Finally, we would like to thank all the patients and staff who contributed to this research. The NSIC place an emphasis on research in order to further knowledge about SCI and improve health services. Much research is carried out at the NSIC by professionals from a range of disciplines. If you would like any further information regarding this research please contact the Department of Clinical Psychology at the NSIC.

The **Stoke Mandeville Spinal Foundation** is a foundation established to promote research to improve the quality of living with a spinal cord injury. It hopes to establish a research institute at Stoke Mandeville Hospital to promote clinically relevant research that will address the full range of people's needs following spinal cord injuries. If you are interested in finding out more information or making a donation please write to:

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National Spinal Injuries Centre  
Stoke Mandeville Hospital  
Mandeville Road  
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Spinal Cord Injury Research

By the Department of Clinical Psychology, National Spinal Injuries Centre
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The Department of Clinical Psychology at the National Spinal Injuries Centre (NSIC) has been carrying out research with people with spinal cord injury (SCI) for over 20 years. The main aim of our research is to improve rehabilitation and help support people with SCI through the adjustment process. The following is a brief overview of the research activity over the past year and that which is currently being undertaken.
References:


Perceptions of Gain Following SCI: A Qualitative Approach

As part of this longitudinal research, we asked participants to respond to the question 'what do you think you have gained (since the injury)?'. Many of the answers given to this question relate to a change in perspective, a greater appreciation of life and improvements in relationships with family and friends. Many responded to this question with feelings of an increased awareness of others with disability. The research team continue to collect data and plan to compare the overt responses to this question with the psychological outcome measure of 'Stress Related Growth'.

**Appraisals of Disability: Primary & Secondary Scale (ADAPSS)**

Appraisals are defined as being the process by which people initially evaluate a situation or event. Although there are several well established measures of appraisal used in psychological research, none of these measures specifically targeted themes which were specific to disability. In collaboration with the Oxford Doctoral Course in Clinical Psychology, items were generated from the scale using themes from qualitative research, i.e. personal quotes. This scale was then subjective to rigorous testing to assess its reliability and validity and to look at how individual items were grouped together in themes.

The results of these tests proved successful, and produced a valuable assessment of an individual’s appraisal of disability. The subscales confirmed were 'Growth and Resilience', 'Personal Agency', 'Determined Resolve', 'Fearful Despondency', 'Overwhelming Disbelief' and 'Negative Perceptions of Disability'. The psychology team have produced a short and long form questionnaire measure which will be used as part of the standard assessment. The measure has also been utilised in research looking at the effect of such appraisals on coping, adjustment, and long term psychological wellbeing after SCI.
Scale of Perceived Manageability

The degree to which an individual believes that they have control of a situation is considered to be directly related to their attitude towards the event and their subsequent behavioural response. Similarly, the degree to which a person believes that they are able to manage a stressful event will impact on their ability to cope with the circumstances, and also on the psychological impact on the individual. The psychology team were interested in developing a brief and sensitive measure of 'perceived manageability' which could be used as part of the Needs Assessment Checklist which is used routinely as part of clinical care.

The items which were tested on this scale were “I believe that this situation is manageable”, “I feel that I have learnt the skills to cope with most of the problems that have arisen from the injury”, “I believe that I am able to continue to take part in activities that I find enjoyable and rewarding”, “I feel supported by the people around me” and “I am motivated to engage in what happens to me”. These items were all found to be grouped together on one factor (i.e. measuring the same thing). A sixth item loaded on to a different factor and was therefore removed from the final scale. This scale was also subject to rigorous testing and is now being administered as standard within the 'psychological' section of the Needs Assessment Checklist.
Quality of Life, Appraisals and Coping: One Year On

Following on from earlier research which looked at psychological wellbeing, appraisals and coping across specialist spinal centres across Europe, the psychology team have investigated changes in quality of life (QOL) measures in the first 12 weeks following SCI and looked at how this relates to appraisal measures and social involvement.

Significant improvements in outcome measures were found across the data set within the first 12 weeks following spinal cord injury and changes observed in the appraisals and coping strategies employed. Significant differences were found between participating centres on both outcome measures and in the coping and appraisal processes used, with Switzerland revealed as the most psychologically well adjusted. Coping and appraisal processes at 6 weeks post injury were found to contribute significantly to the variation in psychological wellbeing at 12 weeks post injury, supporting the theoretical structure proposed in the 'Sense of Coherence' research. Employment was found to show significant differences in measures of physical QOL, depression, appraisals of loss and threat and the coping strategy of behavioural disengagement, which supported earlier research in SCI rehabilitation.
Multi-Centre Study of Appraisals and Coping

As mentioned, the research team here at Stoke Mandeville are aware of the need for research to be conducted over time-longitudinally- in order to investigate coping and adjustment across the years. We continue to collaborate with specialist spinal injuries centres in Germany, Sweden, Switzerland, Austria and Ireland in order to facilitate such developments and have recently begun to analyze our data. The developments from these analyses are detailed below.

- **Sense of Coherence and Coping Styles: One Year On**
  
  A sense of coherence (SOC) is defined as a belief of the world being meaningful, manageable and comprehensible, and it has been found to be important to physical health and wellbeing. Recent developments have now implicated SOC as also being important to psychological health, which prompted the research team to look at how SOC may impact on the adjustment process in people with SCI.

  Investigation of the UK sample at 6 weeks, 12 weeks and one year post injury revealed interesting findings. The results suggested a theoretical pathway from SOC at 6 weeks after injury to psychological quality of life at 1 year post injury. This relationship was a result of the type of interpretation of SCI the individual had and the coping strategies they used as a result of these interpretations. Those with a strong SOC interpreted their injury as a challenge, and adopted adaptive coping strategies which led to a higher psychological quality of life. Those with a weak SOC were found to think of their injury as a loss or as a threat, and would use maladaptive coping strategies such as withdrawal and social reliance- these coping strategies led to much lower ratings of psychological wellbeing later on.
Coping and Adjustment: A Literature Review

The psychology department recently conducted a literature review looking at current research findings in coping and adjustment in people with spinal cord injury. This review of international spinal cord injury research confirmed the findings and developments of the Stoke Mandeville psychology team; the importance of appraisals, perceived control and a strong sense of coherence and manageability were integral to healthy adjustment and maintenance of social participation. The review highlighted the need for robust measures which have been specifically tailored to people with spinal cord injury, and the importance of longitudinal research looking at how appraisals and coping strategies may impact on adjustment over long periods of time.
Community Needs in SCI: The first 18 months
The psychology team at the NSIC sent out questionnaires to people who had been discharged in the previous 3-18 months. In addition to assessing psychological wellbeing and life satisfaction, the questionnaires asked about: the degree to which environmental barriers were considered to be a problem; the level of social participation the individual had; the degree to which pain and secondary complications impacted on day-to-day life; the degree to which they were satisfied with their sexual activity; the amount of functional independence the individual had, and also asked questions on how well they felt their needs had been addressed in the community. Open ended questions also addressed issues of delays in equipment, accommodations and adaptations, and what they felt had made transition to community living easier.

The main findings showed community needs to be generally well addressed however psychosocial needs were rated significantly lower than physical. Responses suggested no environmental impact on participation levels however qualitative data highlighted delays in accommodation, adaptations and availability of equipment to interfere with transition to community living. A substantial amount of respondents reported significant impact on independence and activity from secondary conditions and pain. Nearly all the sample reported dissatisfaction with their sexual life and these needs were not well addressed.

The study concluded that societal participation continues to be affected by secondary conditions and pain, while delays in equipment and structural adaptations impact on the transition to community living. Sexual needs and problems remain an issue for the spinal cord injured population and a need which is left unaddressed in the community.
The research team were interested in what relationships the ADAPSS measure would have with psychological and functional outcomes in SCI. In a study of 81 people with SCI living in the community, we looked the relationships between responses on the ADAPSS and responses on measures of participation, functional independence and life satisfaction.

The results found that scores on how people interpreted and responded to their injury were significantly related to all three outcomes. Of most interest to the research group was the amount of impact such psychological factors had on functional outcomes- the scale ‘Negative Interpretations of Disability’ had a significant impact on levels of independence in this sample and was also strongly implicated in participation and life satisfaction scores. The findings suggest that those having a negative perception of physical independence after injury may not be as inclined to participate fully in the rehabilitation programme. This style of responding may lead to sub-optimal outcome and poorer psychological wellbeing- explaining the impact on participation and life satisfaction.