the subjects living in the community. This could be due to low educational status and lack of awareness, which precluded them from seeking medical help; lack of pre-discharge home-visits and lack of regular follow-ups. Although these individuals were able to ambulate with wheelchair, they tended to spend more time in bed due to socio-cultural or environmental constraints as described earlier.

Limitations

Intensity and variation of pain patterns were not considered in the study because of the inherent difficulties associated with evaluating these in a survey of individuals in the lower educational status. Tetraplegic individuals were not sampled for this study.

Implications

As pain was found to be the major morbidity among all the groups, preventive measures should be taken from the beginning such as:

- Regular change in patients' position or avoidance of prolonged activity in one position.¹
- Regular stretching and range of motion exercises for all the joints as there is an association of pain with spasticity.¹
- Individual should be taught proper transfer techniques to put less pressure on the shoulder joint. This is because overuse related to weight transfers and wheelchair propulsion could lead to pain in shoulder and upper extremity.¹
- Seating posture must be taken into consideration for pain relief in wheelchair users as they tend to sit in a kyphotic posture to be stable in wheelchair propulsion and other activities. This leads to forward and downward movement of the scapula, depression of the acromion processes and changing the facing of glenoid fossa, thus posture must be evaluated.¹⁵
- Wheelchair can be modified by changing the position of axle as more forward axle position has been correlated with improvement in wheelchair biomechanics.¹⁶
- Propulsion technique with least energy expenditure can be taught to the individual with paraplegia such as semicircular propulsion technique. Semicircular propulsion technique displays characteristics consistent with reduced repetitions and more efficient propulsion. Use of this propulsion style may reduce trauma to the upper extremities.¹⁷
- And if still the pain persists, it should be assessed and treated accordingly with modalities or surgical measures. Individual's pain should always be taken into consideration and activities should be paced accordingly.

Conclusion

More than half of the subjects complained of pain in the study. Pain was found to be associated with age, duration since injury and ambulation. As pain has a dramatic effect on

a subjects' quality of life, there is a need to evaluate it in detail and treat accordingly with preventive, rehabilitative or surgical procedures.

Conflict of interest

The authors declare no conflict of interest.

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References

- Turner JA, Cardenas DD, Warms CA, McClellan CB. Chronic pain associated with spinal cord injuries: a community survey. *Arch Phys Med Rehabil* 2001; **82**: 501–508.
- New PW, Lim TC, Hill ST, Brown DJ. A survey of pain during rehabilitation after acute spinal cord injury. *Spinal Cord* 1997; **35**: 658–663.
- Rintala DH, Holmes HA, Fiess RN, Courtade D, Loubser PG. Prevalence and characteristics of chronic pain in veterans with spinal cord injury. *J Rehabil Res Dev* 2005; **42**: 573–584.
- Kennedy P, Frankel H, Gardner B, Nuseibeh I. Factors associated with acute and chronic pain following traumatic spinal cord injuries. *Spinal Cord* 1997; **35**: 814–817.
- Dalyan M, Cardenas DD, Gerard B. Upper extremity pain after spinal cord injury. *Spinal Cord* 1999; **37**: 191–195.
- Curtis KA, Drysdale GA, Lanza D, Kolber M, Vitolo RS, West R. Shoulder pain in wheelchair users with tetraplegia and paraplegia. *Arch Phys Med Rehabil* 1999; **80**: 453–457.
- Rintala DH, Loubser PG, Castro J, Hart KA, Fuhrer MJ. Chronic pain in a community based sample of men with spinal cord injury: prevalence, severity and relationship with impairment, disability, handicap and subjective well-being. *Arch Phys Med Rehabil* 1998; **79**: 604–614.
- Siddall PJ, Taylor DA, Cousins MJ. Classification of pain following spinal cord injury. *Spinal Cord* 1997; **35**: 69–75.
- Stormer S, Gerner HJ, Gruninger W, Metzmacher K, Follinger S, Wienke CH et al. Chronic pain/dysaesthesia in spinal cord injury patients: results of a multicentre study. *Spinal Cord* 1997; **35**: 446–455.
- Donnelly C, Eng JJ. Pain following spinal cord injury: the impact on community reintegration. *Spinal Cord* 2005; **43**: 278–282.
- Cork RC, Issac I, Elsharydah A, Saleemi S, Zavisca F, Alexander L et al. A comparison of the verbal rating scale and the visual analogue scale for pain assessment. *Internet J Anaesthesiol* 2004 [http://www.ispub.com/ostia/index.php?xmlFilePath=journals/ija/vol8n1/vrs.xml].
- Weitzenkamp DA, Jones RH, Whiteneck GG, Young DA. Ageing with spinal cord injury: cross-sectional and longitudinal effects. *Spinal Cord* 2001; **39**: 301–309.
- Anke WAG, Stenehjem AE, Stanghelle KJ. Pain and life quality within 2 years of spinal cord injury. *Paraplegia* 1995; **33**: 555–559.
- Klotz R, Joseph PA, Ravaut JF, Wiart L, Barat M, The Tetrafigap Group. The Tetrafigap survey on the long-term outcome of tetraplegic spinal cord injured persons: Part III. Medical complications and associated factors. *Spinal Cord* 2002; **40**: 457–467.
- Samuelsson KAM, Tropp H, Gerdle B. Shoulder pain and its consequences in paraplegic spinal cord injured, wheel-chair users. *Spinal Cord* 2004; **42**: 41–46.
- Kotajarvi BR, Sabick MB, An KN, Zhao KD, Kaufman KR, Basford JR. The effect of seat position on wheel chair propulsion biomechanics. *J Rehabil Res Dev* 2004; **41**: 403–414.
- Boninger ML, Souza AL, Cooper RA, Fitzgerald SG, Koontz AM, Fay BT. Propulsion patterns and pushrim biomechanics in manual wheel-chair propulsion. *Arch Phys Med Rehabil* 2002; **83**: 718–723.