**IBIA Conference Report– 08.03.16.**

**Published 24(7) 1 July 2016: OT News**

I was lucky enough to attend the International Brain Injury Association's Eleventh World Congress 'Brain Injury; from cell to society', in The Hague, from March 2-5th 2016. I was hoping to gain lots of information, inspiration and evidence to inform my practise, and that of the clinicians I support.

The World Congress is the largest gathering of international professionals working in brain injury. Delegates included neuroscientists, neurosurgeons, psychiatrists, neuropsychologists, occupational therapists, speech therapists, rehabilitation physicians, physiotherapists, social workers, nurses, case managers and legal professionals, as well as a number of brain injury survivors.

There were a plethora of poster presentations, alongside demonstrations of new technology used in both specialist equipment and virtual rehabilitation. A mixture of keynote sessions, plenary addresses and multiple abstract summaries were given on the themes of neurotrauma, technology and neurorehabilitation; categorised as basic research, clinical research, public policy, activities and participation. There truly was a wealth of information, 'from coma to community'. I will summarise some of the information I was able to glean during the congress below.

Technology

Demonstrations of technology relevant to formal rehabilitation included the Intendu. I spoke with Sivan Maoz, the OT on the development team in Israel, and she demonstrated the body-controlled video game platform used in cognitive rehabilitation. There are several research references available on the Intendu Ltd website.

Ekso Bionics demonstrated their robotic exoskeleton technology, used to augment mobility in people with limited walking ability, and being used in some centres in the UK who provide neurorehabilitation. Clinical research supporting this technology is available from the Ekso Bionics website.

Anti-gravity walking harnesses were demonstrated as a means to focus on standing, balance and walking in early rehabilitation, and allowing the therapists to focus on the quality and normality of movement patterns, rather than supporting the patient in standing.

A poster presentation outlined the latest evidence in predicting neurobehavioral problems using the Jansari assessment of executive function (JEF); a virtual reality, office based assessment of executive function, developed in recent years by Dr Jansari. A second poster outlined a study using the JEF to evaluate executive problems in ex-offenders and consider possible connections to child hood head injuries.

Management of fatigue and sleep disturbance

Professor Jennie Ponsford, neuropsychologist, spoke about creating an evidence base for effective treatment post TBI. Her research to date shows that fatigue is one

of the most common symptoms following TBI, in both the short and long term. She highlighted the physiological (central and peripheral nervous system) causes of fatigue, and the psychological causes of fatigue following TBI.

She summarised various studies she had undertaken with research colleagues from 2005- 2015. They found no association between fatigue and severity of brain injury, but a strong association between fatigue, and depression and anxiety post injury. A second study found a relationship between impaired attention and information processing, and increased fatigue. Professor Ponsford suggested (and found evidence of when testing blood pressure while completing complex tasks), that this was due to the increased effort in completing tasks when attention and processing capacities are reduced; the ' coping hypothesis' of brain injury related fatigue.

Useful fatigue measures included the Brief Fatigue Inventory, and the Fatigue Severity Scale.

She summarised study findings relating fatigue to endocrine abnormalities, hypothalamic injury and fatigue being caused by sleep disturbance post TBI- but fatigue not having a causal relationship to sleep disturbance itself. The most common types of sleep disturbance post TBI were found to be delayed onset sleep, early wakening and reduced sleep quality.

Treatment suggested, based on research findings to date included a multifaceted assessment approach to: attention, pain and medication, lifestyle management, decreasing information overload, decreasing stress and time pressures, reducing multi-tasking, taking breaks, automatization of tasks to reduce conscious attentional demands, psychological adjustment to these lifestyle changes, sleep hygiene, avoidance of naps, relaxation techniques, pain management, and avoidance of worrying thoughts prior to sleep. It was reassuring to find that all of these techniques are well evidenced and recommended, and are part of the 'toolkit' I already refer to when considering sleep and fatigue post ABI.

Pilot studies are being undertaken into CBT to address sleep disturbance and sleep, the use of melatonin and modafonil in treating sleep disturbance and fatigue, and also bright light therapy.

<u>Post-concussion syndrome and mild TBI</u>

There was an almost overwhelming volume of information and research about this topic.

Nathan D Zasler, a physician and world expert in concussive care from Virginia, highlighted that PPCS (persistent post concussive syndrome) must not be confused with ABI, PTSD, anxiety disorders, or malingering. Clinicians must be aware of the potential of iatrogenic factors in inhibiting recovery (the language we use about recovery, the label we give to mild TBI/concussion, the expected recovery trajectory we outline).

Professor Ponsford spoke about the predictors of PPCS as being a pre-injury history of psychiatric or physical ill-health, concurrent anxiety, life stress, PTSD or pain. She outlined common symptoms as being headaches, dizziness, sleep disturbances, photophobia, fatigue and intolerance to noise.

The takeaway point for me was that as clinicians encountering people who have sustained a concussive injury, or mild TBI, we must take great care in our understanding and treatment of their symptoms, as the approach used has potential to compound their problems and negatively affect recovery. It is imperative that we direct them to a clinician who has the experience to diagnose accurately their condition, and agree a team approach to their treatment.

All speakers highlighted the need for early intervention in mild TBI to elicit the most favourable outcomes. The questions this raised for me are how are this group identified as requiring any intervention at all, and who are they referred to for that intervention? Specialist OTs would be well placed to deliver intervention around strategies and graded return to activity, as well as identifying those individuals whose recovery is not within normal expectations.

Communication and relationships post brain injury

Takeaway themes were around the devastating impact ABI can have on family relationships, the huge challenges and losses experienced as part of that, and the importance of having a professional 'companion' who truly understands this impact, and can help families navigate what lies ahead of them.

Jacinta Douglas presented an emotive piece of research entitled 'nobody wants to know you- the experience of friendship post ABI'. She highlighted global evidence that relationships are the most frequently reported source of meaning in our lives and that lack of relationships has a very strong association with poor health. Her research indicated that loss of relationships is a significant post ABI experience and a risk factor for increased vulnerability, low mood and poor quality of life. She suggested that therapists consider involving existing friends during post ABI rehabilitation, to facilitate preservation of existing relationships where possible though education and engagement.

Driving post ABI

There is an ongoing, global project underway to identify risks to driving ability post ABI and create guidelines for clinicians to use. There is evidence of increased crash rates in drivers who have had a previous TBI, and of multiple crashes for drivers with a previous TBI. There has been a trend identified for under-reporting of patients to the DVLA in the UK, by health professionals. Project results are currently pending.

Paediatric brain injury and social participation

Professor Gary Bedell, OT, spoke about the challenges of measuring children's level of participation post ABI. He outlined several assessment tools; the child and adolescent scale of participation (CASP), the COPM performance measure,

Vineland adaptive behaviour scales (VABS), Child behaviour checklist (CBCL), the participation and environment measure- children and youth (PEM-CY), use of GAS goals, focused observation of measurable behaviours, and focusing on child specific rating scales to measure observable participation. He also advocated focused interviews to identify what is important and desirable to a child, and what hinders or supports that participation, as being the most likely to lead to goal setting and action planning.

Professor Bedell concluded that we need not 'reinvent the wheel' as OTs working with children post ABI. Assessment of the child, family and environment are key, and in choosing a measure we ought to consider using the tool that best matches the child's goals and is feasible to use.

He also outlined his role as part of an MDT research team for 'SPAN', and app based coaching tool for adolescents post TBI. Its focus is on social participation, and includes goal setting, problem solving, and a top down approach to social participation. A usability study has shown that the app is feasible to use, has real life outcomes for users and has been liked by participants. There is more research being undertaken at present.

For further information and resources, he directed us to the website www.canchild.ca- a 'hub for applied clinical and health services research concerning children and youth with a variety of developmental conditions'.

Ethical dilemmas

This session offered insights into the ethical dilemmas faced by clinicians in emergency medicine and acute care of individuals following ABI. How despite the advances in neuroscience and medicine, clinicians simply cannot predict long term outcomes while someone remains in the very acute stages of brain injury. It highlighted the very human and ethical nature of the dilemmas faced by families and professionals in those circumstances, and added weight to the view that the families of brain injured individuals need support to adjust to the traumatic experience they have themselves been through.

Goal setting in brain injury rehabilitation

There was so much information to digest, from so many contexts, I can feedback only themes. The main theme being that engaging people in their own goal setting, rather than imposing therapist or rehabilitation centre directed goals on them is key to engagement and participation. Also the use of timescales with an ABI population as being problematic, which raised the question of whether SMART goals are entirely appropriate for this client group.

One research project used Wrosch et al's model of goal adjustment, and found it applied to an ABI population in terms of the need to adjust to previous life goals having become unattainable. The study highlighted the need for intervention in terms of goal re-engagement i.e. talking about and acknowledging past losses and pre-injury goals being a key component of rehabilitation.

This is just a small proportion of the information which was available at the congress. I came away feeling reassured that much of what I do is in keeping with evidence and current practise on a global scale, enthused about new research into this area of practise, some outcome measures to research further and consider using, and with lots of ideas for research I would like to be involved in myself. I feel very lucky to have attended such an event, and to have the opportunity to present a poster of my own and introduce non OTs to some of the theory grounding our practise.

One rehabilitation physician from the USA said to me 'I love OT's- you're all fantastic at what you do'- and we are, aren't we?

Anita Pascoe, BSc (hons) OT

Clinical support manager, Westcountry Case Management

**note The terms TBI (traumatic brain injury) and ABI (acquired brain injury) have both been used as some research was specific to the specific TBI sub-group of ABI in terms of the subject cohorts.*