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Maori and Epilepsy: Personal perceptions of the cause, treatment and consequences of epilepsy by Maori in the Bay of Plenty

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This paper discusses the perceptions of epilepsy held by Maori in the Bay of Plenty. The paper begins by introducing the purpose and rationale of the research. It then moves on to describe the aims and qualitative research methods that were used to collect the data. Finally the paper discusses the findings of the research, this includes: a close look at the unique perceptions of epilepsy that were reported by Maori in the Bay of Plenty; the lack of resources and services available in a small rural town of the Bay of Plenty; the services desired by Maori; attitudes towards medication and the inappropriate behaviour many of the participants experienced by the medical profession.

Question: What do Julius Caesar, Alexander the Great, Napoleon, Socrates Tchaikovsky and Keith Quinn all have in common?

Answer: They all have or had epilepsy.

The purpose of the research

The purpose of this research was to examine how Maori people in the Bay of Plenty perceive epilepsy. Through this, I hoped I might also be able to gain an understanding of how Maori with epilepsy and their whanau cope with epilepsy, what services they utilise and require and what are the key issues for them.

Through this paper I will explain how I arrived at this topic, why I think it is important how I went about researching my topic and finally I will concentrate on what my research found.

What is epilepsy?

Epilepsy is a relatively common but quite complex condition. About 1% of the population have epilepsy, 38,000 people in New Zealand.

Epilepsy takes the form of recurring seizures and these seizures can be controlled to a degree through medication. A seizure is a temporary malfunction of the brain's communication system caused by abnormal electrical discharge of neurons in the brain or, more simply, abnormal brain cell activity.

There are many types of epilepsy however they are usually categorised into two main types: **generalised seizures** where the whole brain is affected by the abnormal brain activity and the person becomes unconscious, and **partial seizures** where only part of the body is affected by the seizure since the abnormal brain activity is localised.

Rationale for the research

I chose to do this research after working as a caregiver. As a caregiver, I heard many stories that inspired, intrigued and saddened me. The stories that saddened me usually involved my client being denied a fair deal, an appropriate service or information that may allow them to progress. These stories inspired me to look further into the services offered to people with disabilities and in particular Maori. I also wanted to narrow my field of disability down and I discovered that there was very little (if any) research on what Maori thought about epilepsy.

I sought to increase the understanding of epilepsy in order to better ensure that Maori with epilepsy are assisted in accessing appropriate information and services. I also wanted to provide a document that would act as a basis for ongoing research into future developments for Maori with epilepsy and their whanau in the Bay of Plenty. I thought this important because there was a lack of literature relating specifically to Maori and Epilepsy.

Beginning with a wide literature search I was only able to find one paragraph that pertained to Maori and epilepsy in a document written by L.K. Gluckman about the medical history of New Zealand prior to 1860. The article specifically addressed “the history of insanity in the Maori”. In 1849 Dr A. Thomson made the following observation:

Epilepsy he believed was rare, never having encountered a medical man or European who had seen a Maori epileptic, nor did he meet a Maori who could describe the disease. There was then a current Maori word for a sickness in which a person falls without obvious cause but this term was commonly used for fainting episodes. He noted the children of natives not uncommonly had convulsions. (Gluckman, 1976, p.229)

So with that sole paragraph to go by I thought surely I could produce something a little more accurate and up-to-date.

Methodology

The questions which guided my research were:

- How do Maori people with epilepsy, their caregivers and other key informants view epilepsy?
- What are the key issues relevant to Maori people with epilepsy?
- How do Maori deal with epilepsy?
- What services Maori people with epilepsy desire or require?
- What traditional and contemporary views of epilepsy were/are held by Maori?

I planned to cover the Bay of Plenty region as a focus area as I have whanau, hapu and iwi connections throughout the Bay of Plenty. It was my intention to provide knowledge that would serve the community justly and would benefit my iwi (c.f. Cram, 1997). However I wanted to maximise participation in my research which meant extending the sample area to include the Paeroa and Waihi.

Qualitative methods of data collection were used for this research. That is, an indepth and

detailed interpretative study was completed. Semi-structured interview schedules were used to conduct face to face interviews with the participants. The interviews took place between May and November 1998 and a snowball technique was used to recruit participants. Nineteen participants were interviewed and these consisted of eight Maori with epilepsy, six caregivers and five key informants. The last group consisted of field officers, a general practitioner and an ex-director of services for the EANZ. Field Officers are employed by branches of the Epilepsy Association of New Zealand to educate the community about epilepsy, provide information about community resources to people with epilepsy and to provide social and psychological support in coping with epilepsy.

The purpose of interviewing key informants was to gather information about how Maori with epilepsy perceive epilepsy and how this might affect their knowledge about epilepsy, the services that are available to them and their treatment. Key informants were also helpful in accessing other participants such as caregivers and Maori people with epilepsy.

The purpose of interviewing Maori with epilepsy was to gain an understanding of how they perceive and cope with their epilepsy, what services and support they have found useful and what services they would see as being useful

Caregivers were interviewed to gain an appreciation of what they cope with when a seizure occurs, how they cope, what support services are useful and most importantly how they perceive epilepsy. How caregivers perceive epilepsy is important to establish as it may provide an indication as to what services they may seek for their child.

Findings

Views of epilepsy: There was a clear distinction between contemporary and traditional views of epilepsy. Traditional beliefs about epilepsy were associated with spiritual events such as breaking tapu.

Participants who viewed epilepsy in a contemporary fashion considered epilepsy to be medical condition.

The traditional views of epilepsy were highlighted by comments such as the following:

My mother had told me it was cos I played with a ouija board. I was playing with a ouija board a few years ago, in 1985 I think, with my mate and neighbour and when I told my mother about it she blamed it on that. When I asked how can other people play and Maori people can't mum? She said 'Oh I don't know'.

Key informants though such views had implications for the services Maori seek and their compliance with the advice given by these services. For example although the person may visit the doctor about their epilepsy they may be reluctant to take their medication correctly, possibly because they did not regard taking their medication as important. This in turn has implications on how well seizures are managed and the overall wellbeing of the person with epilepsy.

Lack of resources and services for Maori: More accessible information was a key issue mentioned by participants. Participants said that health professionals should spend more time with clients explaining epilepsy, the implications of taking medication correctly, and the basic safety issues such as not leaving a person with epilepsy in the bath unattended. One field officer also reported that GP's were not getting information through to Maori people with epilepsy and their whanau and that this was having an impact on whether people took their medication correctly.

One reason why GP's are not getting the information across is that not many are up to date with what is happening in the field of epilepsy. Whereas in better serviced areas, people with epilepsy have access to Neurologists, in the Bay of Plenty they have to rely on poorly informed GP's to explain

what epilepsy is and the implications or having it. Field Officers help fill in the gap, but like most health professionals they are stretched to the limit and Small rural towns like Opotiki tend to feel the stretch the most. Another limiting fact is that GP's have only 15 minute consultations which is insufficient time to discuss fully the client's epilepsy.

The following illustration shows why it is so important to be informed about epilepsy. One participant had told me that their daughter had been diagnosed with epilepsy and it was the kind where her daughter loses consciousness. The doctor had explained a little bit about epilepsy but had failed to give her some basic safety advice. At home one evening the daughter was in the bath and the phone rang so the mother went to answer the telephone. After a while she had noticed that her daughter was not making any noise. The mother went in to check on her and found that she had had a seizure. Luckily she had fallen with her to the side of the bath, rather than straight back, and wasn't seriously hurt, but the failure to tell this mother about leaving her daughter unattended could have easily been fatal.

Services/required and desired: Participants reported that they would like to see more education about epilepsy, the establishment of support groups and the provision of an advocate. Support groups would provide Maori people with epilepsy and their caregivers with the opportunity to meet and share their experiences. Another positive suggestion was the provision of Maori services by Maori on Marae.

Another issue that arose when discussing the services for Maori with epilepsy was the insufficient services being offered in Opotiki. This finding is consistent with those of the Health and Disability Unit, Midland Health (1997) who report that resources are not being allocated to the areas, including the Eastern Bay of Plenty, that most need them.

An implication of this is that Opotiki's small population is unlikely to see an increase in services. But perhaps a realistic short term

solution is to improve the current delivery of services being provided in the Opotiki area. This may be as simple as making regular visits to the area by field officers, or information sharing between the health professional in the Opotiki area.

Medication: Taking medication correctly seemed to be an issue when talking with participants. Half of the participants (including caregivers) had either chosen not to take their medication or were not taking their medication correctly. Of those who had chosen to take themselves off medication only one had stopped having seizures. Others had opted to take themselves off medication as they have absence seizures (where the person appears to “black-out” or “drift off into a day dream”) and do not seem to place as much emphasis on this type of seizure. However taking medication correctly is important to controlling seizures. Being subject to uncontrolled seizures can have a ripple effect. For example unless seizures are controlled one can not obtain a driver’s licence. There are many other psychosocial effects epilepsy can have.

Inappropriate behaviour: Participants frequently mentioned that they had experienced inappropriate behaviour by the medical profession. Many caregivers reported that they had to be assertive with medical staff to either get referrals to specialists or a diagnosis. One participant had reported that a doctor had told her parents that there was nothing wrong with her that she was pretending to be ill and needed a good kick up the backside. This same person was later admitted to a psychiatric ward.

Such inappropriate treatment can lead to a delay in the diagnosis of epilepsy, thus increasing the possibility of the person injuring him or herself during a seizure. Perhaps a minor step in addressing this inappropriate behaviour may be through the provision of education about epilepsy by Field Officers to health professionals.

Conclusion

Through this paper I hope I have clearly illustrated why I chose this topic, the way in which I carried out my research, but most importantly I hope I have given you an indication that it was important to research Maori perceptions of epilepsy in order to better ensure Maori with epilepsy are assisted in accessing appropriate information and services.

References:

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