Traumatic Brain Injury in New Zealand: A Silent Epidemic?

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"Having a head injury can be a ticket to hell. Fortunately, it may be a return ticket".
Stephen, THINK (The Head Injury Network for Kiwis)

In 2008 I was fortunate enough to be invited to be part of a research team on a large population based project focusing on the incidence and outcome of traumatic brain injury (TBI) in New Zealand (led by Professor Valery Feigin National Institute of Stroke and Applied Neurosciences, AUT University). At the time I knew little about TBI or population based research, but the last five years have changed that. My involvement in the project has led to on-going collaborations and friendships, and continues to provide me with on-going challenges as a researcher. More importantly, however, thanks to those who participated in our research, it has given me an enormous appreciation of the daily challenges faced by those affected by TBI and the desire to do research that ultimately will make a difference for them and other TBI survivors.

The initial population based TBI study (Brain Injury Outcomes New Zealand in the Community; BIONIC), has led to several related projects which focus on genetic influences on outcomes from TBI (led by Professor Robert Kydd, Auckland University); experiences of recovery and adaptation following TBI (led by Professor Kathryn McPherson, AUT University); and the consequences of brain in childhood (COBIC, led by Dr Nicola Starkey, University of Waikato). This article provides a brief overview of TBI, what we already know, followed by details of our current research programme and what we hope to do next.

What is traumatic brain injury? A TBI occurs when there is damage to the brain from an external mechanical force such as a blow to the head, rapid acceleration or deceleration (e.g., in a car crash) or from a penetrating injury (e.g., gunshot). Traumatic brain injuries are classified as mild, moderate or severe, depending on the Glasgow Coma Scale score (level of consciousness), length of post-traumatic amnesia and length of loss of consciousness at the time of injury. Unsurprisingly, moderate and severe TBI survivors develop the most significant disabilities and require the most treatment and rehabilitation. However, even mild injuries can lead to long lasting and persistent problems which often go unrecognised. Mild TBIs account for 95% of all TBIs, while moderate and severe injuries account for 5% cases, (Feigin, et al., 2013). The acute symptoms of mild TBI (including concussion) may include loss of consciousness, headache, vomiting, lethargy, fatigue, dizziness, balance problems, blurred vision, confusion, memory loss, trouble concentrating as well as behavioural and mood changes. More severe injuries may lead to convulsions or seizures, weakness and loss of co-ordination, cognitive problems (e.g., attention, concentration, inhibition, reasoning and planning), sensory processing deficits (e.g., sight, hearing, taste) and behaviour or mental health problems which can include aggression, personality changes, socially inappropriate behaviour, depression and anxiety.

TBI is the leading cause of long-term disability among children and young adults in New Zealand as well as internationally, (Langlois, Rutland-Brown, & Wald, 2006). Those at highest risk are the under 4 year olds, young

people aged 15-25 years and those over 70 years. Rates for males and females are similar until the teenage years, after which the risk of TBI for males is almost twice that of females, probably due to higher levels of risk taking and thrill seeking in young males. There are also significant ethnic inequalities in TBI incidence (New Zealand Guidelines Group, 2006) with Māori and Pacific Island men more likely to be hospitalized for TBI, and Māori women at increased risk compared to Pacific and Pakeha women, (Barker-Colllo, Wilde, & Feigin, 2009).

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Around 60 million people are affected by TBI each year (Feigin, et al., 2013; Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007) and by 2020 it is thought that TBI will become the third largest cause of global disease burden, ("Traumatic brain injury: time to end the silence," 2010). In New Zealand it has been estimated that 20,000-30,000 cases of TBI occur per year, (New Zealand Guidelines Group, 2006) but accurate figures are difficult to obtain as many people do not seek medical treatment. Given the high incidence, the financial cost of TBI is also substantial, with annual direct costs of TBI estimated as over $100M. In 2005, ACC allocated 14.4% of total expenditure and 38.6% of social rehabilitation expenditure to moderate and severe TBI. TBI not only affects the life of the individual with the injury, but also causes emotional distress in family members who take on caregiving roles, often resulting in increased use of tranquilisers, alcohol, and counselling, (Kreutzer, Gervasio, & Camplair, 1994).

Following up cases of moderate to severe TBI is relatively straightforward as the majority of patients are hospitalised. In contrast, most mild TBI cases are not and many don't seek medical attention. However, even mild injuries can lead to long-term difficulties in a significant proportion of individuals, including post-concussion symptoms, (Sotir, 2001) epilepsy, depression, (Jorge & Starkstein, 2005) and cognitive deficits, (Stalnacke, Elgh, & Sojka, 2007). Many people with mild TBI continue to experience concentration difficulties, impulsivity, irritability, and impairments in executive function (e.g., awareness, planning, abstract reasoning) for months, (Deb, Lyons, & Koutzoukis, 1999; Levin, Eisenberg, & Benton, 1989) and sometimes years post-TBI, (O'Shaughnessy, Fowler, & Reid, 1984). In some cases, and particularly with children, the full effects of an injury may not be apparent for some years. Even though TBIs are relatively common, accurate data on the incidence, longer term outcomes and the effects of TBI on the family are scarce.

The overall aim of the first study (the Brain Injury Outcomes New Zealand in the Community study, BIONIC, funded by the Health Research Council) was to provide accurate data on the incidence and outcomes (up to twelve months post-injury) of TBI in a population based sample. To do this we attempted to document every case of TBI in Hamilton and Waikato District (chosen because it has demographic and social characteristics similar to the whole of NZ) over a 12 month period. People sustaining a TBI were identified via the hospital, GPs, schools, rest-homes, prisons and by self-referral. Assessments were carried out at baseline, 1 month, 6 and 12 months post- injury and covered a range of areas, including employment, health service utilisation, medication use, care costs, post-concussion symptoms, health-related quality of life, and cognitive and behavioural functioning (assessed using questionnaires and a computer-administered cognitive test battery). For those who are interested, details of the study methodology can be found in Theadom et al, 2012.

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Over the 12 month period of case ascertainment, we identified 1369 cases of TBI, equivalent to a rate of 790/100,000 people per year (around 36,000 brain injuries each year), which was much higher than previous estimates and greater than rates of stroke and heart attack. The majority of people had a mild TBI (95%), over 70% of cases occurred in those aged under 30 years and over a third did not seek hospital treatment at the time of injury. The rate of TBI for males was nearly twice that of females and Māori had significantly higher rates of TBI compared to Europeans and other ethnic groups, particularly those over 35 years of age. Falls were the most common cause of injury (38%), followed by mechanical forces (i.e., blow to the head, 21%), transport accident (20%) and assault (17%), (Feigin, et al., 2013). We also examined computerised tomography (CT) scans to determine if indices of raised intra-cranial pressure were related to injury severity. CT scans indices were found to share a linear relationship with injury severity , and may be a useful marker of injury severity, even in mild TBI, (Barker-Collo, Starkey, Kahan, Theadom, & Feigin, 2012). We are still analysing the data related to TBI outcomes, but

preliminary analyses indicates that up to 30% of our participants had cognitive deficits 12 months post-injury.

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One aspect of TBI recovery of particular interest is why people with similar injuries have different recovery trajectories. As well as demographic and general health factors, there is accumulating evidence that genetic factors contribute to outcomes after TBI, by modulating the molecular/physiological response of the brain to the acute physical trauma. These secondary processes are responsible for a large amount of the final tissue damage. In addition to directly modulating the response to trauma, genetic variants (and their interaction with environmental factors) may influence other factors related to injury outcomes such as pre-injury health, the likelihood of developing co-morbid conditions and the response to pharmacological treatment. To date, studies conducted in this area have been limited to small sample sizes and findings are somewhat inconclusive. To address this, DNA samples (from saliva) were collected from all consenting participants aged >7 years. Future analysis of these samples will focus on how specific genetic variants relate to the speed and extent of recovery from TBI. As well as providing information about the relationship between specific genetic variants and recovery from trauma, these findings may lead to treatments and rehabilitation options tailored to suit an individual's genetic profile (led by Prof Robert Kydd, Auckland University; funded by the Faculty of Medical and Health Sciences, University of Auckland).

As mentioned earlier, TBI may have enduring effects for the individual and their whānau / family, however for those who have persistent problems and symptoms, we know very little about the strategies that individuals and their families use to adapt to their life after TBI. People with persistent difficulties at 6 months post injury have been invited to take part in longitudinal study (6, 12 and 24 months post-injury) to share their experiences of recovery and adaptation after TBI (led by Prof Kathryn McPherson, AUT University; funded by Health Research Council). We are particularly interested in strategies that people find most useful in living life after TBI, as well as identifying barriers to recovery and adaptation. It is hoped that findings from this study will be used to inform the development of health and support interventions for TBI survivors and their whānau/family in New Zealand.

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As young children and adolescents are at high risk of TBI, their inclusion in the study was particularly important. Until recently, it was thought that the effects of TBI during childhood were less severe than a similar injury sustained during adulthood due to the increased plasticity of the developing brain. In fact, evidence now suggests the opposite, that is, the younger the age at injury, the worse the outcomes from TBI, (Anderson & Yeates, 2010). A TBI during childhood which causes damage to developing brain tissue may disrupt current skills and alter the path of subsequent development, inhibiting the learning of new skills and preventing the attainment of normal developmental milestones, (Anderson, Morse, Catroppa, Haritou & Rosenfield, 2004). Over time impairments in previously acquired skills may diminish, but the development of new skills may be slowed with these deficits only becoming apparent some time after the injury. This suggests that longer term studies of childhood TBI are needed to assess children's current abilities as well as the development of new skills. Funding from a variety of sources (Health Research Council, Lottery Health Research, Waikato Medical Research Foundation, FASS, University of Waikato) has enabled us to carry out a longer term follow up (up to two years post-injury) of the children and adolescents from BIONIC and also to recruit an age-matched TBI free cohort for comparison purposes (the Consequences of Brain Injury in Childhood study, COBIC; led by Dr Nicola Starkey, University of Waikato). As well as finding out how children are doing at home, we have also sought information from teachers to find out more about how the children cope in the more complex school environment. Preliminary findings suggest that twelve months after injury, children with mild TBI (mTBI) are more likely than their non-injured peers to demonstrate symptoms of emotional and behavioural disorders. In addition, levels of overall cognitive functioning and academic performance appear lower and learning disorder rates higher in the mTBI group. Further analysis will hopefully provide some insights into whether pre-existing factors place some children at higher risk of TBI or if these symptoms are a result of the TBI.

Overall, we hope that this research

programme will increase our understanding of TBI and ultimately lead to more effective prevention strategies, better interventions and improved services for individuals with TBI and their families. Our research is not going to stop here; we have applied for funding to examine the longer term (4 years post-injury) outcomes from TBI, with a particular emphasis on the effects of recurrent TBI. Almost a third of the BIONIC participants had experienced a TBI before they became involved in our study and a significant proportion experienced another TBI during the twelve month follow up period.

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Sustaining repeated TBIs can result in symptoms much more severe than would be expected by that injury alone, but little is known about the long term cumulative effects of recurrent TBI. To date the effects of recurrent TBI have focused on specific populations (e.g., high performance sports people) but with recent reports of TBI (particularly recurrent injuries) being linked to increased risk of Parkinson's Disease, Alzheimer's Disease and psychiatric disorders further information from a population based sample would help to inform rehabilitation and preventative campaigns.

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