Current Research Activity at the National Spinal Injuries Centre

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“From the beginning of our work, clinical practice went hand-in-hand with research”

Sir Ludwig Guttmann
1899-1980

Director of the first Spinal Injuries Unit, Stoke Mandeville Hospital
Founder of the Paralympic Games
The National Spinal Injuries Centre (NSIC), Stoke Mandeville Hospital, Buckinghamshire Hospitals NHS Trust is dedicated to improving the lives of people following spinal cord injury through research as well as through clinical care and education.

The Centre has been prolific in its research output, from the seminal work produced by Sir Ludwig Guttmann and colleagues through to current day.

This booklet contains a brief summary of some of the current research being conducted at, or in collaboration with, the NSIC.
SPINAL CORD INJURY ACROSS THE LIFESPAN

Ageing with spinal cord injury study

Ageing with spinal cord injury (SCI) study is a collaborative study between Stoke Mandeville and Southport Spinal Centres, UK and Craig Hospital, Colorado, USA. This longitudinal project aims to provide information on health, functional ability, life satisfaction, community integration and psychosocial wellbeing in persons with long-term spinal cord injury over the twenty year study period. Since 1990, when it first started, the patients from the two British spinal centres, all injured more than 40 years ago now, have been seen every three years for the study follow-up. The results so far show that in spite of a rise in medical and functional problems, reported quality of life and life satisfaction remain relatively good and stable in patients ageing with SCI. The final study follow-up is planned for 2010.

Life expectancy following spinal cord injury

This multicentre study on long-term survival following spinal cord injury (SCI) aims to provide information on changes in life expectancy and causes of death since 1945 in a population based English sample. The results so far show that life expectancy of persons with SCI, though shorter compared with the general population, has improved dramatically over the last five decades and that the leading causes of death have begun to shift from the typical spinal cord related causes to those of the ageing general population. Regular study updates are planned for the future.

OUTCOME MEASURES in SPINAL CORD INJURY
Assessment of the reliability and validity of the cutaneous electrical perceptual threshold test following spinal cord injury

The purpose of this study was to complete the development of the quantitative sensory test Electrical Perceptual Threshold (EPT), which has potential to improve assessment of sensory function following spinal cord injury (SCI) and could be a useful outcome measure in future clinical trials. EPT was first applied in patients with SCI during our collaboration with Imperial College London and International Spinal Research Trust (ISRT), UK when it was shown to have good validity in assessing the level and severity of SCI. The next phase of the study, funded by David Tolkien Trust, proved its good intra and inter-rater reliability (test-retest repeatability when assessed by the same and by different examiners). The latest work, funded by the Trust Davenport award, showed its sensitivity to change (responsiveness) in a longitudinal study of subjects with incomplete SCI. Proven validity, reliability and sensitivity to change make the EPT test a useful outcome measure for longitudinal studies in subjects with SCI, both during natural recovery and in prospective therapeutic clinical trials (e.g., spinal cord repair).

Development of a Clinically Reliable Outcome Measure in Spinal Cord Injury Rehabilitation

This research evaluated the clinical utility of the Needs Assessment Checklist (NAC) that is used as a means of assessing the strengths and needs of patients with spinal cord injuries during their time in rehabilitation. The NAC identifies those areas of rehabilitation in which the individual would benefit from further support and practice and also provides a structure to the goal planning process.
The study analysed the data collected as part of routine care over a period of two years and looked at the validity of the measure, how sensitive it is to change and to what extent it was sensitive to differences in patient demographics. The NAC was demonstrated to be clinically reliable and sensitive measure of rehabilitation progress, through which person-centred goals can be generated to suit the needs of the individual. Significant differences were found between subgroups according to gender, age and injury variables. There were significant relationships found between items on the NAC—between pain severity and mood was observed and pain was related to differences in mobility scores. ‘Psychological Issues’ was significantly related to scores on ‘ADLs’, ‘Skin Care’ and ‘Mobility’, while questions regarding pain interference and sexuality issues highlighted patient concerns in these areas.

The results of the study underscore the potential for this measure when working in spinal cord injury rehabilitation and also highlight the importance of assessing psychological issues and pain early in rehabilitation as this may impact on patient progress.

- **NUTRITION FOLLOWING SPINAL CORD INJURY**

  **Association of nutrition risk score and nutritional indices in patients with spinal cord injuries – the result from a UK multicentre study**

  There are limited data regarding the relationship between nutritional status to other clinical parameters in patients with spinal cord injuries (SCI). This study aimed to examined whether nutritional status (classified by a validated nutrition screening tool, MUST: Malnutrition Universal Screening Tool) is associated with 1. biochemical indices including total protein, albumin level, C-reactive protein (CRP), magnesium and corrected calcium levels; 2.
haematological indices including haemoglobin (Hb) and white cell counts (WCC); 3. body mass index (BMI); 4.) nutrient intake recorded by food record charts and 5.) numbers of medications prescribed. After multicentre ethics approval and signed informed consent, 137 SCI in-patients aged between 18 and 87 years admitted to three SCI centres during July to December 2009, were assessed. The prevalence of undernutrition was 36.5 % (MUST ≥ 1) and 57 % were overweight or obese (BMI >25 kg/m²) at the time of admission (Table 1). Malnourished patients were found to have significantly reduced concentrations of total plasma protein level, albumin, magnesium, Hb, BMI and appetite. They had a significantly higher CRP and WCC and received more prescribed medications. Malnutrition was common in this SCI population, and may be a risk factor for poorer outcomes and increased hospitals costs. Special attention should be given to this group of vulnerable patients.

**Dietary intervention for individuals with spinal cord injuries – a 1 year report of Spinal Clinic for Obese Out-patient Project (SCOOP)**

Obesity in the spinal cord injury (SCI) population is an ongoing problem which needs urgently tackling as it is associated with adverse clinical outcomes and increased financial costs. SCI individuals appear to be at higher risk of nutrition related complications than the able-bodied population. This 12 months study aimed to assess the effectiveness a dietitian led weight management clinic and describe their nutrient intake with reference to Reference Nutrient Intake (RNI) and national survey data. Fifty four patients with chronic SCI with a body mass index (BMI) range of 26.4 – 46.4 kg/m² were referred for interventions in three consultations over three months. Outcomes measured include nutrient intakes by a 7d food diary, body composition by anthropometric measurements of BMI, mid upper-arm circumference (MUAC), triceps-skin fold thickness (TSF), mid-arm muscle circumference (MAMC) and sitting blood pressure. Twenty seven attended
their follow-up appointment and 19 completed the three month interventions. There was a significant reduction of mean weight (kg), BMI (kg/m²), TSF (mm) and an increase of MAMC (cm). Sitting blood pressure (mm/Hg) was reduced. Total energy intakes were lower than general able-bodied population. When estimated energy requirement (EER) was compared with Schofield approach, SCI individuals appeared to be 9 % less than EER. Insufficient intake of fibre, calcium, sodium, selenium, iodine and vitamin D and excess intake of sugar and alcohol were found.

We conclude the clinic helps individuals with SCI to achieve weight loss without compromising lean body mass. Reduced nutritional requirement in SCI is likely due to enforced inactivity, immobilization and change in body composition. Current guidance may overestimate nutritional requirements in SCI population, apart from introducing appropriate interventions to treat obesity, clinician must be aware of possible pre-existing nutritional deficiencies. Additional organisational cost will be incurred initially, but can potentially decrease long-term healthcare costs if patient’s outcome and quality of life is improved. This clinic plans to continues in the tertiary SCI centre with further research with a larger sample to assess long term outcomes in this specific ‘at risk’ patients group.

**Prevalence of malnutrition in patients admitted to UK spinal injury centre – a multi centre study**

Malnutrition often goes undetected and unmanaged especially in specialised patient groups, and is therefore a major UK public health problem. Whilst nutritional screening of patients is used increasingly, the validity of all of the wide variety of nutritional assessment tools in use is uncertain. The aims of the present study, therefore were to compare the disease specific nutrition screening tool, Spinal Nutrition Screening Tool (SNST) developed for patients with spinal cord injury (SCI), which takes age, body mass index (BMI), level
of SCI, presence of co-morbidity and appetite, against a validated generic nutrition screening tool, malnutrition universal screening tool (MUST) and establish the prevalence of malnutrition including, overnutrition (overweight: BMI > 25 kg/m²) and undernutrition (MUST score ≥1).

One hundred and thirty seven patients with SCI aged 18 years and above admitted to 3 major spinal injury centres. Anthropometric measures of BMI and nutritional screening using SNST and MUST were performed. The present study found that the prevalence of overnutrition was 57 % (BMI > 25) and undernutrition was 38.6 % (with SNST > 10) versus 36.5 % with MUST score >1. When compared with MUST as a reference method, SNST had a sensitivity of 79.0 % and a specificity of 85.3 %. Agreement in the assessment of undernutrition between the two methods using κ-statistics was moderate to substantial [k 0.538 (95% CI 0.396, 0.679)].

Malnutrition is common in patients with SCI and SNST is a valid and practical tool for nutritional screening. Further research on the association of nutritional status and clinical outcome is being conducted.

- MANAGEMENT OF NEUROGENIC BOWEL DYSFUNCTION IN SPINAL CORD INJURY

Research into the management of neurogenic bowel dysfunction continues apace at the NSIC. Current projects include both international collaborations and a National Institute for Health (NIHR) funded study. We are participating in a study to validate the ISCoS bowel data sets with colleagues in Denmark and Italy. An on-line bowel irrigation research registry is also about to commence. It will initially include study centres in the UK, Denmark and Italy but is planned to expand to include up to 7 European countries. The NIHR funded study will develop a patient reported outcome measure for neurogenic bowel management to be used in research and to evaluate outcomes of care for
individuals with spinal cord injury in the clinical setting. The study will be undertaken in collaboration with two other UK spinal centres and with the International Consultation on Incontinence.

- CARDIOVASCULAR FITNESS IN SPINAL CORD INJURY

Audit into the effectiveness of a “Fitness Class” for newly injured SCI individuals on cardiovascular fitness as part of their rehabilitation program

Cardiovascular disease (CVD) is the major cause of morbidity of both the able bodied and the spinal cord injury (SCI) population, however it appears that individuals with SCI have an increased CVD mortality rate, at an earlier age. This has been attributed to physical inactivity and marked deconditioning among the SCI population. Therefore, within the NSIC, it was decided to introduce a fitness program to run alongside the current rehabilitation program offered. The aim was to introduce the concept of physical exercise early on within an individuals rehab in order to help promote ongoing exercise through the use of a simple program within the home environment after they have been discharged home. The focus of this audit was to evaluate the effectiveness of the fitness class as part of the rehabilitation program for newly injured SCI patients in improving overall fitness. The class comprises of pushing drills, skills and circuits (cardiovascular and strengthening stations) of 1.5 min duration and was ran twice a week for 1 hour.

Heart Rate Reserve (HRR) was then calculated for 11 patients attending the class and used to analyse the effectiveness of individual activities and the overall intensity levels that individuals were working to. HR readings showed that the majority of the activities were only working the individuals at a low intensity (40-50% HRR), with the exception of some of the circuit exercises.
To try to raise HRR within a higher intensity parameter, the current class needs to be adapted to increase exertion and duration of each exercise. It is acknowledged that most of the activities were working the participants to a low intensity; however, they were still raising the individual’s heart rate as well as working on upper limb strengthening, balance and wheelchair skills, all of which are beneficial as part of their rehabilitation. The class provides patients with a basic program which may be continued at home, and increases awareness of ways to reduce secondary disability and illness as a result of SCI.

- **PSYCHOLOGICAL FACTORS IN SPINAL CORD INJURY**

**Psychological Contributions to Functional Outcome after Spinal Cord Injury**

Research in other population groups reports that variables of mood and cognition can explain the variance in FIM, while Kennedy and colleagues (2009) found that appraisals played a significant role in explaining the variance in functional independence in patients with spinal cord injury. Through using standardised assessments of such variables during the early stages of rehabilitation, services may be able to offer additional support and intensive therapies to those individuals identified as at risk of sub-optimal rehabilitation outcomes. The purpose of this study is to provide support to previous findings and to validate the predictive relationship through using a longitudinal design. Patients sustaining a spinal cord injury aged 17 or above were recruited from specialist spinal injuries centres in four European countries, UK, Germany, Switzerland and Ireland. Measures of appraisals, coping strategies, mood and functional independence were administered at 6 weeks, 12 weeks, 1 year and 2 years post injury. Early analysis would seem to support the hypothesis of a
relationship between psychological factors and functional outcomes. Currently, we are awaiting final 2 year data before re-analysing. This study aims to be completed in spring 2010.

- SLEEP HEALTH IN SPINAL CORD INJURY

A prospective, randomised controlled trial of Continuous Positive Airway Pressure (CPAP) for obstructive sleep apnoea after acute quadriplegia: the COSAQ trial

This study has been developed by the Institute for Breathing and Sleep, in Australia and is being conducted across several UK spinal centres, including the NSIC. The purpose of this study is to examine the effect of CPAP therapy for OSA on thinking (especially memory, learning and concentration), quality of life, autonomic problems and breathing in people with acute quadriplegia. Autonomic problems include excessive sweating, a heart rate which is too fast or slow and periods of high blood pressure.

This study is a prospective, multi-national randomised controlled trial of three months of CPAP for OSA after acute quadriplegia. As soon as medically stable, people with acute quadriplegia will undergo a sleep study to screen for OSA. Those with OSA will be trialled on an auto-titrating CPAP for three nights. Subjects who use the device for at least four hours on at least one of these three nights will be randomized to receive CPAP immediately or not for three months. During the three months, the patients will complete a neuropsychological test battery, questionnaires and respiratory function tests. We hypothesise that those randomized to receive nasal CPAP treatment for OSA after acute quadriplegia will have improved neuropsychological functioning, quality of life, respiratory and autonomic functioning compared to those who received usual care alone.
\textbf{LIMB FRACTURES IN SPINAL CORD INJURY}

\textit{Incidence of lower limb fractures in persons with chronic spinal cord injury}

All persons with spinal cord injury (SCI) who are regular wheelchair users develop osteoporosis below the level of SCI and are therefore at risk of pathological lower limb fractures. However, only a relatively small proportion goes on to fracture their legs.

This study was undertaken to establish the incidence of lower limb fractures in people with long standing spinal cord injury and to identify those at highest risk. It will enable development of preventative strategies. In addition the study will identify how long the healing process is and how the fractures are treated. From this the cost of these fractures, both financial and personal, can be estimated.

The data has been collected directly from the patients using a questionnaire because it was not possible to get all necessary information from the medical notes.

It was undertaken in collaboration with the Midlands Centre for Spinal Injuries in Oswestry and was partly funded by the United Kingdom Spinal Cord Injury Research Network (UKSCIRN).

The data is currently being analysed and prepared for publication.

\textbf{PAEDIATRIC SPINAL CORD INJURY}

\textit{Childhood spinal cord lesion: - a longitudinal study of skeletal development}
Thankfully spinal cord injury in childhood is comparatively rare. As a consequence few practitioners have the opportunity to gain substantial experience in this field.

At the NSIC, children have been treated and managed throughout most of its history. We are therefore in the unique position to be able to follow the development of the children into adulthood as well as offer the adolescent a relatively seamless transfer into the adult spinal cord service. In order to maximise this fortuitous situation, a longitudinal follow up of those injured during childhood has been undertaken during the last 20 years. This has been done in accordance with several management protocols that were set up in 1990 following a study of adults who sustained their injury during childhood.

One of the most serious musculoskeletal consequences of spinal cord injury sustained during childhood is the development of spinal curvature. This in turn will lead to increased risk of developing pressure sores, decreased functional ability and decreased cardiopulmonary capacity. If the curve development cannot be halted it may eventually have to be surgically fixated.

The following papers are being prepared for publication.

1. The use of X-rays and photographs to monitor the development of the spinal column in these children is being evaluated and compared, with the aim to reduce the amount of radiation these children are exposed to.

2. The process of developing a neurogenic spinal deformity includes the stages of collapse into the curve (but it can still be straightened out with traction) and a later stiffening of the spine in its curved state. After the stiffening of the spine any surgical correction will be less, proportionally to the stiffness. For the optimal result of the surgery it is therefore important to identify when this stiffening occurs. This is being done by longitudinally monitoring the development of the curvature through a series of x-rays in sitting and lying positions.
3. Previously presented data about the aetiology of non-traumatic spinal cord lesions in children between 1945 and 2000 is being updated by adding the latest decade and prepared for publication.

**WHEELCHAIR PROVISION AFTER SPINAL CORD INJURY**

*Changes in wheelchair provision to people with SCI after the introduction of the voucher scheme*

This is a repeat survey investigating the changes in wheelchair provision in England in the periods before and after the introduction of the voucher scheme, 1991-97 and 1997-2004 respectively. Participants were recruited from all SCIC in England. In total over 1200 took part in the most recent survey. The surveys collected data relating to the types of wheelchairs used at the time of discharge, at the time of the survey and, if different, the reasons for change. Data was also collecting concerning user satisfaction with provision, funding sources and the professionals involved in the assessment process. The data is currently being prepared for publication.

This study was funded by the David Tolkien Award, UKSCIRN and the Buckinghamshire Hospitals NHS Trust.

**UPPER LIMB PRESERVATION FOLLOWING SPINAL CORD INJURY**

*Wheelchair propulsion biodynamics in the first year post-discharge from spinal cord injury centre*
Collaboration with ASPIRE Centre for Disability Sciences at Stanmore. Patients recruited from Stanmore and NSIC. 19 newly discharged patients with SCI were investigated at discharge and followed up at 6 and 12 months post-discharge. Data relating to propulsion biomechanics was collected using an instrumented handrim called the Smartwheel. The participants followed the Smartwheel protocol which involved pushing in a straight line on lino, carpet, up a slope and doing a figure-of-eight track. Data from the newly discharged participants was compared to data from 10 experienced users all >2 years post-discharge. The protocol was carried out in the participants’ own chair as well as in a control chair (Quickie GPV) in usual set-up and optimised set-up. Analysis of data is currently being finalised and prepared for publication.

Shoulder pain in people with SCI <10 years post onset

The participants in a national survey of wheelchair provision to people with spinal cord injury (SCI) were invited to complete the wheelchair user’s shoulder pain index (WUSPI). Of the 1206 respondents, 610 full-time, manual wheelchair users completed the WUSPI. All respondents were < 10 years post-onset of SCI. Of the WUSPI respondents, 62% of paraplegics and 74% of tetraplegics reported shoulder pain in one or more of the 15 variables. A greater proportion of folding frame wheelchair users reported severe pain on pushing for > 10 minutes and pushing up ramps than rigid frame users. Data is currently being prepared for publication.

• SPORT AND RECREATION AFTER SPINAL CORD INJURY

The Impact of participation in the Inter Spinal Unit Games after discharge
The aim of this study was to find out whether people who have had a spinal cord injury are more likely to take up sports after competing in the Inter Spinal Unit Games.

The purpose of this study is to see whether there is a need to put on another Inter Spinal Unit Games Event.

At present the annual event consists of all 12 spinal units bringing up to 8 participants who compete against each unit. Each participant has to have been injured within the last year April-April. This therefore excludes a number of patients who may have been injured in February however are still too weak to take part in such an event. The games provide opportunities for participants to discover the tremendous benefits of leading a healthy lifestyle as well as letting them try a wide variety of sports which include archery, bowls, rugby, athletics, fencing, basketball and tennis.

Wheelpower are a charity helping to support people who partake in wheelchair sports. Wheelpower run the annual Inter Spinal Unit Games and are very keen to find out the results as to whether having a biannual Inter Spinal Unit Games may give many more people a chance to try new sports and take up sports after discharge.

The Inter Spinal Unit Games form an essential part of many patient’s rehabilitation.
If you would like further information on any of the studies outlined in this booklet, or previous research conducted at the National Spinal Injuries Centre, a reference
list can be found by following the ‘publications’ link on the NSIC website at http://www.buckinghamshirehospitals.nhs.uk/spinal.