

Research Report

A Qualitative Investigation of the Impact and Barriers to Use of Antipsychotic Medication by Māori Tangata Whaiora in Aotearoa



*“ My whanau thought that they might catch it
– whanau education is crucial to making a change for us...
because if whanau don't understand, they judge you...
often wrongly ”*



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“you know, you can't even lose your temper in a normal situation, everyone freaks out and rings the crisis team or tells you to take your medication”



Executive Summary

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This research report is the culmination of three discrete stages. The initial stage was to conduct a literature review that examined the current context in which Māori Tangata Whaiora and whanau access and experience antipsychotic medication. The literature review illustrated the unique nature of this research investigation in that none of the literature reviewed directly corresponded with the investigation that was proposed.

The literature review identified that the key considerations in exploring the use and understanding of antipsychotic medication include; understanding of mental illness; societal and community understanding; culture and beliefs; barriers to accessing care; and supports in place to assist individuals and families to cope¹. Consequently, the following two stages of this research inquiry followed these considerations as a framework for investigation and exploration with Māori Tangata whaiora.

The second stage was to develop a unique methodology to meet the research imperative 'to be able to accurately map the experiences and knowledge of Tangata whaiora in the use and adherence to antipsychotic drug use'. The methodology needed to ensure that the research imperative would provide tangible evidence to inform the development of resources for Māori Tangata whaiora and whanau in this area.

The final stage was the application of the research investigation through a series of hui that were held across Aotearoa to elicit the views and experiences of Tangata whaiora and their whanau drawing on the two previous pieces of work as a framework for investigation and analysis.

During the research, two pieces of nationally significant research were released that directly complement the findings of this investigation. The National Health Survey undertaken by the Ministry of Health clearly identified that Māori experience significant issues of discrimination based on ethnicity when accessing health services. Similarly the Epidemiological study into mental health that was released in the last week of this

research project clearly identifies a higher prevalence and disadvantage experienced by Māori in mental health services². These themes were also consistently identified through all of the sample groups. This is of particular significance when considering the language, format and form of educational resources for Māori Tangata whaiora and whanau.

Other issues that were highlighted consistently included the issues of literacy and comprehension. This requires careful consideration in regards to the types of education material that could be developed. There was a consistent theme that identified a general lack of understanding by mental health professionals of the context in which Tangata whaiora live and operate in. This discrimination is furthered by general society including whanau and friends.

¹Literature Review, 2006, Use of Antipsychotic Medication by Maori Tangata Whaiora in Aotearoa

²Te Rau Hinengaro, 2006, Mental Health Prevalence Study, Ministry of Health. Wellington

Context

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WHO (2001) identify that mental disorders can range from mild to severe with specific symptoms and signs. Without intervention mental disorders tend to follow a predictable process. Diagnostic criteria have been internationally standardised and continue to be refined as more is understood (ICD-10, 1998, DSMIV, 1996). This differentiates mental disorders from the normal social distress felt by people in their everyday lives. The cause of mental illnesses is still not fully understood and debate continues between the significance of biological and psychosocial factors (Arben, 1996; Harris, 2001). WHO (2001) suggest that it is not an either/or question but a combination of both. It is clear that illnesses are influenced by a combination of biological, social and psychological factors (WHO, 2001). Mental illness is of huge concern for global health with the World Health Organisation estimating that 450 million individuals suffer from a mental or behavioural disorder at any one time.

In Aotearoa it is estimated that 3% of the population suffer from a severe mental illness, 17% from a moderate disorder and 24% from a mild disorder at any given time (MHC, 1996). For the Māori population these figures are almost doubled with an estimated 6% for severe, 26% for moderate and 32% suffering from a mild disorder (MOH, 2001). Te Rau Hinengaro (2006) conducted by the MOH surveyed 2,595 Māori individuals, and captured the diversity of Māori across a range of demographic, social, economic and cultural indices. Te Rau Hinengaro identified that the prevalence of mental disorders in Māori was 50.7% over their lifetime (before interview), 29.5% in the past 12 months and 18.3% in the previous month. They also identified that the most common 12-month disorders among Māori were anxiety disorders (19.4%), mood disorders (11.4%) and substance use disorders (8.6%). The most common lifetime disorders among Māori were anxiety disorders (31.3%), substance use disorders (26.5%), mood disorders (24.3%) and eating disorders (3.1%). Of Māori with any mental disorder, 29.6% had serious disorders, 42.6% moderate disorders and 27.8% mild disorders. Health care contact increased with severity. Of Māori with serious disorder 47.9% had some contact with health services compared with 25.4% of those with moderate disorder and 15.7% of those with mild disorder.

This research in combination with Te Puni Kokiri's historical data from 1993, which was based on inpatient activity only, illustrated that there are major differences in the way Māori use mental health services. Māori are seen accessing services later and with greater severity at the point of entry and tended to stay for shorter periods of time (MOH, 2003). Admission rates for Alcohol Induced Psychosis and Drug Induced Psychosis for Māori are approximately five times that of Non-Māori .

Diagnostic issues were highlighted with Schizophrenia accounting for 17 % of first admissions and 45 % of readmissions. Readmission rates were significantly higher especially for Māori men, and a third of Māori men were admitted under the Mental Health Act (1992). Māori comprise 50% of inpatients at Forensic Units, Māori have multiple and complex high support needs that include head injury, history of criminality, issues with employment, accommodation, co-existing substance abuse, significant risk issues and issues with primary support (MOH, 2003).

This data suggests that Māori Tangata whaiora experience mental health services differently from the general population. Therefore, the ability to ascertain the experiences and knowledge of Tangata whaiora and whanau on the use and discontinuing use of antipsychotic medication is an essential contribution to understanding how to develop effective resources to increase antipsychotic medication uptake for Māori, to further assist in improving mental health outcomes in Aotearoa.

All of the Tangata whaiora groups that we spoke with were grateful for the opportunity to participate in the research as a way to try and improve the context they experience everyday.

Approach

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Yesterday Today & Tomorrow Ltd. adopted an 'inquiry approach' based on the themes gained from the literature review and described in the Research methodology. The researchers' previous mental health practice experience was utilised to guide the discussions. A discussion guide³ was developed to ensure consistency between hui and ensure that the key themes were investigated with each sample group.

Recruitment of participants for each hui was managed through existing Tangata whaiora/ Consumer Advisor positions and existing Tangata whaiora networks around Aotearoa. The uniqueness of this investigation is reflected in the recruitment process. The core considerations for the sample group were:

- Māori;
- Prescribed or previously prescribed antipsychotic medication;
- Able to articulate their experiences to strangers;
- Have support available to them in the instance that this process may distress them; and
- Willing and able to participate.

These core considerations limited the degree of 'randomness' that the recruitment process was able to produce. Limits on privacy and confidentiality further restricted the researchers from randomly selecting individuals to participate. Utilising the Tangata Whaiora Advisors and existing networks ensured that the recruitment process was undertaken in a safe and considerate manner.

While this approach may have limited the range of participants i.e. it is anticipated most participants will be being seen by the local Māori Mental Health Service, it was agreed that this recruitment approach was the most ethical in the given set of considerations of the participants' situations.

³Refer Appendix One

All of the hui were facilitated using tikanga and kawa (Māori cultural processes) to ensure a safe and culturally relevant environment for Tangata whaiora and whanau. This included providing koha and kai for participants in line with the principles of manaakitanga (active support and hospitality).

METHODOLOGY

'To gain a qualitative evidence base to support the development of resources that will further assist Māori Tangata whaiora and their whanau to increase uptake and adhere to a prescribed treatment regime'.

Four sample groups were facilitated by the researchers. This deviated from the six originally proposed. The deviation was negotiated and agreed on with PHARMAC, the key rationale being the difficulty of co-ordinating hui with Tangata whaiora due to the busy and unpredictable nature of their work. While it reduced the sample number, it did not in the researchers' view reduce the validity or reliability of the qualitative analysis. The consistent themes articulated throughout the four groups reassured the integrity of the analysis and the significance of the themes identified.

| SITE | PARTICIPANT # | DATE |
|--------------------|----------------------|----------------|
| Napier | 9 | 17th May |
| Auckland (central) | 6 | 26th May |
| Auckland (west) | 12 | 1st June |
| Christchurch | 12 | 20th September |

All workshops were one day long and were based on the discussion guide attached as appendix one. This provided for a consistent framework of investigation and analysis, while also providing the opportunity for unique experiences to be discussed.

Findings

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The following section provides an account of the findings from the focus hui held across the country.

Te Maramatanga o te Mate Hinengaro Understanding of Mental Illness in Society

The literature review suggested that the public generally have a poor understanding of mental health disorders and how they impact on a person (Priest et al 1996; Simonds, 2003, Phelan et al 2000; Lauber et al 2004; Lauber et al 2003). This was reaffirmed by the Tangata whaiora interviewed. The discrimination and judgements made by society and communities are ill informed and create significant barriers for Tangata whaiora.

“There should be education for employers, my employer just sacked me, because they didn’t know, and well, I couldn’t explain because I was unwell. Then I got more unwell and then I ended up in the unit”.

“The stigma associated with taking medication is pretty hard, at the chemist we might wait till it is empty before we get our script and asking questions is too much if there are other people in the chemist”.

Whakaaro me ngā Awangawanga a te Mate Hinengaro Attitudes and Perceptions Towards Mental Illness

As suggested by the literature, the participants interviewed identified that they experience a range of stigma and discrimination based on the attitudes and perceptions of society. The lack of understanding in regards to mental illness and the resulting stigma attached to mental illness is still evident in our communities in spite of programmes such as the ‘Like Minds Like Mine’ campaign. Participants identified that this lack of understanding around mental illness was as strong in their whanau as in the wider community. Tangata whaiora identified that often this tension created further barriers between them, their whanau, and their communities.

“A major issue is lack of whanau understanding and also at times the approach that they take to always reminding you about your medication. Sometimes it seems quite condescending and patronising at times bordering on nagging. It also is at times a constant reminder of the fact that you have a mental illness. You can never get away from it. It is so important for whanau and others to remember and understand that mental illness is a very small part of who we are, not all we are”.

“My whanau thought that they might catch it – whanau education is crucial to making a change for us...because if whanau don’t understand, they judge you....often wrongly.”

“The community doesn’t understand and have their own stigma. It’s too hard for us to challenge...it wears you down and then you just don’t want to go out...”

Tangata whaiora described many situations of discrimination both within their whanau context and within the community. The clear theme that emerged from all the focus groups was that any resources developed would have greatest success if they were able to cover key aspects of the community including employers and whanau.

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The second barrier identified was the medication itself. Some of the side effects of the antipsychotic medication are significant. The literature suggested that they are some of the key reasons for discontinuing use, particularly in the first year of drug treatment (Marriott, P. F., et al 1985). Side effects from medication in the first year are referred to as Extrapyramidal Symptoms. Marriot (1985) goes on to identify that these side effects can include such things as; weight gain; dry mouth; loss of libido; impact on sexual functioning; low white blood cell count; Parkinsonism; dystonia; akathisia; and Tardive dyskinesia. Often prescribing will include a range of other medications to assist in managing the side effects, resulting in a 'cocktail' of medications.

"The medication side effects are a huge impact at times on the things that you can do especially from a physical point of view. Feeling sleepy, dozy, drowned out, hungry all the time, putting on weight, dizzy, low energy levels, body slowed, feel run down, shaking, all these things impact on relationships as well and the ability to participate".

"It is important to remember that everyone's experience is different and that my body may react differently to yours. Not all the side effects are that standard and sometimes it feels like no one is listening and that you must be making up what you are experiencing because it's not in the side effect book".

"One of the big issues and one that people don't really talk with us about is our relationships and in that way our sexual relationships the medication impacts on our sexual performance. You lose interest because maybe you are too tired as well. You don't feel things physically in terms of sexual arousal. This creates tension in a relationship and also makes you feel stink. The tension and friction can be a major in the relationship not carrying on all due to the medication. This issue sometimes leads you to go off the medication. It's a biggie".

"I can't get a job because the medications make me drowsy – I'm a health and safety risk they say, this means I'm trapped on a benefit even though I want to work".

The experiences of side effects were described by Tangata whaiora as frustrating and concerning for them and their whanau. A consistent majority throughout the sample groups identified that they did not have the side effects and implications of the medication explained to them in a way that they understood. Participants also identified that the information that was supplied was difficult to understand and if you can't read, you get very little information.

"There wasn't enough information about the pills, it wasn't written down for me and I forgot...because of the medication I was on."

"I don't think that they [psychiatrists] give the full details of the chemical implications – or how to balance those implications with the reactions I might have. Good information would make it much easier to make informed choices about my care. The information that is given I can't understand."

"Information in the pill packets needs to be more simplistic for the patients – I'm not a doctor and I don't understand all the big words, but I want to know what is going into my body".

"I can't read real well, and the nurses talk to you but because of the meds I walk out the door and I've forgotten. I need like a video or something to help me understand and remind me".

“ The College of Psychiatry should share the power of healing with Māori, the place of oranga. Actions speak louder than words, the College could try and see the answers that we have as Māori with our Rongoā and mirimiri wairua, There is enough space for us to all work together ”



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Tikanga me ngā Kawa Culture & Social Considerations

Culture may be defined as the set of beliefs, norms and values that shape the networks in which human interactions take place (Moldavsky, 2004). [With this definition in mind the cultural dynamics between the Māori view of health and the western based medical model are in conflict around the care and treatment of Māori Tangata whaiora and whanau]. Māori definitions and descriptions of health are holistic and whanau centred (Durie, 1998; Cram et al., 2003; MOH, 2003).

“When I go for my appointments they just check my physical me, they don’t look at the other bits that make me whole”.

“It’s real hard when you have physical concerns as well, you gotta go here for this appointment there for that one, and it seems like they don’t even talk to each other, I’ve got to try and work it out – its too hard sometimes”.

The participants interviewed consistently articulated a Māori view of health from a holistic perspective that considered physical, spiritual, mental and family well-being as essential considerations. Te Whare Tapa Wha was discussed in detail at all four hui and emerged as a common model of Māori health that all participants operate from.

“My recovery is about my hinengaro/mind, tinana/body, wairua/spirit and whanau/family, my treatment seems to be only about my tinana with pills and injections”.

Māori health is inclusive of cultural practices and beliefs as fundamental contributions to wellbeing. Key components considered in this are the use of karakia (prayer), tapu (sacred) and noa (common), and mate Māori (Māori illnesses). These considerations and practices have come into conflict with the dominant non-Māori views on health (Simon et al., 2001).

“Since I have been coming to the Te Reo programme, I’ve become more sociable. It gives me a different side to whanaungatanga, and builds a positive sense of self and others”.

The literature suggests that, with the holistic definition base of health, Māori are more sided to the psychosocial aspects of health and wellbeing, the dominant non-Māori ethos is more to the biomedical. This was affirmed by the participants as they discussed their experiences in the different services. The notion of recovery has appeared to further support the psychosocial approach. Participants also articulated the difficulty in communicating with clinical staff, believing they were often misunderstood and judged.

This cross cultural miscommunication has been discussed in the literature and suggests that this has created mistrust and negative perceptions of non-Māori healthcare and professionals (McMurchie, 1984; Durie, 1998; Mertge, 1986; Cram et al., 2003). These perceptions include suspicions about treatment, reluctance to engage in treatment, reluctance to engage with health professionals and the range behaviours that are referred to in the sociological literature as resistance. Participants spoke of these suspicions and the impact that this has on their recovery.

“I was becoming unwell so I rang the crisis team, I was being proactive I thought, next thing there are 3 police cars outside to come and take me away. I guess because I have a history, but that was then and this is now, when this happens you get worried what’s going to happen to you, so you try and do it yourself rather than getting the help”

“A major thing I know happens is our whanau self medicate with marijuana, but people don’t disclose this because they are worried they will get labelled, moved to dual diagnosis or A&D, but they are only using it to manage voices or other things like sleep. It must have an impact on the drugs they are using but they won’t tell anyone and they get sick”.

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Cram et al (2003) suggest that the inclusion of traditional practices in the care and treatment of Māori could significantly increase the participation and engagement of Māori in the health system, particularly paying reference to Rongoā (traditional medicines) and wairua (spiritual considerations). Their findings identify that many Māori believe that generally non-Māori practitioners have little to no understanding of wairua, which many Māori hold pivotal to understanding health and illness as it gives access to the whole person, not just their physical symptoms. As a result non-Māori practitioners are seen as only treating the symptoms rather than what Māori may consider as the cause of the problem or illness.

“Everyone has looked everywhere except the wairua. Here’s a pill for this, here’s a pill for that, what about me. Everyone knows their own wairua”.

In the programme we notice the change between each other – getting to understand the power of whanaungatanga in a real way”.

Significant gains have been seen in Māori mental health service provision and treatment since 1995 when kaupapa Māori⁴ mental health services were formally contracted. Māori models of engagement and intervention such as Te Whare Tapa Wha (Durie, 1994) and Te Wheke (Pere, 1986) have received positive feedback from Māori Tangata whaiora and whanau across the nation.

This has also been reflected by Māori professionals working in the sector (He Ara Ahu Whakamua, 1999). All of the participants interviewed echoed these considerations. They all identified culture as a crucial contribution to their recovery and management of their illness. When their culture was ignored, their recovery processes were ignored creating further difficulty in maintaining a state of wellbeing.

Of particular note was the consistent message presented on Rongoā and how Rongoā should be integrated with the antipsychotic medication. One example was given where this was being supported by the psychiatrist with positive outcomes.

“Our psychiatrist here, he’s real good. He works with our kaumatua to let us have Rongoā and pakeha medication. It works really well for some of us, they should do this everywhere”.

“I want to try other ways to manage my sleep but the alternatives are expensive and I can’t afford them if I don’t sleep then I need to take more of my anti psychotic meds and then that has a big hit on my tinana, and my psychiatrist won’t help me to use Rongoā”.

“The College of Psychiatry should share the power of healing with Māori, the place of oranga. Actions speak louder than words, the College could try and see the answers that we have as Māori with our Rongoā and mirimiri wairua, There is enough space for us to all work together”.

⁴ Kaupapa Maori in this context refers to the provision of care and treatment from a Maori context, core characteristics of which include; the governance and mission of the service is based on a Kaupapa Maori model; the consumers are mostly Maori; the local community supports the service; the kaupapa of the service is consistent with the wider aims and aspirations of Maori development; the service operates using Maori Tikanga, Maori beliefs, values and practices and these are incorporated into the operational aspects of the service, the majority of the staff required are usually Maori – Ministry of Health: Nationwide Mental Health Service Framework – General Requirements 2001;3

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Tau Arai ki te Pūtanga o te Oranga Hinengaro Barriers to Accessing Mental Health Care & Treatment

MOH (2005) identify that good mental health and wellbeing is more than the absence of mental illness or addiction, it is vital to individuals, families and societies. Good health, wellbeing and whānau ora are fundamental contributors to good mental health (MOH, 2005). Addressing barriers to accessing mental health treatment and care have been a government priority since 1996, with the clear rationale that increased access will result in a reduction in prevalence of serious mental illness (MOH, 1996; 2000; 2003; 2005). Participants echoed this notion, however are still waiting for the impact of such strategies to deliver better access. Participants at all four hui identified very similar barriers to accessing care and treatment.

Despite improvements in service provision and overall Māori health status over the last four decades, Māori still tend to access mental health and addiction services at a later stage of illness and with more severe symptoms (MOH, 2005). The participants identified that this in their experience was because of the suspicions and previous 'bad experiences' they had had with the services in the past.

The Ministry of Health (2005) has identified that for many people, the primary health care sector will be their first point of contact with the health system. Participants strongly advocated picking up problems at the earliest possible time and providing the right treatment is essential. Participants openly advocated for the use of the new atypical medications such as risperidone and olanzapine as a first line response, with the hope that this may prevent some problems becoming more severe and enhance recovery for those who are experiencing mental illness for the first time.

A key issue that was discussed in the Auckland sample group referred to the number of individuals who access mental health services through the justice system.

One participant spoke of their experience within the justice system and the lack of expertise and support provided in that system.

"It was three years before I got help for my mental illness, they thought I was just acting mad to get off"

The experience of this participant was that the stigma of having been in the justice system follows you forever, creating an ongoing barrier and 'fear factor' in how services are accessed and delivered to them. Following on from this was the suggestion that Police receive training in dealing with the implications of mental illness and the medication.

It was identified by the Auckland central participants that Police are often used in crisis situations as the Crisis Intervention Team is often too busy to respond. Police often have no understanding of the medication that Tangata whaiora are on and so don't always allow enough access to fluids and quiet places which can increase the acuity of the individual.

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Ngā Mea Tautoko o te Tangata me ngā Whanau Supports to Assist Individuals and Families

An essential contributor to positive mental health outcomes is an effective relationship with those delivering care (MOH, 2001). Failure to achieve an effective relationship can add further difficulty and treatment adherence issues. Communication and transference of information is at the crux of an effective relationship. For Māori this includes knowledge and understanding of those core components that are seen as essential to holistic wellbeing.

The participants discussed the advent of the Recovery Approach actively advocated by the Mental Health Commission, as a useful framework to advocate for the supports that they want and need. In their experience this philosophy has not expanded to include whanau. Caldwell & Jorm (2000) cite research which illustrates that consumers perceive the quality of care to be higher from nurses and case managers than doctors and psychiatrists, and participant experience is in general support of this notion. Some of this however may be linked in the Aotearoa experience to the fact that nurses and case managers have more frequent contact and interaction with Tangata whaiora.

The literature identifies that resentment against mental health professionals can serve as a deterrent to seeking help and intervention (Angermeyer & Matschinger, 1999; Hugo, 2001). Conversely effective relationships increase the potential for positive mental health outcomes (MOH, 2003, Te Roopu Awhiowhio, 2004). A number of participants spoke of the significance of being supported by a Māori mental health service and how being supported by a Māori mental health service made a significant difference in their journey to recovery.

“When I was in mainstream, all they did was check my meds, make sure I was sleeping and eating, at [...] they have got me into mirimiri (therapeutic massage), got my whanau involved with Kapa Haka and that. Much better in Māori Mental Health because they consider all my taha”

Key Themes

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The key themes that emerged through the research process for consideration in the development of educational resources for Māori in regards to antipsychotic medication are:

Multimedia – There are significant literacy issues amongst the Māori mental health population as well as in the general mental health population. Educational resources need to be developed in a range of formats and media to ensure access to the widest possible audience. Suggestions included DVD, Video and simplistic written materials.

Education domains need to include but are not limited to: the demystifying of medication and mental illness; aligning antipsychotic medication to something 'normal' like insulin – you know you need to take it to stay well; attestations from others who have been through mental illness and can talk about the reality from a position of authority; the reality of medication; what happens when you drink alcohol or take other chemical substances into your body when on these types of medicines; practical strategies to manage multiple medications.

Multiple Audiences – the issues of stigma and discrimination are significant for the Māori mental health population. This is particularly so for Māori men. There is a need to consider education resources that assist the community to 'normalise' mental illness. Of particular note audiences for consideration include:

- Police;
- GP's;
- Employers;
- Whanau;
- Pharmacists;
- Mental Health Staff.

Māori in design and delivery – The experiences expressed by Tangata whaiora Māori strongly advocate the unique contributions that culture has made to their recovery. Māori cultural practices have assisted a number of participants to develop a more positive sense of self and others. Any educational resource should be developed within this context for greatest effectiveness. Te Whare Tapa Wha was a consistent framework that was discussed across the sample group and may provide a useful inclusive framework for the basis of resource development.

Tangata Whaiora Focussed – Participants identified that the current resources are more focussed to medical staff than them. All participants actively supported the notion that Tangata Whaiora should be active in assisting to develop educational resources.

Recognition of Rongoā – Rongoā Māori is unique to Aotearoa, it resembles the unique properties of our indigenous flora and has been tested over 500 years. The opportunity to combine Rongoā with antipsychotic medication should be actively supported and encouraged by psychiatrists. Educational resources need to promote this as a treatment option for Tangata whaiora and whanau. Educational resources for psychiatrists should be developed to assist them in understanding the properties contained within traditional Rongoā to forge effective treatment strategies in partnership with Kaumatua.

Complimentary Options – Educational material should discuss and promote where possible the use of other supplements such as vitamins and herbal medicines to support Tangata whaiora in managing their side effects. The cost of some of these complementary options often make them prohibitive to Tangata whaiora. Subsidy options for complementary vitamins and herbal medicines should be explored for Tangata whaiora as part of a public health strategy in mental health.

“I was becoming unwell so I rang the crisis team, I was being proactive I thought, next thing there are 3 police cars outside to come and take me away. I guess because I have a history, but that was then and this is now, when this happens you get worried what’s going to happen to you, so you try and do it yourself rather than getting the help”



Key Themes

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Establishment of an 0800 line – This would be a very useful and practical tool for inquiries and information about medication, side effects, use of alcohol and other chemical substances etc. Participants advocated for this due to the anonymity such a service allows them and therefore enables them to ask ‘risky’ questions that they feel they could not ask their workers for fear of judgement or consequence.

Establishment of a specific Website – The establishment of a specific website with a chat room, information, research and other resources that relate to medication use. This website could also link to other sites that are useful for Tangata whaiora and whanau. Within the website the creation of an interactive program that allows you to ask questions, personalise your details and then look at what medication options you can discuss with your doctor.

CONCLUSION

This research report is the culmination of three discrete stages. The findings and key themes are a representation of views and experiences of Māori Tangata whaiora and their whanau. There is a clear need for educational resources for Māori Tangata whaiora and whanau and, from the experiences expressed, an even clearer need for educational resources for the wider community.

The impact of antipsychotic medication on individuals is significant. These impacts are polarised by the attitudes and perceptions of the community and even by families of Tangata whaiora. Any resources developed must cover these aspects to achieve the goal of improving the uptake and adherence to the prescribed regime.

The use of an inquiry approach proved to be a useful methodology with this sample group. It provided a platform for free and frank discussion within the parameters of the discussion guide. The narrative discourse provided by Tangata whaiora and whanau sample groups across the country provided clear themes and experiences that complemented the findings from the literature review.

As researchers the experiences and views that were shared with us were extremely powerful and illustrate the extreme situations that Māori Tangata whaiora have to deal with. We consider it important that PHARMAC invest in these resources to assist in creating a climate of understanding and information that will improve outcomes for us as a community.

References

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Appendix One

Tangata Whaiora & Family Whanau Discussion Guide

Please note that the outline in the topic guide is indicative of the line of questioning. The sequence and degree of emphasis covered in each hui will depend to an extent on the participants' natural conversational flow and degree of involvement with particular issues.

1. Powhiri/Mihi Whakatau (30 mins) 2. Whakaahuatia/Introduction (10 mins)

- Introductions, (contact details on sheet provided)
- Establishing time expectations, check if time constraints or risk of disruption
- Outline purpose of the research overall, (refer to information sheet) are there any questions of clarification before we start?

Purpose of this interview is to understand Tangata Whaiora perceptions and experiences of :

- Antipsychotic medication
- Social and community beliefs and values on mental illness
- How culture assists in wellbeing
- The triggers and barriers for Tangata whaiora and antipsychotic medication
- The ideal supports and resources from a Tangata whaiora perspective
- Confidentiality and risks of participation

The interview is confidential, your input will not be identified in any reporting or discussion external to the research team (remember to mention that this includes PHARMAC Staff).

- Access to information in the report and feedback of results
- Recording & note taking of the hui
- Check happy to continue to participate, inform of rights to withdraw at any stage

INTERVIEW OUTLINE

Kia Ora, ka mihinui ki a koutou a o koutou koha ki tenei rangahau, hei whakaahuatia nga whakaaro o nga whanau o te motu – no reira ka mihi atu

Thank you for agreeing to be apart of this research examining the use of antipsychotic medication from Tangata whaiora perspective. YTT have adopted an 'inquiry approach' to this research so we will be asking questions that lead us to understand more from your contribution.

This research has come about because PHARMAC are interested in determining insights into what would improve the uptake of antipsychotic medication for Māori Tangata whaiora. With particular interest on what the current barriers in establishing a medication regime and what are the supports that individuals and whanau need for the medication regime to be sustainable.

Presentation of Literature Review – What we have learnt from the books.

All information is treated as confidential (PHARMAC only), with no names of whanau that come into contact with the research.

We anticipate that this hui will take around five hours to conduct. With the final hour being for you to add any further points that you think will be useful in the process of this research.

Do you have any questions?

Kia Ora

Appendix One

Tangata Whaiora & Family Whanau Discussion Guide

INTERVIEW:

Context Questions:

1. Mental Illness: What does it mean for you, your family and your friends. What types of medication do you use to manage your illness?

Check: Beliefs, values stigma, medication, formal informal processes, degree of involvement, participation mechanisms, other participants in the process

2. Social Issues: e.g. How does your community help or hinder your recovery? How does medication impact on your social participation?

Check: Implications of medication on social participation - Degree of involvement - Social barriers, stigma, internalisation of external

3. Culture: Has culture assisted you in managing your recovery? How? Have you been able to use Rongoā as part of you treatment approach.

Check: Participation in cultural institutions. Investigate use of Rongoā, psychiatrist supported, individual decision - complimentary therapies.

4. Barriers: What barriers have you experienced in using antipsychotic medication. Have these stopped you using your medication as prescribed? What would help address some of these barriers in a practical sense?

Check: Side effects, practicality of medication in public situations threats to treatment regime

5. Supports: What supports are included as part of your treatment. What would be useful to help keep to the treatment regime.

Check: What is currently provided as supports, what would be more useful.

Questions;

Thanks for participation, Koha, Where to from here

Karakia Whakamutunga

Appendix Two

Consent and Ethical Issues

This piece of research is an exploration of the current issues faced by Tangata whaiora in adhering to a prescribed treatment of antipsychotic medication. Participation is completely voluntary and is facilitated by key Tangata whaiora contacts nationally.

We will conduct the research to operate under the provisions of the **Code of Marketing and Social Research Practice** of the Market Research Society of New Zealand Incorporated. This covers the range of ethical issues, which are pertinent to the proposed research.

In Section 4, Rules, Subsection B, The Rights of Respondents deals very comprehensively with the issues of Respondents' rights to privacy (Articles 2 and 6); Respondents' rights of anonymity and confidentiality (Articles 5, 7, 8 & 10); and Respondents' rights not to be adversely affected in any way as a result of participating in research (Articles 9 & 12).

Subsection C, The Professional Responsibilities of Researchers deals with the issues of research design and integrity in the conduct, analysis and interpretation of research data.

Subsection D, The Mutual Rights and Responsibilities of Researchers and Clients deals with a range of issues, including storage of research materials and data, which have a bearing on confidentiality.

For any external interviews the researchers will abide by the concept of **informed consent** which has a specific meaning in terms of the Privacy Act 1993, so that where an agency collects personal information from an individual, it has a duty to inform the individual of why the information is being collected, who for, and how it will be used (Principle 3 of the Act). However, there are exemptions from this specifically for research, provided that the information collected from respondents:

- *“will not be used in a form in which the individual concerned is identified; or*
- *will be used for statistical or research purposes, and will not be published in a form that could reasonably be expected to identify the individual concerned”.* (Principle 3, Section 4(b)).

The key tenets of ethically valid informed consent, are:

- disclosure, full information about the research; a statement about procedures in place to ensure respondent anonymity
- understanding, including the opportunity to ask questions
- voluntariness: consent to participate must be free of any coercion or promises of benefits likely to result from participation
- competence:
- consent: either in writing or orally.

Glossary

A Qualitative Investigation of the Impact and Barriers to Use of Antipsychotic Medication by Māori Tangata Whaiora in Aotearoa

| | | | |
|-----------------|--|-------------------|--|
| Aotearoa | <i>literally “Land of the long White Cloud”; Māori name for New Zealand</i> | Te Reo | <i>the Māori language</i> |
| Hinengaro | <i>mind</i> | Te Whare Tapa Whā | <i>a conceptual model put forward by Mason Durie that details the multi-faceted nature of Māori health. Te Whare Tapa Whā refers to four walls of a house, with the four walls representing mind, body, spirit and family.</i> |
| Hui | <i>meeting, gathering, convention</i> | | |
| Kawa | <i>customary protocols and practices</i> | Te Wheke | <i>alternative health model by Rose Pere based on the Octopus and the eight conceptual tentacles that collectively contribute to Māori wellbeing.</i> |
| Kai | <i>food</i> | | |
| Kapa haka | <i>Māori performing arts</i> | Tikanga | <i>Māori customary values and beliefs</i> |
| Koha | <i>gift (often to be reciprocated), contribution</i> | Tinana | <i>the physical body</i> |
| Karakia | <i>chants, prayers or incantations</i> | Rongoā | <i>Māori traditional medicines, healing methods and remedies</i> |
| Manaakitanga | <i>the concept of caring for or entertaining others</i> | Oranga | <i>wellbeing, health</i> |
| Marae | <i>ceremonial courtyard and community centre</i> | Kaumatua/kaumātua | <i>elder or elders</i> |
| Mate Māori | <i>Māori illness and affliction</i> | Pākehā | <i>non-Māori; used predominantly for Europeans or New Zealanders of European descent.</i> |
| Mihi Whakatau | <i>formal speech of welcome and greetings</i> | Wairua | <i>the spirit</i> |
| Mirimiri | <i>traditional healing massage</i> | Whanau | <i>family</i> |
| Noa | <i>a state of balance, neutrality, free from tapu.</i> | Whanaungatanga | <i>the concept of relationships and family</i> |
| Pōwhiri | <i>Māori traditional welcome that includes formal oratory and a feast.</i> | Whanau ora | <i>family health</i> |
| Taha | <i>sides</i> | | |
| Tangata whaiora | <i>those afflicted by Mental Health disorders</i> | | |
| Tapu | <i>a state of sacredness or restriction under Māori religious or superstitious beliefs</i> | | |

“ A major issue is lack of whanau understanding and also at times the approach that they take to always remind you about your medication. Sometimes it seems quite condescending and patronizing, at times bordering on nagging. It also is at times a constant reminder of the fact that you have a mental illness. You can never get away from it. It is so important for whanau and others to remember and understand that mental illness is a very small part of who we are, not all we are ”





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Report prepared for: PHARMAC, October 2006
by YESTERDAY TODAY & TOMORROW LTD.