

NSW Office for Science and Medical Research Spinal Exchange Program



Dr Paul Kennedy
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Fellowship Report



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PREFACE

"Knowing is not enough, we must apply. Willing is not enough, we must do" (Goethe)

My 2005 Australian odyssey began with an email in November 2004 from Dr James Middleton, inviting me to apply for the Inaugural Spinal Exchange Visiting Fellowship, established by the New South Wales Ministry for Science and Medical Research. I was awarded the Fellowship and I arrived in Sydney on 1st August 2005.

The objectives of the programme were to facilitate communication on techniques, treatment and therapies that would improve the rehabilitation and quality of life for people with spinal cord injuries and related conditions. The focus to be on rehabilitation rather than acute care, applied research rather than laboratory based research, and intervention techniques. Aided by a very able local team that included James Middleton, Medical Director at the Moorong Spinal Unit, Susie Wilson, Senior Project Officer (MSMR), and Annalisa Dezarnaulds, Clinical Psychologist at the Moorong Spinal Unit, a schedule of workshops, lectures, consultations and visits were arranged. These workshops were held across a variety of hospital and university sites in New South Wales, with the focus being on the Royal Rehabilitation Centre in Sydney. Seminars were given on; psychological aspects of spinal cord injury – adjustment, coping and rehabilitation; pain management after spinal cord injury; the expert patient – a twenty-first century paradigm for the healthcare management of chronic conditions; and psychological aspects of spinal cord injury – childhood onset, self-concept and quality of life.

These seminars and workshops were attended by over 650 people, including nurses, physiotherapists, occupational therapists, psychologists, social workers, medical doctors, user representatives and managers involved in physical rehabilitation in general, and spinal cord injury rehabilitation in particular. This also included consultations with ParaQuad, Spinal Cord Injury Australia and researchers in the rehabilitation studies unit in the RRCS, University of Technology in Sydney, and the University of Sydney.

From a personal point of view, it was an exhilarating and enjoyable visit and I am considerably honoured to have been the first visiting fellow and would like to thank the host team for their support and encouragement which helped to make the visit so successful.

Paul Kennedy
September 2005

Post script

"Knowledge comes, but wisdom lingers" (Tennyson, Locksley Hall)

For too many years the primary focus of rehabilitation has been on physical restoration, giving insufficient attention to psychological adjustment. I believe that this fellowship has been pivotal in highlighting locally the crucial role that psychological interventions should play in rehabilitation. As a very important contemporary influence in the field today, it was a great pleasure to be host to Paul during his fellowship. Paul shared his experience and expertise with us providing a broad range of information, skills and techniques. He stimulated and challenged us all to review our current practices and examine what our services offer and in the process to conceive ways to improve health care models and rehabilitation practices in the future to better engage and empower our clients and their families.

James Middleton
October 2005

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Chapter 1: Executive Summary

1.1 INTRODUCTION

The NSW Government Spinal Exchange Program (SEP) was initiated as an outcome from the Premier's 'Making Connections' Forum in 2003, enabling an internationally renowned clinician, practitioner or clinical researcher to take up a Visiting Fellowship for a period of 1 to 6 months. SEP is run by the New South Wales Ministry for Science and Medical Research, in partnership with the Motor Accidents Authority of NSW, WorkCover NSW and the Rehabilitation Studies Unit, University of Sydney.

Broadly, the strategic objectives of SEP are to facilitate communication on techniques, treatment and therapies that would improve the rehabilitation and quality of life for people with spinal cord injuries and related conditions in NSW. The focus was to be on rehabilitation rather than acute care, applied research rather than laboratory based research, and intervention techniques.

Following his successful application, supported locally by Dr James Middleton and Ms Annalisa Dezarnaulds from the Moorong Spinal Unit, Royal Rehabilitation Centre in Sydney, Dr Paul Kennedy commenced the Inaugural SEP Visiting Fellowship on 1st August 2005. Paul is Reader in Clinical Psychology at the University of Oxford, Academic Director on the Oxford Doctoral Course in Clinical Psychology, and Head of Clinical Psychology at the National Spinal Injuries Centre, Stoke Mandeville Hospital in the United Kingdom. The host organisations for this Fellowship were the Rehabilitation Studies Unit, The University of Sydney and the Royal Rehabilitation Centre in Sydney. Susie Wilson, Senior Project Officer from the NSW Ministry for Science and Medical Research coordinated, administered and project managed the Fellowship.

1.2 PURPOSE, AIMS AND OBJECTIVES

This Fellowship aimed to address three priority areas, namely: 1) General Psychological Support, Understanding and Management; 2) Psychotherapeutic Interventions targeted individually, with patient and staff groups, and the organisation, and 3) Information Exchange, Education, Research and Development.

Key activities were to include the following:

- Review, consult and supervise on methods for treating the psychological needs of people with spinal cord injuries (SCI).
- Train staff on resilience and Coping Effectiveness training programs for people with newly acquired SCI.
- Review and consider inclusion of Coping Effectiveness components into a multidisciplinary Cognitive Behavioural Therapy Pain/Adjustment groups that were currently being developed at the Moorong Spinal Unit.
- Train rehabilitation teams working in SCI and general rehabilitation how to establish, run and review needs assessment and goal planning training programs to increase engagement in rehabilitation, reduce dependency and provide clear evidence-based outcomes.
- Review patient and family information resources on coping, managing depression, anxiety, anger, and chronic pain.
- Share recent research findings on adjustment, psychological predictors of outcome, community needs, coping and cognitive appraisals.

- Establish research network for ongoing collaborative research and research exchange, building upon existing and/or proposed local research projects (eg. self-efficacy, coping and adjustment, chronic pain management).
- Highlight general organisational change issues in relation to service planning, provision and management.
- Participate in Australia and New Zealand Spinal Cord Society (ANZSCoS) meeting on Gold Coast, Queensland from 8-10 September 2005, as Keynote and Workshop Presenter.

1.3 PROCESS

These aims and objectives were achieved using a variety of approaches, including formal programme of seminars, workshops and forums, individual supervision and training, consultation with key stakeholders about current practice models, interventions and portfolio of psychological skills employed in NSW, as well as discussions held with key researchers. Seminars and certain workshops targeted multi-professional groups (Medical, Nursing, Physiotherapy, Occupational Therapy, Case Managers and other service providers) working in spinal cord injury, as well as neurological rehabilitation more generally, whereas others were more specifically targeting clinical psychologists, liaison psychiatrists and social workers. Various non-government agency staff, professional patient representatives and service users were also involved.

Seminars were presented on:

- Psychological Aspects of SCI – Adjustment, Coping and Rehabilitation;
- Pain Management after SCI; and
- The Expert Patient – a Twenty-first Century Paradigm for the Healthcare Management of Chronic Conditions.

The workshop programme included half-day and full-day workshops on:

- Needs Assessment, Goal Planning and Physical Rehabilitation - Putting the Evidence into Practice,
- Coping Effectiveness Training (CET) and Integrating CET into Client Education,
- Challenging Behaviour - Managing Difficult Behaviour in Rehabilitation; and
- Psychological Aspects of Paediatric SCI - Childhood Onset, Self-concept and Quality of Life.

1.4 OUTCOMES

The series of seminars, workshops and forums conducted by Dr Kennedy were attended by over 650 people, including nurses, physiotherapists, occupational therapists, psychologists, social workers, medical rehabilitation specialists, consumers and their representatives, and managers working in adult and paediatric multidisciplinary rehabilitation teams in inpatient, outpatient and community settings.

The participant feedback from this programme was largely positive, indicating that Paul's psychological focus, methods and expertise were considered relevant and extremely valuable. The educational strategies employed were successful in increasing awareness and enhancing understanding of psychological issues, as well as providing practical approaches to implementation of current best practice. The training presented combined theory-practice

perspectives, empirical evidence and professional themes to ensure high applicability and local contextualisation. Several examples of this include:

- ‘Psychological Aspects of Spinal Cord Injury’ seminars enabled a wide variety of staff to have a broader understanding of the psychological impact of injury, the processes of adjustment and methods for enhancing engagement in rehabilitation. Staff attitudes toward disability were also explored.
- The ‘Challenging Behaviour - Managing Difficult Behaviour in Rehabilitation’ workshop proved very popular attracting over 70 participants. In it, Paul explored contextual factors, strategies and real life scenarios to help staff understand why difficult behaviour arises and how to prevent it. He raised awareness of issues and strategies for managing various difficult behaviours, such as client anger and aggression, and sexually inappropriate behaviour in clients.
- ‘Coping Effectiveness Training’ (CET) workshops were targeted more towards clinicians delivering psychosocial interventions, such as clinical psychologists and social workers, in which participants developed practical skills and experience of CET through a variety of training exercises concerning ‘perceived manageability’, ‘changeability’, ‘problem scenarios’ and ‘activity ratings’. To support this educational process, Dr Kennedy provided a range of his resources used at the Stoke Mandeville Spinal Unit in UK, including manuals, handouts, patient information sheets, assessment protocols, relaxation CD, etc (a full list of which appears in Appendix to report). These programmes increase patients’ perceived manageability, self efficacy and social support in the post acute rehabilitation period.

In addition to the more formal programme, Dr Kennedy had opportunities to discuss many clinical issues with a broad range of colleagues and observe the pioneering spinal cord injury pain management programme in Moorong. In particular, he met with local providers of clinical psychology services. Broad organisational themes were reviewed as well as the need to ensure local services accessed the full range of competencies. Paul discussed models of assessment, psychological formulations and approaches to treatment. Practical approaches to service planning, referral management and staff liaison procedures were explored. Multidisciplinary team working, rehabilitation planning, staff training and supervision methods were also examined. In addition to reviewing clinical governance systems, personal and professional development issues were emphasised. It was clear from discussions that rehabilitation care models were quite similar in Australia to the United Kingdom and that the challenges involved in rehabilitating people with acquired physical disabilities were apparent as well. A notable difference which impressed him was the Spinal Outreach services that have been developed over the last couple of years as well as the partnerships with consumer groups in providing post discharge community support.

Over the six weeks of his Fellowship Dr Kennedy conducted a range of consultations and reviews of models of care to assist clinical services and community groups with strategic planning and development of new services, programs and facilities to better meet the needs of people with spinal cord injury in NSW. This included consultations with The Paraplegic and Quadriplegic Association of NSW (Paraquad) and Spinal Cord Injuries Australia (SCIA), the two consumer and advocacy organisations, in which possible new models of care were discussed and how best to incorporate a greater psychological focus into programmes for people with SCI and related conditions living in the community.

The Chief Executive and Senior Managers of the Royal rehabilitation Centre Sydney met Paul to consider their organisational restructuring, models of service delivery and clinical competencies. Paul advised on future models that placed more emphasis on service user involvement, community participation and the expert patient model. He stressed that effective management required processes that ensure transparency, staff involvement and clear community focussed quality of life outcomes. Innovative approaches such as the

Scandinavian Rehabilitation Instructors project which utilised service users as employed team members were also considered.

In addition to the training, clinical consultations and lecture programme, Dr Kennedy had the opportunity to discuss potential future research collaborations with the researchers in the Rehabilitation Studies Unit, University of Technology in Sydney, and the University of Sydney. He also convened a research priorities forum involving NSW based clinicians and researchers and research specialists from the USA and Sweden. The weaknesses in SCI research were reviewed, such as the small sample sizes and the lack of awareness of community needs post-discharge. The group were asked to nominate their top five research priorities and then select one of these as their primary priority. The selected priorities identified by the group included:

- The need for integration between SCI psychosocial research and medical research (i.e. psychosocial therapies should be seen as integral to the physical management of SCI and not as an add on)
- How best to facilitate psychological adjustment following SCI
- The role of psychosocial approaches/research to SCI within the emerging technologies;
- Strategies to increase engagement in psychosocial research
- The need for replication studies of psychosocial research to increase the validity and robustness of the research

Additionally consultations and workshops identified a number of areas of current need and ideas for future collaboration. These included child and family impact of spinal cord injury, longitudinal investigation of cognitive appraisals and psychological adjustment, and community needs post injury and post discharge. He also had the opportunity to advise the Australian Paralympic Committee on ideas for future research, this included a review of methodological approaches, the sharing of research the perceived benefit of being a paralympian.

His visit culminated with keynote address to the Australian and New Zealand Spinal Cord Society on the Gold Coast, Queensland.

1.5 FUTURE DIRECTIONS AND RECOMMENDATIONS

The following recommendations are a result of the feedback from workshops and seminars, the various consultations and in depth review and discussion with Dr James Middleton. Various informal and formal discussions also enlightened these recommendations.

Recommendation One:

Develop enhanced model for psychological support during inpatient rehabilitation and community reintegration phases of management.

Rehabilitation models that involve early psychological intervention and support to engage in goal planning and motivate clients to assume responsibility and control have been shown to facilitate improved adjustment and better adaptive coping.

Strategies to implement this recommendation include:

- Formalise referral guidelines for Psychology and Consultation-Liaison Psychiatry services based on NICE 4-tier model, whereby all health and social care staff have training in recognising psychological need. Some relevant staff can be trained to develop some skills in frontline recognition and basic counselling (eg. listening and hearing), these staff should have access to psychological supervision from a trained practitioner. Accredited staff may assess psychological distress and provide specific

treatment, such as counselling or anxiety management techniques, according to a recognisable and explicit theoretical framework. Trained clinical psychologists and psychiatrists provide expert interventions for those with significant mental health needs.

- Develop clinical markers of psychological vulnerability/maladaptive coping (eg. behavioural and cognitive avoidance).
- Integrate Stress Appraisal model and Coping Effectiveness Training approaches (eg. Dr Kennedy's MY SCI Programme) into inpatient rehabilitation (and community-based outreach) education programmes, with reference to self-management model (by Lorig).
- Review and revise existing Patient Information materials based on resources provided by Dr Kennedy.
- Educate and support all staff to participate in psycho-educational programmes (with use of resources provided by Dr Kennedy such as 'Frequently Asked Questions' and 'Managing Challenging Behaviours').
- Develop protocol for assessment of individual learning styles and a range of different/flexible approaches to adult education.
- Develop strategies for engaging family members to promote positive, yet realistic expectations in client with SCI, and to reinforce the importance of education and assuming responsibility for self-management of SCI or related condition.

Recommendation Two:

Develop new and enhanced Service Delivery models in inpatient, outreach and community-based services.

The health care system is continuing to change with reduced access and length of stays, escalating costs and limited resources challenging service delivery and necessitating creative solutions with a shift of focus into the community to maintain high quality outcomes.

Strategies to implement this recommendation may include:

- Develop Expert Patient model in inpatient, transitional and community-based rehabilitation services.
- Give consideration to the possible employment of 'rehabilitation instructors' with SCI in units, who with appropriate training can harness message by speaking from experience and help to validate/reframe issues for patients and normalise rehabilitation processes. The Stockholm Spinalis Centre employs and trains people with SCI to deliver frontline rehabilitation practice, such as transfer practice and dressing.
- Review approaches to goal planning (with broader focus on resumption of life roles and participation), devising 'Community Needs Assessment' and 'Competencies' Checklists to address key issues in community (eg. ability to direct/self-manage carers, pain management, sexuality, employment).
- Review Multidisciplinary Association of Spinal Cord Injury Professionals (MASCIP) (www.mascip.com) regarding pathways, standards and targets.
- Upskill staff in motivational interviewing and life coaching techniques.
- Continue to develop, evaluate and refine SpinalADAPT Programme.
- Explore new models for enhanced Peer Support and Vocational Rehabilitation /Employment Services in early rehabilitation, in partnership with non-government consumer organisations Paraquad and SCIA.

- Explore use of technology to provide ongoing psychological support after discharge to clients and family members, including online chat rooms, bulletin boards, TeleHealth, etc.

Recommendation Three:

Strategic development of Psychological Services for individuals with SCI and related conditions in NSW.

This Fellowship report emphasises the importance and variety of roles fulfilled by Clinical Psychologists, as well as an enormous potential for growth in their role in inpatient and community settings.

Strategies to implement this recommendation may include:

- Examine workforce issues and develop strategies to increase education, continuing professional development and manage recruitment and retention issues.
- Define staff roles, competencies, education and training requirements.
- Establish a network of clinical psychologists working in adult or paediatric rehabilitation and SCI to provide additional support and increased opportunities for professional development.
- Ensure each staff member has annual appraisal and personal development plans.

Recommendation Four:

Expand current/establish new research collaborations in SCI and related conditions.

Many opportunities to expand current research initiatives and establish new research partnerships arose from individual and group discussions with established clinical researchers and academics. Some priorities for future research in NSW were also highlighted in the Research Forum facilitated by Dr Kennedy during his Fellowship.

Strategies to implement this recommendation include:

- Review feasibility of establishing a clinical research network and/or initiating projects arising from Research Forum, which mapped 'future directions in psychosocial research'.
- Investigate 'impact of SCI on child and family'; a protocol has been developed to be shared with NSW practitioners.
- Collaborate on European Longitudinal 'investigation of cognitive appraisals, coping, impact and adjustment'. This study has ethical approval from Oxford and has started in the UK, shortly to start in Germany, Switzerland and Sweden. Protocol currently being reviewed in RRCS and RSU, Sydney.
- Develop and pilot 'Community Needs Assessment' Checklist, through partnership between Stoke Mandeville and Hunter Rehabilitation SCI Service Newcastle, NSW.
- Collaborate with international spinal cord injury research community in refining and developing common agreed rehabilitation and functional outcome measures.
- Contribute to mutual research strategic development, and the identification of research gaps and integration initiatives.

1.6 CONCLUSIONS

Specialised spinal cord injury units and community services in NSW currently provide a quite comprehensive and co-ordinated approach to the management of SCI, with existing networks and defined practices in place. Models of care are evolving with recent developments in NSW Health such as the State-wide SCI Service and Spinal Outreach Service, as well as recent or proposed changes within the non-government sector consumer organisations Paraquad and SCIA. There remains, however, a continued need to explore and develop new and innovative models of healthcare provision in the twenty-first century and to recognise the critical need for partnership with patients in the delivery of optimum care. Research experience demonstrates that patients are more than recipients of care and they can become key decision makers and be empowered to take responsibility for managing their condition and preventing further morbidity and mortality. There is good evidence that such collaborative approaches to the management of chronic conditions reduces symptom severity, decreases pain and improves self-efficacy, as well as reducing visits to physicians and enhancing mood.

Most importantly, we also need to more effectively integrate into our planning and provision of services bio-psychosocial factors, which give sufficient attention to the context, social supports and personal responses. Psychological research and interventions have grown in significance, status and sophistication in the past 30 years. It is vital to recognise that psychology is not just an add-on, but that psychological factors and awareness should be fundamental to the rehabilitation process from onset of illness to community reintegration.

Dr Kennedy's visit and Fellowship program clearly had a significant impact in terms of increased awareness, knowledge and attitudes of stakeholders and improvements in skill levels of professionals providing rehabilitation, care and support services, as well as consideration and planning for changes in policies/procedures, treatment protocols and practices of services. Another lasting legacy of Paul's Spinal Exchange will be dissemination of a comprehensive resource kit to a wide range of stakeholders (including all Spinal Cord Injury Units in Australia and New Zealand), which will include an educational series set of 5 CDs of key workshop and forum activities recorded during his visit.

All parties involved in this exchange, rather than see it as an event view it as the beginning of a process of collaboration, networking and exchange of research, clinical practice themes and professional liaison. We are grateful for the NSW Ministry for Science and Medical research in making this possible.