Foreword: Dr Joachim Stoeber

Head of School & Reader in Psychology School of Psychology, University of Kent

"It's an honour to be part of this multidisciplinary regional symposium on spasticity. I notice a broad based themes and home grown research / audit in the agenda. I'm particularly impressed to see the collaboration between UoK & EKHUFT in adopting an educational and research based approach whilst delivering a clinical service for a complex neurological disorder. The psychosocial implications of movement disorder like spasticity needs careful appraisal, as these are often over-shadowed by the grossly observable motor symptoms. The neglect of psychological well-being post-stroke is a common, though unaddressed, concern in the neuro-rehabilitation community and many would be sympathetic to you highlighting this. With the intention of generating new research collaborations, it would also be instructive to remind clinical staff of the expertise that we have here in the School to assess anxiety, coping and deficits in social communication".

1) Patients with hemi-spatial neglect are more prone to limb spasticity, but this does not prolong their hospital stay

D Wilkinson, M Sakel, S Camp, L Hammond. Arch Phys Med Rehabil 2012.

Abstract

Design:

Retrospective analysis of in-patient medical notes.

Setting:

In-patient neuro-rehabilitation To determine whether stroke patients who suffer from hemi-spatial neglect tend to stay in hospital longer because they are prone to limb spasticity unit of a regional UK teaching hospital

Participants:

All 106 patients admitted to the neuro-rehabilitation unit between 2008-2010 who had suffered a stroke, as confirmed by CT or MRI.

Intervention:

Not applicable.

Main Outcome Measures:

Statistical coincidence of hemi-spatial neglect and spasticity; Length of hospital stay.

Results:

Chi-square analyses indicated that individuals with left neglect were nearly a third more likely to develop spasticity than those without neglect (87% vs. 57%), while nearly one half of those with left-sided spasticity showed neglect (44% vs. 13%). Individuals with neglect stayed in hospital 45 days longer than those without neglect, but the presence/absence of spasticity did not affect length of stay.

Conclusions:

The results provide the first statistical evidence that neglect and limb spasticity tend to co-occur post-stroke, though it is only the former that significantly prolongs stay. Diagnostic value aside, these results are important because they tell us that the treatment of neglect should not be overshadowed by efforts to reduce co-morbid spasticity. Despite its poor prognosis, hemi-spatial neglect continues to receive little targeted therapy in some units.

2) Experience of patients having botulinum toxin therapy for adult spasticity - a qualitative study

Sakel M, Madzokere H, Mackenzie R, Barton J, Jamil A. J Rehabil Med, Supplement no 51, 2011, p67 Manuscript in preparation

Objective:

Despite the increasing use of BT in adult spasticity treatment, only one published satisfaction survey is available. That hinted at lack of correlation with objective rehabilitation outcomes and patient reported satisfactions. Unlike satisfaction survey, a qualitative study may provide the nuances and a rounded appraisal of the context of treatment settings and the impact on patients.

Method:

We formed a research team and a Steering committee, with members from the Local Stroke Association. Research Ethics Committee (10 / H1101 / 13) and Institutional approval (2010/NEURO/01) were obtained. Eligible and consented patients were invited to participate in the group discussion of 3 carers and 3 patients in each session.

We used an open-ended interview to enable respondents to provide flexible responses which reflected their own opinions and expectations without being influenced by assumptions. Further prompting or questioning by the interviewer was based on the responses seeking clarification and probing for details. The group discussion was then transcribed electronically and reflected upon to derived themes. 5 interviews (n=20) over a 6 months period in 2010 produced data saturation and themes.

Results:

7 themes emerged

- Treated as an individual
- Access: to car park & speed of appointment.
- Co-ordinated continuity of care
- Logistics: splints.
- Clarity of information exchange between lay and experts.
- Equitable follow-up.
- Information resources for carers.

Implication & Impact on Rehab service:

The patient experience constitutes a major plank of the quality appraisal of a service. We sought to transform the service by getting the service users involved in the creation of knowledge which will facilitate better designing of the service. A better insight into what aspects of processes contributes to patients' and carers' experience of the service will facilitate that.

References:

.

1) **Sakel M**, Mackenzie R (2009) Patient Satisfaction survey for botulinum toxin therapy in adult spasticity. *Itl J Ther and Rehab* 2009;5:280-8

2) **Sakel M**, Mackenzie R: How patient satisfaction surveys can inform service delivery. International *Journal of Therapy & Rehabilitation , July 2009;7:401.*

3) Botulinum toxin (BT) therapy for adult spasticity- the 1st completed audit cycle

Sakel M, Jamil A, Prasan N, Woolford, J. *Rehabil Med, Supplement no 51, 2011 J P67* Manuscript in preparation

Royal College of Physicians (RCP) (UK) produced Guidelines (2003 & 2009) detailing the Standards of multidisciplinary (MDT) rehabilitation of adult spasticity (AS) using BT. In 2006, an audit was conducted (n=100) against that Standard ¹ which identified certain action points and were implemented. This re-audit analyses the process, outcome and risk of this complex peripatetic service. This comprehensive data focussed on the gaps in the local context as well as the RCP Standards.

Methodolgy:

Retrospective case notes review of data of 70 consecutive patients (2006-9) were analysed, led by a University hospital based Neurorehab Unit.

Results And Discussion:

Demography and case mix remains similar to 1^{st} audit. We noted substantial improvements in defining treatment goals with patients and carers 94% (Cf 68% in the 1^{st} audit). The follow up of patients by therapists 2 weeks & 6 weeks were 54% & 46%. Standardised outcome measurement tools used in 49% cases. Written communication between community physiotherapists and hospital team showed no improvements. Specific gaps identified in the initial audit showed improvement eg documentation of aggravating factors (100%), dilution of BT improved (62%), named therapist was identified pre-injection in 96% (cf 26%) in 1^{st} audit.

Conclusion:

Such complex service requires co-ordinated care plan by MDT from different organisation. The local context needs to be considered whilst trying to implement the RCP Standards. The key gap in such service anywhere in the world is co-ordinating the timely post-injection physiotherapy (PT). Identifying a named PT, a major action plan, was implemented. Poor communication by community & the hospital team may underestimate the actual post-injection PT provided. This project highlights the value of the iterative process of re-auditing to improve services since more gaps will be identified requiring different action plans.

Reference:

Sakel M (2008) An audit of Botulinum toxin therapy services for adult spasticity. *Int. J. Therapy Rehabilitation* 15:15-21

4) Resource utilisation in the management of poststroke spasticity (PSS) in UK patients: baseline data from the BOTOX® Economic Spasticity Trial (BEST)

AB Ward , **M Sakel ,** J Kulkarni , N Haboubi , C Roy , R Prempeh , L Landham , T Aung, M Walsh , M Phillips , N Wright and the BEST study group

Objectives:

To document health resource use by UK PSS patients prior to use of BOTOX® (BoNT-A) in BEST.

Methods:

Adults with focal PSS (n=273) were randomised to BoNT-A+standard care (SC) or placebo+SC for up to 2 treatment cycles, followed by an open-label phase up to 52 weeks. Eligible patients were BoNT-A-naïve, demonstrated preserved function in the limb to be treated, and were considered likely to benefit from intervention. Health resource use for all patients (both treatment arms) during the 12 weeks prior to study baseline are reported.

Results:

A total of 91 patients were randomised in the UK (median time since stroke=21 months). At study entry, 92% were living in their own homes, 39% were retired and 12% were in employment. During the 12 weeks before baseline, 64% of patients had received physiotherapy (mean of 1.7 sessions/week), 19% had received at least 1 session of occupational therapy, and 25% of patients had received physical interventions, e.g. splinting. 24% of patients visited their General Practitioner at least once during the 12-week period prior to baseline. A total of 7 patients required hospitalisation due to their spasticity (mean duration=14 days). Furthermore, 31 patients (34%) were prescribed specialist equipment, e.g. wheelchairs and mattresses. Caregiver support was required by 71 (78%) patients, for a mean of 6 hours/day.

Discussion/Conclusions:

Management of UK PSS patients before entry into BEST required substantial healthcare resources and a substantial level of caregiver support. This indicates a high level of dependence and impaired functioning prior to the study interventions.

5) Using A Goal Attainment Scale In Patients With Post-Stroke Spasticity (Pss): An Analysis Of Goals Set From The Botox® Economic Spasticity Trial (Best)

Borg J., Wissel J., Ward A. B., Ertzgaard P., Herrmann K., Kullander K., **Sakel M.**, Wright N. and the BEST study group

Objectives:

The objective of this analysis was to identify the priorities of PSS patients with respect to improving their functional capabilities, using goal attainment scaling.

Methods:

In the prospective BEST study, adults with focal PSS were randomised to BOTOX® (BoNT-A)+standard care (SC) or placebo+SC over a 52-week study period. Eligibility criteria included patients who were considered likely to benefit from intervention, BoNT-A-naive and demonstrated preserved function in the limb to be treated. We excluded patients with fixed contracture or who did not have PSS. The primary outcome measure was the percentage of patients achieving their principal active functional goal. Patients also set secondary active or passive functional goals.

Results:

The intent-to-treat study population comprised 273 patients. For the principal active functional goal, the majority of patients (55%) chose those associated with walking/mobility (including improvements in speed, distance, gait and climbing stairs). The other most commonly selected principal active functional goals concerned grasping and reaching for objects (18%), the ability to manipulate objects, e.g. cutlery, pens (9%), and dressing/washing themselves (7%). A similar pattern was observed for the selection of secondary active functional goals (n=113): walking/mobility (49%), dressing/washing (5%), hand/finger/arm extension and flexion (12%) and object manipulation (10%). For those patients selecting secondary passive functional goals (n=160), the most common were relief of spasms and/or pain (54%), improved limb positioning/posture and self-image (26%), reductions in nursing/caregiving time (8%) and opportunities to benefit from orthoses (6%). Multiple factors may influence the choice of goals: other impairments or co-morbidities , impact of spasticity, goal negotiation style, coping style, personalities, carer's wishes and the belief system of the clinicians. Patients may prioritise goals that enhance their independence and self esteem.

Implications & impact on rehabilitation medicine:

For patients with PSS, goals set for functional improvements should be sufficiently challenging but appropriate and achievable within their rehabilitation programme.

References:

- 1. Borg J, Ward A, Wissel J, Kulkarni J, **Sakel M** et al. *Rationale and design of the BOTOX® Economic Spasticity Trial (BEST): Evaluating patient outcomes and costs of managing adults with post-stroke focal spasticity. J Rehabil Med. 2011;43:15-22*
- Using a goal attainment scale in post-stroke spasticity- an analysis of goals set from the Botox Spasticity Economic Trial (BEST). Borg J, Wissel J, Ward A, Ertgaard P, Sakel M et al. J Rehabil Med, Supplement no 51, 2011P 64 Manuscript in preparation

6) Neuro-imaging Assessment of Spasticity Developed after Acquired Brain Injuries and Multiple Sclerosis

Bertoni M, Sakel M, Hojattosleslami A, Bertoni I, Ratnarajah N: *Neuroimaging assessment of spasticity developed after acquired brain injuries and multiple sclerosis. Neurorad J 2012, 25:31-37*

Abstract:

This study evaluated whether different imaging techniques correlate with specific variables routinely used to grade the types and complexities of patient conditions in neurorehabilitation services and their clinical outcomes, and if there are radiological patterns, topography or distribution of the lesions correlated to spasticity. The cohort studied included 75 patients, 38 patients with multiple sclerosis (MS) and 37 patients with acquired brain injuries (ABI) referred to the neurorehabilitation department from April 2009 to March 2010. Data included age, gender, diagnoses, complications, spasticity, length of stay, Rehabilitation Complexity Scale (RCS) and Northwick Park Dependency (NPDS) scores on admission and discharge. Forward stepwise multiple regressions were performed considering Spasticity as dependent and considering NPDS. RCS on admission and discharge, age, gender and length of stay as independent variables. Standardized intra-axial lesions in those with spasticity were fused with standardized axial DTIs from normal controls obtained under 3 T and 1.5 T MRI scanners. Spasticity was present in 36 patients. Regression was found between spasticity and all the other variables with r = 0.42, $r^2 = 0.42$ 0.17, adjr2 = 0.12r, F(4,66) = 3.53, p < 0.01. Residuals were acceptable. If the same is calculated excluding MS patients the results are higher with: r = 0.59, $r^2 = 0.35$, $adjr^2 = 0.30$, F(2,27) = 0.307.1885, p < 0.003. In MS subjects, spasticity appeared if lesions affected pyramidal tracts, callosal radiations extensively or brainstem. Those with ABI did develop spasticity if the lesion involved the internal capsules, pericomissural areas, optochiasmatic cistern or brainstem. Findings suggest that NPDSa and discharge and RCSd are higher in those developing spasticity. No obvious correlation between spasticity and RCSa was found. Subjects with MS are more likely to develop spasticity especially if the lesions are numerous and affect the corticospinal tracts, callosal radiations extensively or brainstem. In patients with ABI lesions affecting pyramidal tracts, pericommissural areas and optochiasmatic cisterns seem more likely to develop spasticity