

Official Report
2005 Friends Fellowship
Women's and Children's Hospital

Chronic pain, conversion disorder and chronic fatigue syndrome in the United Kingdom

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Acknowledgments

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Katrina Hall, Manager WCH Research Secretariat. Thank you for assisting me in preparing my trip and with the administrative aspects of the fellowship.

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Physiotherapy, WCH. Thank you for your support in undertaking this opportunity.

The Division of Paediatric Medicine for their support through provision of special leave for this trip.

Dr Jon Jureidini. Thank you for help in preparation of the application and continued support in the treatment of patients with unexplained signs and symptoms.

Executive Summary

In February 2005, the author travelled to the United Kingdom to investigate the management of conversion disorder, chronic pain and chronic fatigue syndrome in children and adolescents. This was made possible through the grant of a Women's and Children's Hospital Friends Fellowship which provided \$4670 towards the travel and accommodation required to make the trip possible. The author visited health professionals at the following hospitals : Kings College London (KCL), Great Ormond Street Hospital for Children (GOSH), Birmingham Children's Hospital (BCH), The National Hospital for Rheumatic Diseases in Bath and Nuffield Orthopaedic Hospital in Oxford. An analysis of the treatment principles at each location was made. At each location the author presented on the management approach of the Women's and Children's Hospital that has been published and presented previously at national level. Numerous individual interviews regarding management approaches, research and patient observation was achieved. The author has been able to be involved at a high level in the evaluation of the WCH program for inpatients diagnosed with conversion disorder as a direct result of this opportunity. In addition, presentation will be made at the National Paediatric Physiotherapy Conference in Alice Springs in September 2005.

Introduction

Definitions:

Conversion Disorder

Symptoms affecting voluntary motor or sensory function that suggests a neurological or other medical condition that is not able to be displayed using the normal range of medical examination methods. (Gooch et al 1997)

A discrepancy between signs and symptoms and sensory and motor loss that does not conform to an anatomical or physiological pattern that is recognised. (Brazier 1997)

The primary diagnosis treated in a rehabilitation approach by physiotherapy staff at the WCH is that of children who present with unexplained signs and symptoms or conversion disorder. This patient group is frustrating because management is time consuming, is often not incremental in progress and leaves staff often questioning their role because the pathology is often not organic.

Whilst the author has published and presented on conversion disorder management, there has been little world wide criticism of the WCH approach. Anecdotal reports have suggested that the WCH approach is consistent with other centres in the western world and in many cases is a leader in clinical excellence.

Much of the work that has been done in implementing the WCH approach has been taken from work done by the chronic fatigue syndrome unit at Kings College London. This team were among the first to thoroughly describe the use of graded exercise and activity modification in the treatment of chronic fatigue in children. The WCH have adopted this regime, and modified it for us in children with chronic pain and conversion disorder. Referrals for diagnoses of chronic fatigue syndrome (CFS), chronic pain (CP) and conversion disorder (CD) have steadily increased for physiotherapists at the WCH in the last 5 years. This has been mainly due to an increased awareness amongst hospital referrers of the expertise and provision of a service for these children.

Previous presentations / publications

Calvert P and Jureidini J (2003): Restrained rehabilitation: an approach to children and adolescents with unexplained signs and symptoms. Arch.Dis.Child. 88:399-402.

Presented at the National Paediatric Physiotherapy Conference, Perth, 2003.

September 2004 Panel member : Consultation and Liaison Conference. Adelaide. Treatment of unexplained signs and symptoms in children.

August 2004 “Conversion Disorder Management” Presented to the Physiotherapy staff of Novita Children’s Services

August 2000 Presenter at WCH Grand Round on restrained rehabilitation of patients with conversion disorder.

Birmingham Children's Hospital

The clinical management program at the BCH was very similar to that used at the WCH. Of particular importance was the support and positive patient outcomes achieved using joint physiotherapy and occupational therapy sessions. This allowed a more thorough and consistent direction for patients and families. It also provided for a much more supportive environment for the professionals involved than could be achieved through individual treatments. Unlike the WCH, inpatient management was minimal at the BCH. This was primarily due to funding issues, however the staff felt that outpatient management was clearly successful in their clinic. Psychological involvement was minimal, however staff felt that their success with patients proved that psychological involvement was clearly secondary to a therapy based rehabilitation model in the management of chronic pain and psycho-somatic conditions.

Most patients that were seen in the setting at the BCH were initially seen by a consultant rheumatologist who was very specific about the absence of organic pathology. The staff felt that this was important in focusing the family and limiting the push for further investigations.

In their description of how pain is affected by other aspects of a patient's life, staff use the pain spider diagram. The premise is that pain affects and is affected by all parts of a patient's life. These aspects must be included in a rehabilitation plan to effect long term improvement. Staff also incorporate the use of a vicious cycle pain pathway that shows the individuals symptoms and how increasing periods of inactivity increase them. Staff pick a point along the continuum and then aim to reverse the cycle using rehabilitation.

There is a strong emphasis on school visits to reinforce the values required for effective rehabilitation of the patient. Of note was the importance placed on regular movement, the best example being that of teachers allowing patients a short break and walk in between long lessons.

There was no strong feeling about the need for anaesthetic support by staff at the BCH mainly because of the feeling that it may over legitimise the patient's condition. Video of gait analysis was seen as an important reassessment tool but also to assist patient gait re education.

There was strong agreement with cost effectiveness of a rehabilitation approach. Hydrotherapy was not routinely used as there was no pool on site, however at times the local pool was used. The pool was occasionally used to wean patients from therapists when dependence became an issue.

Kings College Hospital, London (KCL)

This component of my trip was the most keenly anticipated. The work that the KCL Chronic Fatigue Syndrome Unit (CFSU) has produced in the past had encouraged both Jon Jureidini and myself to describe our own approach that was published in the Archives of Disease in Childhood in 2003. This unit are keen advocates and leaders in the research of CFS in both adolescents and adults. Their use of the model of treatment known as cognitive behavioural therapy has proven to be successful in the clinical setting when used by highly trained experts.

The experience that I gained at KCL over the full week that I spent there enabled me to learn more about the way the unit works, speak with the staff in the unit about the current situation at the WCH and discuss specific difficult patients that we had experienced. The WCH coined term of restrained rehabilitation is based around the hierarchy of functional activity that the CFSU has utilised.

Permanent staff were all mental health trained nurses and psychologists led by field expert Professor Trudie Chalder. The unit employs an occupational therapist and physiotherapist part time to assist in their current multi centre trial, the PACE Trial. The PACE Trial involves four tertiary hospitals in the UK and compares outcomes of people with CFS who are randomly assigned to one of three groups : having cognitive behavioural therapy only, graded exercise only and adaptive pacing therapy only. The concept of adaptive pacing or non-incremental pacing is a type of activity modification that moves away from the WCH style of gradual increases in activity and exercise. This approach I feel has great applications for our WCH program. Primarily I feel we should incorporate it for the first two weeks of the patient's admission period where patients where disability is severe. This would allow a non-threatening introduction to rehabilitation, a chance for the development of rapport between patient and therapists and the chance for the patient and family to develop consistency in their daily life.

A meeting that was arranged with Professor Matthew Hotopf was extremely positive. Matthew indicated that the data set that the WCH currently has access to would be a very important addition to the body of knowledge in adolescent conversion disorder. A long term functional follow up of patients treated at the WCH over an 18 month period has been planned and will be presented at the national Paediatric Physiotherapy Conference in Alice Springs in September 2005. Matthew has indicated his willingness to review the WCH research proposal prior to presentation / publication.

The summary of suggestions and management options that could be incorporated by the WCH include:

- The specific guidelines used for exercise prescription. Exercise limits are only increased after 4 days of consistency after the previous levels. At that stage there is only an increase by 20% at a time. It is felt that increases at a faster rate is too quick.
- The use of non-incremental or adaptive pacing in the initial period of a child's inpatient admission.
- The use of the specific exercise tests of the 1 minute sit to stand test, the 2 minute walk test and the timed up and go test. These tests provide a documented and semi functional approach to isolating a child's baseline level.
- The method in which the CFSU utilises the boom / bust or good day / bad day concept. The CFSU advised to use this approach on a daily level. Previously, most WCH cases had been described using the concept on a weekly basis. Being more specific with activity modification on a daily level within a child's program as an inpatient is an area the WCH should focus on further.
- The model of describing CFS and other chronic pain situations utilises an awareness of factors in a patient's life that may not be immediately obvious. These factors are explored in a holistic way and linked into a vicious cycle of fatigue / pain. This way of explanation should be incorporated into the WCH approach.
- The possible use of increased joint initial assessments of new patients between physiotherapists and staff from psychological medicine. It was clear that the CFSU was envious of the multi disciplinary approach that the WCH enjoyed.

Great Ormond St Hospital for Children (GOSH)

My experience at GOSH centred around three professional teams working within the hospital, led by three very impressive professionals.

Susan Maillard is the clinical specialist physiotherapist working within the rheumatology clinic that is responsible for physiotherapy management of patients with chronic pain and conversion disorder. Susan also is involved in an allied health chronic pain clinic that also involves a psychologist and occupational therapist.

Dr Richard Howard is a consultant pain specialist / anaesthetist who leads the chronic pain clinic at GOSH. His team consist of a paediatrician and clinical nurse consultant and is consultative in its approach.

Robyn Hudson is an Australian physiotherapist newly appointed to the role of clinical specialist physiotherapist in chronic fatigue syndrome at GOSH. Robyn had previously worked in a senior capacity at Monash Medical centre in Melbourne. My time with Robyn was brief but involved interview and observation of her team. This approach was very similar to that at the WCH.

Initially, it struck me as very strange that a hospital could foster two chronic pain teams that worked in almost complete isolation, and following quite different management styles. The allied health team seemed very therapy based and lacked guidance on pain relief from an analgesic perspective. The medical team seemed to lack therapy input and advice. Despite this, both teams were extremely knowledgeable and covered the principles of chronic pain management to a very similar level as is done in Australia. Both Susan and Richard were very accommodating with their time and enjoyed the opportunity to discuss management styles as much as I did. Susan has also published on the management of complex regional pain syndrome (CRPS) and reviewed the WCH physiotherapy protocol for rehabilitation of this difficult condition.

The summary of suggestions and management options that could be incorporated by the WCH include:

- A holistic approach including therapy professionals and anaesthetic advice is ideal. Some clinics would argue that anaesthetic advice and consultancy might cause family and patient to focus on the aspect of pain and possibly over legitimise the condition. However a good team is able to recognise these signs and work with them.
- Group session for children with these conditions can be successful. Inpatient management under Susan's care involved gymnasium and hydrotherapy work.
- The use of a hospital hotel or day program for patients can be an extremely cost effective method of treatment. This is especially so for children who do really not need the constant nursing care provided by a rehabilitation bed. At the WCH this is because there is not the same throughput of patients as there is in a large centre like GOSH. However the implications of reducing bed days should be investigated here.
- For the management of CRPS or RSD, it is my belief that physiotherapy staff at the WCH have been comparatively gentle in their rehabilitation approach. Principles of management are consistent between the WCH and GOSH, however a greater emphasis on aggressive increases in Range Of Movement (ROM) in children seems to have greater success. It is also felt that through quicker ROM increases, other changes such as temperature and skin colour can also change more quickly.

The National Hospital for Rheumatic Disease in Bath (NHRD)

Whilst at the Chronic Pain Unit at the bath facility, meetings were arranged with three staff:

Jeremy Gauntlett-Gilbert : Psychologist

Emma Wheatley : Occupational Therapist

Rosie Passington : Physiotherapist

This facility was a very well staffed, very well organised and team orientated centre. A strong psychological approach was the cornerstone, however physical rehabilitation was seen as highly important. The staff were very insistent that their approach was only offered once parents and family had accepted a psychological reason for presenting symptoms. Given that this unit offers the only chronic pain inpatient program in England and often offers the last resort for treatment for families, it is not difficult to see why acceptance is high.

The use of the patient hotel was a feature as was the attitude towards parents. Parents are actively involved in the program from day 1. Staff felt that this gave them the opportunity to positively affect parents' language and behaviour with their children. There is a strong emphasis on self-help and management. Interestingly, staff have shown that the greatest functional improvements in their patients occurred at about 3 months post discharge which implies that their programs focus very much on developing families' abilities to cope with pain and stress. This facility utilised a very rehabilitative model of care with no anaesthetic support. The inpatient program for adolescents runs for three weeks full time.

The summary of suggestions and management options that could be incorporated by the WCH include:

The treatment of patients together with unexplained signs and symptoms may not be detrimental. It has been the view of the WCH that group sessions enable patients to "feed" or mirror other patients symptoms and thus be negative. It has always been thought that these patients were best managed in groups of patients with organic causes for symptoms.

A strong emphasis on joint treatments but particularly assessments. In initial assessment by paediatrician and psychologist, there is strong importance placed on both physical and psychological reasons for symptoms. Both professionals are active listeners and really work hard to promote the image that the program is a holistic and multi disciplinary one – not just a physical rehabilitation focus.

Nuffield Orthopaedic Hospital, Oxford

During my period of observation at Nuffield, I was escorted by Dr Karen Barker, Head of Physiotherapy Services. This observation occurred at the end of my trip and was comparatively shorter than the other placements. I was able to observe and meet staff working in the chronic pain area. The centre predominantly ran program for adults but did offer a small adolescent program. Principles of management were basically identical to those being utilised by the WCH. This centre employs nearly 70 physiotherapy staff and is a specialist orthopaedic centre. Of particular interest was the work being done by advanced scope practitioner physiotherapists in managing back pain. These physiotherapy staff will see all new back pain referrals and have the ability to order any appropriate diagnostic test to assist in diagnosis. In part, referrals to the chronic pain unit come from this initial point. There were no particular management issues that I would suggest for implementation at the WCH

Summary:

This fellowship has allowed me the incredible opportunity to network with, develop contact with and learn from professional staff that would not have been otherwise possible. For example strong research links with Professor Hotopf from KCL, the development of a contact list of expert staff who are prepared to consult on difficult cases and the refinement of treatment principles for WCH staff.

In a general sense, it was discovered that staff at the WCH manage patients with chronic pain, conversion disorder and chronic fatigue syndrome in a similar way with centres in the UK. The primary difficulty here is that our hospital does not see the great number of patients that are seen in these overseas centres, thus we do not have the same opportunity for clinical liaison. The development of a strong team environment, continuing education and a streamlined approach need to continue to be the WCH focus. The creation of a chronic pain clinic comprised of consistent staff may assist this focus. Already there has been the development of a reference group for chronic pain at the WCH, which I have been invited to join from a physiotherapy perspective. This is a positive step in the right direction and is consistent with what is happening overseas.

For each centre that was visited, I have indicated positives that were seen and could be incorporated at the WCH. At present both myself and Dr Prue McEvoy are working on a review of the rehabilitation program for children with unexplained signs and symptoms. This will be done with staff consultation as well as education regarding changes. This process should occur regularly and will help to regain our momentum in managing these difficult diagnoses.

The author would once again like to extend a very sincere thank you to the WCH friends who granted this fellowship.

Fellowship Outcomes

Research and Development

Critical review of inpatient rehabilitation program for children diagnosed with conversion disorder.
Currently being undertaken with Dr Prue McEvoy.

Initial stages of research into the long term functional outcomes of children managed as inpatients at the WCH for conversion disorder. To be presented at the national paediatric Physiotherapy Conference in Alice Springs in September 2005.

Presentations Given

Occupational Therapy, WCH, Tuesday 21st March 2005.
WCH School staff, Wednesday 16th March 2005
Department of Orthopaedic Surgery, WCH, Thursday 24th March 2005.
Orthopaedic Physiotherapy, WCH, Monday 18th April 2005.

Presentations Planned

National Paediatric Physiotherapy Conference, Alice Springs 2005.
Panel member for “Children with unexplained signs and symptoms”
Paper accepted for oral presentation “Chronic pain in adolescents – WCH Friends Fellowship – a UK study tour”

Philip Calvert is currently working as Head of the Orthopaedic Physiotherapy Unit at the Women's and Children's Hospital and as a private practice consultant at Burgan and Duncan Physiotherapy in Adelaide. He graduated with a Masters degree in Physiotherapy in 2001 from the University of South Australia. Philip has presented widely and published on conversion disorder management in children. In 2005 he was appointed as the Women's and Children's Hospital Friends Fellow which has culminated in a study tour of centres in the UK that specialise in the management of conversion disorder, chronic fatigue syndrome and chronic pain.

(Taken from Registration brochure)

Requested talk to the Chronic Fatigue Society of SA. Planned for May 2005.

Australian Physiotherapy Association National Paediatric Group

“WCH Friends Fellowship” on Tuesday 8th October 2005