Visiting Associate Professor Indigenous Research
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He Tapu te Upoko: bringing indigenous knowledge forward

Why traumatic brain injury in tamariki/mokopuna is important and what we can do about preventing it.

Tamariki Ora Conference
Te Taiwhenua o Heretaunga 2014
Cultural observation

• He tapu te upoko
Clinical observation

Neuropsychiatric assessment
Whānau responded positively when I asked and wrote about their cultural beliefs and used these to inform my recommendations
Pūrākau

Tama was a 5 year old tamatatāne when I first met him. He had sustained a severe traumatic brain injury at the age of three months.

Cared for by several whānau members including his grandmother who had passed away resulting in him moving house

Whānau were concerned about his irritability, and angry outbursts

Given his positive response to Kuia and Koroua, karakia, waiata and kapahaka I recommended these elements be included in his daily routine so they would reliably and predictably occur.
Traumatic Brain Injury

Brain injury caused by an external force
Mild (70-90%), moderate (5-10%), severe (5%)

**Mild**: LOC less than 30 minutes, PTA less than one day, GCS 13-15 (if abnormality on CT “complex”)

**Moderate**: LOC more than 30 minutes less than 24 hours, PTA more than 1 less than 7 days, GCS 9-12

**Severe**: LOC more than 24 hours, PTA more than 7 days, GCS 8 or less

Multiple possible effects
Delayed effects, neuroplasticity and vulnerability
Non-accidental TBI most common in under 2 yr olds
Falls, motor vehicle accidents, assault
Increased rates of psychiatric illness
Why does tamariki mokopuna TBI matter?

Māori overrepresented:

BIONIC study: 31% of the study Māori (425), more than one per day (Feigin 2012)

Non-accidental TBI (NATBI) 32.5-38.5/100,000 vs 14.7-19.6/100,000 (Kelly, Farrant 2008),

Head injury age adjusted hospital based incidence 2003/2004 458/100,000 Māori vs 342/100,000 non-Māori (Barker-Collo et al 2009)

Risk of TBI is increased in families facing a higher number of adverse events (McKinley et al 2009)

Māori rates of violent TBI in youth three time those of non-Māori (Feigin et al 2012)
Long term outcomes of mild TBI age 0-5

Mild TBI
70-90% of all TBI

Christchurch Health and Development Study (McKinley 2002, 2008, 2013a)

Cohort of 1265
Inpatient for less than 2 days (diagnosis mTBI)
Compared to outpatient group
Diagnosis of concussion excluded
Follow up at age 14-16

mTBI group
4 times more likely to have ADHD
6 times more likely to have Conduct disorder
3 times more likely to have Substance Abuse Disorder
Anxiety and Mood disorders no significant difference
Diagnoses present other challenges
Follow up at age 16-25

Self report:
Alcohol dependence: 3 times control group
Drug dependence: 3 times control group
5 times more likely to be arrested
More than 3 times property offences
More than 3 times violent offences
Is this an unusual finding?

Look at some other data (McKinley 2013b JHTR)

Compared to audit groups of those with mild and a group with moderate/severe TBI when 0-16 yrs of age, minimum of 5 years post injury

18 years at time of study

Control group with other injury

Comparing IQ, age at injury: no significant difference (mTBI a little younger)
Findings

Offending behaviour: mTBI twice greater than control, mod/severe group 3 times greater
Substance abuse mTBI 2.75 times, moderate/severe 5 times greater
Anxiety mTBI almost 6 times greater, mod/severe almost 5 times greater
Depression mTBI group not significant, mod/severe group 3 times greater
Impact of TBI within whānau

Financial (Nabors 2002)
Role change (Gan and Sullivan 2002)
Social isolation (Jordan and Linden 2013)
Poor mental health (Kreutzer 2009)

Family coping is well recognised as the major determinant of TBI recovery
Mokopuna TBI and School

40% teachers believed no lasting effect (Linden 2013)
60% believed one ABI did not increase risk of second (Linden 2013) risk is three x greater
Impulsivity, ‘mood swings’, hyperactivity, socially disinhibition leads to disadvantage, labelled “trouble makers” (Bennington and Wishart 1999)
Health care system fails to provide educators with information, school vital part of recovery
Long term impact of TBI

Strong argument for prevention
How can we do this?
Multiple approaches

Goals:
Build awareness in our community
Use our community cultural knowledge
Build tools based on mātauranga Māori
Ensure tools can withstand critique from Te Ao Māori and Te Ao Pākehā
Sharing our experience
Tools

- Appropriate: answer the question
- Reliable: can be reproduced
- Valid: measure what they say they measure
- Responsive: sensitive to change
- Precise: there is distinction between scores
- Interpretable
- Acceptable
- Feasible
- Cost and time friendly
Where to start?

Daily observations

Awareness of my limitations

Question arose; why isn’t there a resource available that ensures comprehensive and consistently applied cultural analysis and response to traumatic brain injury?
Rangahau

What do Māori people on marae say about traumatic brain injury in mokopuna?
How can this be used to develop theory?
How can this be used to develop practices in response to mokopuna traumatic brain injury?
Methods

Rangahau Kaupapa Māori
Approval from whānau
Ethics approval
9 Marae, 2 wānanga each
Noho puku
Whanaungatanga
Kaitiakitanga
Transcripts and footage data
Analysis
Participants

People of the marae
Deliberately did not invite those who had direct experience of “rehabilitation”
Did not want the discourse to be dominated by a relative perspective
79 first round
56 second round
7 core ideas

① Wairua is fundamental and attended to as a priority,
② Whānau are the functional unit of healing,
③ Whānau experience the clinical world as an alien culture,
④ Mātauranga Māori has a wealth of resources specific to mokopuna Traumatic Brain injury,
⑤ Māori Identity is about connection,
⑥ Places have an important healing role because they define identity, and
⑦ Other trauma is remembered within whakapapa when Traumatic Brain Injury discussion is invited.
Wairua is fundamental and attended to as a priority

He mea wairua (it’s a wairua thing). He mea wairua nei (this is a wairua thing). Te Mahurehure 1

So immediately it was a process of everybody come together and karakia, ngā karakia tawhito (ancient prayers), ngā karakia inanahi rā (modern prayers). Tapu te Ranga 1
Whānau are the functional unit of healing

The tūroro (the patient), if it’s a child, the mother and the father who ever is the closest involved with the child, that unit is the tūroro (patient). Te Mahurehure 2 p1

Because the whānau, because to get to the child, you got to get the whānau, eh? Owae 2 p1
Whānau experience the clinical world as an alien culture

They are all practitioners in their field, nowhere near to understanding you as a Māori person. Owae 1

So if I was to go to the Hauora, I prefer the Hauora because you know when you talk, when you say, “I’m starting to feel my wairua”, you know they actually understand that. If I was to say that up at the Doctors, they’d say, “What’s this guy on?” sort of thing, you know, they can’t relate to the vocab. Piritahi 1
Mātauranga Māori has a wealth of resources specific to mokopuna traumatic brain injury.

I still rely on my kaupapa tikanga mātauranga Māori taketake (indigenous knowledge and practices) in terms of what I would do with my children. Tapu te Ranga 1

...ka patu te upoko, ka patu te whakapapa (when the head is injured, the genealogical line is injured)’. Araiteuru 1
Māori Identity is about connection

something that I admire about being Māori is working together so that we acknowledge that we all have a piece of the puzzle to contribute, you don’t have to be the everything and that I think helps soothe your wairua too. Araiteuru 1
Places have an important healing role because they define identity

What eponymous ancestor runs through your veins, how your umbilical cord ties to the whenua and where your blood runs through that whenua? Rauru 1

What we talking about today is something so very valuable that in order to understand we need to go back, way back in time, way back into the past, where our people had the ability to attend to these problems of the mind, of the spirit, of the soul, because they lived in the harmony with nature the environment and their atua (gods). Rauru 1
Other trauma is remembered within whakapapa when traumatic brain injury discussion is invited.

trauma of incest, sexual assaults, and the damage that it does to affect the wairua and the shock and effect of those sort of acts on the human brain and the developing brain. 
Owae 1
Theory of wairua injury in mokopuna TBI

- Proposes that TBI also causes an injury to wairua
- A culturally defined injury
- Wairua here is understood as a uniquely Māori profound sense of connection with all elements of the universe
- Injury to wairua leads to a cascade of culturally determined responses
- Whānau have latent cultural resources, held within whakapapa which are relevant to TBI healing
- When mokopuna TBI occurs these are activated
How does mātauranga become activated?
The mātauranga comes to the fore via the practice of whanaungatanga, the action of strengthening connection between people, places and across time.
Whanaungatanga itself is an action of wairua.
This whakapapa mātauranga is contained within Te Reo me ōna tikanga (the Māori language and lore)
The visual, sound and vibrational qualities of these practices have potency in healing the wairua injury
These include: korero, oriori, karakia, waiata, Movement combined with touch and sound; mau rākau,
Visual stimuli; tukutuku, whakairo
Combined with specialised forms of touch; mirimiri, romiromi
In particular places, those related to the whakapapa of the whānau, the potency is enhanced
The whakapapa holds other traumatic events within it’s continuum. These other events are remembered in the context of TBI. The response by the whakapapa is to activate the mātauranga of healing modalities for the current injury, which can also help heal past injuries remembered at this time. How do we know mātauranga is held in whakapapa? Because the mātauranga is shared through being passed down through generations in various ways.
This theoretical position suggests where whānau mātāuranga is accessed and implemented in addressing the wairua injury better outcomes for mokopuna TBI and whānau are predicted
Why do we need Māori theory?

Theory building explains concepts in action (compare to Te Whare Tapa Whā)
Theory invites others to challenge and test it, providing a platform for future research.
Theory also helps us think about what we don’t know.
Does this theory apply to Māori who live on the Western Island (Australia)? On the GC (Gold Coast)?
This theory positions whakaaro Māori alongside other theories from other paradigms used in TBI rehabilitation.
Te Waka Oranga

Bringing the recovery destination to you
A way of working that makes the interface of the two worlds of knowledge clear
Mātauranga is an equal partner with clinical knowledge
Te Waka Oranga is developmentally flexible
The clinical team must enter a Māori space
The leadership is Māori
The process follows that of a waka preparing for a journey, on the journey and arriving at a destination
Four navigational tools, wā, wāhi, tangata, wairua practices
First: Hoe tahi; learning to work together
Second: Te Haerenga; the journey and the arrival
Te Waka Oranga

Who is on board for this journey?
What skills and emotions do they bring?
Where are we going?
How will we know when we have got there?
What will we do when unexpected things happen along the way?
Next phase: developing a tool for front line staff

Te Tai Tokerau Whānau Ora Collective

A cultural needs assessment tool for possible TBI

Informs the approach the whānau needs to be taken

Can be used to monitor to what extent ACC and providers addressed the cultural needs
1. The first thing that needs to happen is for wairua to be attended to
2. If that time is not taken the whole journey of healing is limited
3. Time taken at the beginning is the most important time
4. Clinicians do not take enough time explaining what is going on to whānau
5. Clinicians expect whānau to take up as little of their time as possible
Te Wā

6. I get upset if time is not taken for wairua
7. Time needs to be taken to consider other trauma within whakapapa
8. Taking time to build relationships at the beginning keeps hope alive
9. When the whānau spend more time together this builds healing
10. Times when whānau gather together build healing
Te Wāhi

1. When the places in my pepeha are used the healing process is better
2. Being inside buildings like hospitals and clinics do not give such a good outcome
3. It makes me feel better when we can go to the marae
4. Whakaairo teach important lessons that help with healing
5. Tukutuku panels have important lessons for healing
6. The powhiri process ensures the wairua is settled for quality discussion
7. Eating food from home is an important part of healing
8. Visitors from home provide an essential link with the papa kainga
9. Māori people need to come home to heal
10. Being on the marae is a good place to start to feel strong again
1. When the whānau are involved the healing outcome is better
2. Whānau have to go through their own healing process
3. Within whānau there are a lot of resources
4. Within the whānau is the rongoa, whether we like it or not
5. Whānau fear judgment by professionals
5. Whānau switch off when their hear the word “clinical”
6. Māori are very different from Pākehā
7. Professionals are not trained in the culture of the whānau
8. Clinical staff do not address the wairua part of what is going on
9. In hospital they treat the sickness not the wairua Māori that needs to be treated
10. I call on the strengths of my tupuna to cope
11. Trauma to one is trauma to all
12. Trauma to one is trauma to the whakapapa
13. Being whānau means you don’t have to know everything yourself
14. Being whānau means we can use our collective strengths
Wairua practices

1. Practices that strengthen wairua are just as important as clinical interventions
2. Karakia strengthens wairua
3. The presence of koroua and kuia strengthens wairua
4. The closeness of the whānau strengthens wairua
5. Separating whānau from the patient can damage healing
Wairua practices

6. Te Reo me ōna tikanga is important in maximizing healing of wairua
7. Oriori can be powerful healing tools
8. Mirimiri can be a powerful healing tool
9. Romiromi can be a powerful healing tool
10. It doesn’t matter if you can’t understand Te Reo, the effect remains strong
11. Use of Te Reo Māori means wairua is being strengthened
Limitations of this work?

More than 50% of Māori are connected to marae (*TPK 2010, Stats NZ and MO C and H 2003*)

For those Māori most significantly disconnected from their Māori identity this theory and praxis may have limited application

Possible missing data or bias; methods to counter these include the range of types and locations of marae, role of Rōpū Kaitiaki
Possible applications

This theory and practice could be tested in other situations where Māori face insult to the brain such as neurodegenerative disease, CVA, brain tumours, infection, mental illness and addiction.

There may also be application in psychological trauma.

Stepping stone to further theory building about hauora, rather than injury.
Conclusions

Strong argument for the importance of preventing TBI
First indigenous theory of child and adolescent TBI
Theory underpins the approach
Different from current pediatric TBI rehabilitation paradigm where whānau are assumed to have no salient knowledge about the TBI and professionals knowledge is privileged (Braga 2005, Woods 2011)
Next phase

HRC Eru Pomare Post doctoral Fellowship 2014-2018 for

1. development of a questionnaire-based cultural assessment tool for whānau and frontline staff (Tamariki Ora nurses) concerned about brain function

2. Testing Te Waka Oranga with 5 whānau in the real world

3. Use the process to build awareness about preventing TBI
Ehara taku toa i te toa takitahi, engari he toa takatini kē
Mine is not the strength of one, but the strength of many

http://hdl.handle.net/10179/4065
Rukuhia te Mātauranga ki tōna hōhonutanga me tona whānuitanga.

Pursue knowledge to the greatest depths and its broadest horizons