Wāhine Whaiora:

Māori Women's Experiences of Bipolar Disorder and their Pathways to Recovery

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Abstract

This research examines the unique, lived experiences of wāhine Māori (Māori women) who have been diagnosed with bipolar affective disorder and who are currently living 'well'. Recent literature indicates that Māori present at higher rates than non-Māori with bipolar disorder. However, there is little qualitative information about the nature of their experiences, as well as sparse detail of the impacts that bipolar has on their everyday living.

The purpose of this research is to highlight Māori women's experiences of bipolar disorder from initial presentation and assessment through to diagnosis, treatment and recovery. It focuses on the impact bipolar disorder has on women's relationships with their tamariki (children), whānau (family), and partners, while also exploring social and personal impacts, help-seeking patterns, and stories of recovery.

This research heard the stories of 11 wāhine Māori using a narrative-storying technique to allow wāhine to share their unique experiences as they recalled them. A thematic analysis was then used to identify key themes that depicted their journeys of:

- Illness and symptom presentation;
- Consequences and impacts of bipolar disorder;
- Support and help-seeking; and
- Wellness and recovery.

The intent of this research is to create an awareness of the nature of bipolar disorder as it affects wāhine Māori. It endeavours to expose the experiences they have encountered and their aspirations to be better supported by whānau, and community organisations in their attempts to live active and well lives.

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Ehara taku toa i te toa takitahi, ēngari he toa takitini
Success is not the work of one, but the work of many

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Thesis outline

Chapter One provides a brief introduction to the background and motivations of this study, while also presenting a conceptual frame work in which this research will adopt.

Chapter Two follows on to provide a comprehensive background on the socio-historical positioning in which Māori (and other indigenous peoples) have experienced substantial deprivation through colonisation; while also exposing the extent to which Māori suffer from, and are over-represented in, all negative health statistics.

Chapter Two also sets the context from which to understand bipolar disorder and how it impacts on women as mothers, sisters, daughters, work colleagues, partners, and friends. The final section then shifts the focus to the recovery literature, drawing upon whānau ora to assist in understanding positive pathways for wāhine Māori who have a diagnosis of bipolar disorder.

Chapter Three outlines the overall orientation and process for the conduct of this research, briefly discussing the use of kaupapa Māori methodology and narrative psychology.

Chapter Four presents an analysis of the interviews with wāhine, highlighting key themes and experiences in their life pathways leading up to a diagnosis of bipolar disorder, and their pathways from mental illness through to recovery.

The final *Chapter Five* offers a detailed discussion of the key findings from this study, and also presents key areas within the health care system that need addressing. It also places focus on how wāhine whaiora can be better supported on their pathways from mental illness through to full and optimal wellbeing and recovery.

Chapter One: Introduction

This research takes into account the need to address systemic barriers that occur for Māori, their whānau, and their communities, as well as the need to develop services and solutions responsive to Māori. It also seeks to add value to outcomes for Māori and contribute to recognition of Māori potential. The way in which issues and problems are constructed and discussed heavily influences the type of responses considered appropriate, and overlooks the interconnectedness between factors associated with mental health outcomes (Ball, 2010; Guerra & Bradshaw, 2008).

Improving the system of healthcare requires deep knowledge of the lived experiences of people within, or outside, that particular system (Torrey, Rapp, Van Tosh, McNabb, & Ralph, 2005). Māori, in particular, experience significant and unnecessary disparities of outcome in relation to mental health issues (Oakley-Browne, Wells, & Scott, 2006).

Māori are known to experience a higher burden of mental health and addiction problems compared to non-Māori in the general population (Oakley-Browne et al., 2006). They also hold the highest prevalence rates for bipolar disorder among other ethnic groups in Aotearoa (Baxter, 2008). However, little research has been conducted into the nature of Māori pathways and experiences from illness through to recovery.

Wāhine Māori in particular are a vulnerable population, and as females, are at higher risk of experiencing physical, verbal, and sexual abuse (Curtis, 2005; Hyun, Friedman, & Dunner, 2000; Robertson et al., 2013), stigmatisation and discrimination (Corrigan & Shapiro, 2010). They face the impacts that a mental illness such as bipolar disorder may have on their reproductive functioning, parenting capabilities, and familial and intimate relationships (Marangell, 2008). These factors are important to consider and will be further discussed later in this review.

In endeavouring to identify why this state of affairs exists, this research has been a journey of discoveries, revealing the need to have better pathways

towards support services and treatment developed. It has traversed socio-historical backgrounds, indigenous health and health care and its influences on the Māori population, its impacts on Māori health, codes and assumptions, prevalence of mood-related disorders, and barriers to wellbeing.

Conceptual framework

This research applies a conceptual framework that discards deficit theorising about Māori mental health (Bishop, Berryman, Tiakiwai, & Richardson, 2003; Cunningham, 2011). Deficit-based theories tend to individualise issues, and risk factors are pathologised in terms of the individual and/or family deficiencies and dysfunction, resulting in increased susceptibility to poor outcomes (Bishop et al., 2003).

This research, using a value-added approach, seeks to understand Māori women's experiences of bipolar disorder beyond positioning individual or environmental deficits as primary causes of poor health outcomes and disparities. It briefly traverses the socio-historical positioning in which indigenous peoples have experienced deprivation through colonisation and it's similarly consequential effects on the Māori of New Zealand.

This research also seeks to identify the rights of Māori women to determine their pathways to optimal wellbeing, and includes recognition that individual health and wellbeing is determined within a whānau context.

The whānau ora model (Durie, Cooper, Grennell, Snively, & Tuaine, 2010) will be drawn on to help understand positive pathways for Māori who have a diagnosis of bipolar disorder. The framework is particularly relevant as it considers the interrelated needs of all whānau members and does not focus solely on diagnosis or treatment in isolation from the wider whānau, community, social and political context of Māori lives (Durie et al., 2010; Ihimaera, 2007).

Due to the scarcity of research on Māori women's experiences of mental ill health specifically, the aim of the literature review in chapter two is to explore:

1. Māori (and Indigenous) mental health;
2. Bipolar affective disorder;
3. The impacts and consequences of bipolar disorder;
4. Māori models of wellness, assessment, and treatment; and
5. Pathways to wellness, recovery, and management - utilising the concept of whānau ora.

Chapter Two: Literature Review

Socio-historical background of Māori

Like most indigenous peoples, Māori, the indigenous people of New Zealand, experienced a history of colonisation during which they were exposed to new diseases introduced by the settlers. The population prior to the arrival of European settlers was estimated at approximately 100,000, but Māori experienced significant declines because they had no immunity to these new diseases (New Zealand State Services Commission, 2005). Substantial loss of land to the British military (Ward, 1993), land which sustained traditional ways for Māori, created greater deprivation and alienation from their ancestral kāinga (settlements) (Rochford, 2004), resulting in reduced opportunities where Māori were becoming socially and economically marginalised in their own homeland (Ward, 1993).

As the loss of land became more rapid the Māori population continued to decline, and it was thought that the Māori population would eventually die out (New Zealand State Services Commission, 2005). Today however, New Zealand's current population sits just above 4,000,000 people in total (Statistics NZ, 2013a), and Māori make up approximately 15% of that total population (Mauri Ora Associates, 2006; Statistics NZ, 2013b).

Colonisation, urbanisation and globalisation have forced Māori into situations and contexts that many Māori find foreign (Durie, 1999, 2011; Fulcher, 2001; Walker, 2004). The effects of colonisation also resulted in the loss of language, culture, and the erosion of the whānau unit, which is reflected in the negative health and social statistics Māori are presenting with today (Rochford, 2004).

Self-determination has thus become a rightful aspiration for Māori and still continues to be sought after today (O'Sullivan, 2001). The Treaty of Waitangi is New Zealand's founding document that offers guidelines for working with Māori in a culturally sensitive way within a cultural context, as Kingi (2007) stated: "the Treaty was centred around a desire to promote and protect

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Māori health" (p. 4). The Treaty is an agreement between Māori and the British Crown signed in 1840 which affirms Māori rights in New Zealand (Kingi, 2007). It signifies the Crown's commitment to the wellbeing of Māori, and the goal of achieving optimal health outcomes (Hartnoll, 2003; Herbert, 2002; Kingi, 2007; Mauri Ora Associates, 2006; Orange, 1987; Ward, 1993). Through understanding the historical and social factors that contribute to the poor health statistics Māori are presenting with today, ways of approaching and helping Māori can be better understood and developed.

Indigenous health

The health of a population is inextricably linked to their wellbeing as a whole (Durie, 1994, 2001; Dye, Rossouw, & Pacheco, 2012; Herbert, 2002). Indigenous populations tend to be most at-risk of developing mental health disorders (Cohen, 1999) as a result of suffering from issues such as colonisation, marginalisation, and deprivation (Herbert, 2002). The powerful effects of colonisation have alienated indigenous people from their traditional ways of living, and have adversely affected their "physical, social, emotional, and mental health and wellbeing" within their own traditional societies (Gracey & King, 2009, p. 65). The socio-cultural histories of indigenous people when not addressed effectively can lead to health issues and social problems, inadvertently increasing the use of drugs and alcohol to self-medicate in order to ease the plight in which they find themselves.

Indigenous people are at a disadvantage in many everyday situations such as employment, education, income, poor housing, and much more, which plays a significant role in determining their poor health status (Gracey & King, 2009; Marmot, 2005; Ministry of Social Development, 2010). However, there are similar occurrences of mental disorders across indigenous populations, and they also tend to experience similar barriers to overcoming their health conditions, and finding pathways to wellness. This may be a reflection of the inability of mental health agencies to understand the realities faced by indigenous people (Herbert, 2002), or perhaps the lack of concern from policy makers in all sectors to address social determinants of health status (Marmot, 2005).

In spite of these negative influences, many indigenous peoples are seen as a resilient and determined sector of society today. Many are involved in research as a strategy to improve their current situations, and are continuously fighting and working towards equality within their societies (Cohen, 1999; Durie, 2012; Smith, 1997). Through indigenous research, indigenous methodologies and practices have been developed and integrated into health services to better meet the realities and needs of indigenous populations. Furthermore, evaluations of these programmes have shown positive outcomes and an increase in efficacy. Although it is a continuous battle, indigenous people have exerted a powerful ability to adapt to the struggles and survive in a world that is different to what they know.

In the context of New Zealand society, Māori have a disadvantaged status, and continue to live a life of deprivation in their own country (Beautrais & Fergusson, 2006). Māori consistently feature disproportionately across all poor health statistics, and experience the highest rates of health disorders amongst all ethnic groups in New Zealand (Baxter, 2008; Mauri Ora Associates, 2006; Neilson-Hornblow, 2009; Oakley-Browne et al., 2006). Being unwell is related to the social determinants of health (Marmot, 2005) such as poverty, low education, high levels of unemployment, low access rates to health support services, and much more; statistics of which Māori are also significantly overrepresented in (Durie, 2001; Hirini, Flett, Long, & Millar, 2005; Mauri Ora Associates, 2006).

Te Puāwaitanga: Māori Mental Health National Strategic Framework (Ministry of Health, 2002b) emphasised the effectiveness of solutions that reflect Māori cultural contexts, priorities and realities. With social and economic factors such as employment, housing and poverty all impacting on mental health, wellbeing and recovery, improving Māori mental health and reducing inequalities cannot be achieved by health services alone (Cram, 2011; Durie, 1999; Kingi, 2011; Marmot, 2005).

Culture is an "independent determinant of health status" (Mauri Ora Associates, 2006, p. 7), and Māori health continues to be a concern compounded by factors such as poverty, education and location (Scott,

Marwick, & Crampton, 2003; Smedley, Stith, & Nelson, 2003). There is a substantial amount of research highlighting that low socio-economic status continues to be a precursor to mental illness (Baxter, 2008; Baxter, Kingi, Tapsell, Durie, & McGee, 2006; Hodgetts et al., 2010; Ihimaera, 2007; Mancall, Robertson, & Huriwai, 2000), and the improvement of Māori mental health is "not likely to occur until socio-economic, educational and justice issues are addressed" (Dyall, 1997, p. 85), which Marmot (2005) refers to as the social determinants of health.

Māori mental health

The current mental health status of Māori shows an alarming trend of unmet health needs. The negative health status of Māori should not be viewed without understanding the post-colonial historical experiences that have contributed to Māori disposition in society today. The health status of Māori has become a priority health concern for New Zealand (Baxter, 2008; Durie, 1999; Oakley-Browne et al., 2006; Tapsell & Mellsop, 2007), and Māori continue to remind the government of their obligation to Māori health under the Treaty of Waitangi (Bridgeman & Dyall, 1998; Mauri Ora Associates, 2006).

Attitudes and assumptions

Common perceptions and misinformation about Māori responsibility for their health also impacts on their mental health status. Stigmatisation, public prejudice and social exclusion are well-documented consequences and maintenance factors for the mental health population (Corrigan & Shapiro, 2010; Mental Health Commission, 2001). Research once suggested that Māori are genetically predisposed to mental illness (Johnstone & Read, 2000), however, the effect of these beliefs on Māori who have bipolar disorder is not known. Herbert (2002) suggested that high rates of psychiatric admissions are common in minority populations and are less indicative of the level of psychopathology in the indigenous population, reflecting instead, the inability of mental health agencies to understand the social, educational, political and economic realities faced by many indigenous populations.

The assumption that Māori are to blame for their poor position is a view widely held by society and perpetuated by the media (Nairn et al., 2012). Such assumptions shift the responsibility for addressing negative health statistics away from the dominant group, and ignore wider socio-political influences and consequences for Māori.

Prevalence of bipolar and mood-related disorders

Mental health disorders are common in New Zealand. Around 46.6% of the population are predicted to meet criteria for a mental disorder at some time in their lives, with 39.5% having already done so (Oakley-Browne et al., 2006, p. 5). Key findings from the New Zealand Health Survey (Ministry of Health, 2012) identified that more than 16% of adults in New Zealand have been diagnosed with depression, bipolar, and/or anxiety disorder throughout their lifetime. It also identified that diagnoses of mental disorders have increased from 12% in 2006/07 to 16% in 2011/12 for Māori.

In an international epidemiological study, Soutullo et al. (2005) reported that New Zealand has an estimated 2.4% life time prevalence of bipolar in adults. A local example of the frequency of hospitalisation from the Waikato District Health Board documented that between 2000 and 2006, a total of 1568 people were hospitalised due to an episode of bipolar disorder, and of these, 31% were Māori (Waikato District Health Board, 2008).

Studies of particular relevance to this research include *Te Rau Hinengaro: The New Zealand Mental Health Survey* (Oakley-Browne et al., 2006) which included 12,992 people aged 16 and over living in permanent private dwellings throughout New Zealand, and *Te Rau Matatini Mental Health Needs Profile* (Baxter, 2008). Relevant highlights from *Te Rau Hinengaro* are that:

> *Mood disorders are common among Māori, and 24.3% (one in four) had experienced a mood disorder over their life before interview. The most common lifetime mood disorders in Māori were major depressive disorder (15.7%) followed by bipolar disorder (8.3%) (p. 152).*

Over the 12 months before the interview, 11.4% (over one in 10) of Māori experienced a mood disorder, with major depressive disorder being the most common (6.9%). Bipolar disorder was also present in 4.6% of Māori.

In contrast to other groups surveyed, the prevalence of bipolar disorder was higher than that of other groups (Māori, 3.4%; Pacific people, 2.7%; others 1.9%) (p. 210).

The *Te Rau Matatini* report gathered and analysed quantitative data relevant to Māori mental health and highlighted priorities for attention (Baxter, 2008). The report offers a comprehensive evidence base in which Māori mental health needs can be established and addressed. Baxter's (2008) findings concluded that Māori are 1.7 times more likely to develop a mental disorder when compared with non-Māori, and also predicted that 3 in 5 Māori are likely to experience a mental illness at some point in their lifetime, which reinforces this as an area of high priority. Furthermore, her findings raised concerns for mental illness in Māori between the ages of 15-35, with this group holding the highest prevalence rates in New Zealand. Young Māori males were also featured as presenting with the highest rates of youth suicide. More serious mental disorders are more prevalent in Māori women, and Māori youth, as well as those living in low income households (Baxter, 2008).

Māori rates of depression and anxiety were found to be so high that Baxter recommended they be emphasised as key priority areas. Baxter's findings highlight a serious concern as suicide risk in the bipolar population is well-documented (Beautrais & Fergusson, 2006). In light of this, an understanding is needed of how Māori configure the experience of bipolar disorder in their lives and how they navigate mental health services to receive the appropriate support to continue as active and well members of their communities and whānau.

Research conducted from 1990-2007 show an alarming trend of unmet responsiveness to Māori needs. Māori admission and readmission rates to

hospital for psychiatric and alcohol-related problems were higher than non-Māori, and non-voluntary admissions for Māori were double those for non-Māori (Dyall et al., 1999; Gaines, Buckingham, Eagar, Burgess, & Green, 2003; Johnstone & Read, 2000; Mauri Ora Associates, 2006; Wheeler, Robinson, & Robinson, 2005).

Despite service improvements over the past 10-15 years, Māori still tend to access mental health services at a later stage of illness, with more severe symptoms (Ministry of Health, 2005, 2012). The implication of such findings is that Māori experience less responsiveness to their needs throughout the entire course of mental illness. The level of unmet need is such that a cycle of health disparity is apparent. This places Māori at a significant disadvantage compared to non-Māori.

Since the Te Rau Hinengaro Survey (Oakley-Browne et al., 2006), a review of current literature suggests that aside from *Kia Mauri Tau! Narratives of Recovery from Disabling Mental Health Problems* (Lapsley, Nikora, & Black, 2002), there have been no significant qualitative explorations of the experience of Māori people living with mental health issues or their experience of mental health service provision. This in itself implies the need for better attention to be focussed in this direction.

Barriers to wellness

As stated earlier, the multiple influences on the poor health status of some Māori includes their lower socio-economic positioning. Studies show that low educational levels and issues related to unemployment, poor housing conditions, and lower physical health, were also more prevalent among Māori (Baxter, 2008; Baxter, Kingi, et al., 2006; Ihimaera, 2007; Mancall et al., 2000; Milne, 2001; Wharewera-Mika, 2007). Housing issues such as loss of accommodation during acute illness or hospitalisation affect between 10 and 20 percent of Māori with mental health issues (Peace & Kell, 2001). The implication of housing displacement and lack of housing stability impacts on whānau health and can disrupt social networks.

Further barriers to Māori accessing mental health services are that the entry criteria are often restrictive, and Māori have limited choice about psychological intervention or medication. Research shows that Māori are more likely to have prior psychiatric inpatient treatment than non-Māori, and are more likely to experience misdiagnosis and multiple diagnoses, have poorer prognosis, and to have limited knowledge about the mental health diagnosis (Durie, 1999; Dyall et al., 1999; Ferguson, Collings, Blakely, & Allan, 2005; Ministry of Social Development, 2009). In order to better understand whether such barriers to wellness are immovable, attitudes and perceptions of good health by society generally need to be better explored.

Definitions of mental health

Health status is determined by the "degree to which a person is able to function physically, emotionally and socially with or without aid" (Rosenfield, 1998, p. 99). Although mental health is a normal part of everyday life, it is important to define the contrasts between mental wellness and mental illness in order to better understand the two concepts.

Mental wellness

Mental wellness is apparent when individuals are able to connect and participate with others in meaningful groups and communities (Provencher & Keyes, 2011), and involves feelings, thoughts, and behaviours that contribute to a positive and healthy lifestyle (Neff, Rude, & Kirkpatrick, 2007; Provencher & Keyes, 2011). Being mentally 'well' allows people to experience satisfaction and balance in various aspects of life including physical, emotional/intellectual, spiritual, and social (Rybak, 2013).

Mental wellness is also associated with higher educational achievement, improved relationships, and is fundamental for effective coping mechanisms, particularly when individuals may be faced with adverse situations. Having a sense of control over one's life, working productively, and making positive contributions to whānau (family) and communities are also indicators of good health and wellbeing (Dyall et al., 1999; Keyes, 1998; Provencher & Keyes, 2011; World Health Organisation, 2010).

Mental illness

Mental illness is a problematic state comprising many forms, including mood, personality, and substance abuse disorders. It is not uncommon amongst indigenous populations (Cohen, 1999; Gracey & King, 2009; Herbert, 2002) in particular, for those who have experienced traumatic experiences in their past (Durie, 1994; Hirini et al., 2005).

Mental illness does not occur in isolation (Adrian & Hammen, 1993; Ministry of Social Development, 2010). It is largely associated with disruptive life situations which in turn create negative responses as to how an individual perceives their world and their surroundings, thus leading to poor mental health. Disorientation to one's thinking can cause loss of hope, loss of capacity to realise potential, and loss of ability to work productively. It may also inhibit them from participating fully within their whānau and communities (Ministry of Social Development, 2010). Ultimately, these dynamics may result in a loss of control over one's life, leaving individuals feeling vulnerable and at risk of discrimination, stigmatisation, and abuse (Dyall et al., 1999).

The presence of mental illness however does not mean that mental wellness cannot be achieved. Rather, it highlights the possibility of overcoming enduring mental health conditions and enhancing and producing positive outcomes (Lapsley et al., 2002; Mental Health Commission, 2001; Provencher & Keyes, 2011).

Description of bipolar disorder

One of the purposes of this study is to identify why high rates of bipolar disorder are prevalent among Māori. It is therefore necessary to provide a full description of this disorder and its subtypes. In considering the characteristics of bipolar disorder it is evident that the presenting features overlap markedly in disorders such as substance abuse, anxiety, depression, schizophrenia, personality disorders and trauma, and may remain undiagnosed for years (Royal Australian and New Zealand College of Psychiatrists Clinical Practice Guidelines Team for Bipolar Disorder, 2004).

The description of bipolar disorder has changed with the new Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-V) recently released by the American Psychiatric Association (American Psychiatric Association, 2013). The implications of the new classification system have yet to be thoroughly examined in New Zealand; however, because this study began prior to the DSM-5s release, the previous version (DSM-IV) has been used (American Psychiatric Association, 2000, 2013).

Bipolar disorder is a mood-related disorder producing precarious changes in both mood (hypomania/mania and depression) and in functioning (Urosevic, Abramson, Harmon-Jones, & Alloy, 2008). The disorder impacts on emotional regulation producing affective highs and lows with some states combining feelings of mania, depression and other moods or emotions concurrently (Gruber, Eidelman, Johnson, Smith, & Harvey, 2011; Power, 2005). Also known as 'manic-depressive illness', bipolar disorder is a prevalent, chronic, complex and severe psychiatric disorder that is particularly difficult to treat and is often misdiagnosed or underdiagnosed (Jones & Tarrier, 2005; Meyer & Meyer, 2009; Montoya et al., 2010).

Mania is an intense high lasting at least one week (American Psychiatric Association, 2000) where the person feels euphoric and almost indestructible. It often leads to extreme over-spending, impulsive occupational and personal decision-making, promiscuity, and/or misuse of drugs or alcohol (Benazzi, 2007). Decreased sleep accompanied by increased energy, changes in mood and judgment, and impulsivity are also features of mania (Power, 2005). The emotional experience of mania while appearing as a "high" typically consists of dysphoria, anxiety, irritability and emotional instability (Power, 2005, p. 1102). As the high fades, the consequences of the manic activities become apparent leading to self-denials, relationship difficulties, and extreme depression. Hypomania differs from manic episodes in that the moods are less frequent lasting for a period of four days (American Psychiatric Association, 2000).

Bipolar subtypes

Bipolar disorder is conceptualised as a spectrum of disorders occurring on a continuum. Due to the nature and symptomatic presentation of bipolar disorder, the DSM-IV-TR (American Psychiatric Association, 2000) lists three specific subtypes - *bipolar I, bipolar II, and cyclothymia*, and one for bipolar *not otherwise specified*.

Bipolar I disorder (full-manic episodes) involves disrupted affective functioning, including periods of abnormally and persistently elevated mood (i.e., hypomania/mania), and periods of depression (American Psychiatric Association, 2000).

Bipolar II disorder (without full-manic episodes) has features of bipolar I with only mild hypomania. Bipolar II Disorder is distinguishable from Bipolar I as it has recurrent episodes of depression and hypomania (without ever experiencing a manic or depressive episode). While the symptoms are similar, they are not severe enough to cause marked impairment in social or occupational functioning and the individual is not usually at risk of self-harm (Benazzi, 2007). They are, however, sufficiently distinct in terms of severity to warrant separate classifications (Baek et al., 2011; Judd et al., 2003).

Cyclothymia, considered by some to be the precursor to bipolar II, is defined by frequent swings between depressive and manic symptoms that do not develop into full-blown episodes and is often misdiagnosed as borderline personality disorder. It has an early-age of onset and features histrionic and passive-aggressive characteristics (Akiskal, Hantouche, & Allilaire, 2003; Perugi, Toni, Travierso, & Akiskal, 2003). The relevance for Māori and in particular women is that personality disorders and substance abuse disorders are common in victims of sexual abuse (Brown & Anderson, 1991; Hyun et al., 2000; Spataro, Mullen, Burgess, Wells, & Moss, 2004). Given the impact of sexual abuse in the mental health population, accurate and empathetic assessment is needed at all times.

Bipolar disorder, Not Otherwise Specified (BD-NOS) is reserved for when symptoms are similar to bipolar disorder but they do not meet the threshold

or duration criteria of the other types (American Psychiatric Association, 2000).

On a more positive note, some individuals with bipolar disorder may also display traits and characteristics of creativity, spirituality, art, empathy, realism, resilience and humour. Indeed, artists, poets, writers, musicians and designers are well known in the bipolar population. Researchers argue that clinical and research attention is needed to foster, preserve, and enhance those traits to improve outcomes for individuals with bipolar disorder (Galvez, Thommi, & Ghaemi, 2011; Murray & Johnson, 2010).

Co-existing mental health

Bipolar disorder has a very high incidence of comorbidity or the presence of two or more diagnosed mental disorders existing simultaneously. An overwhelmingly high incidence of comorbidity has been documented in New Zealand, with those with bipolar being detailed to have as high as 93.7% prevalence for having another DSM-IV diagnosis during their lifetime (Wells, McGee, Scott, & Oakley Browne, 2010). Within this comorbidity data, Māori were shown as having the highest rates of comorbidity in New Zealand even when controlling for age, sex, education and household income (Baxter, Kokaua, Wells, McGee, & Browne, 2006).

Bipolar disorder shares clinical features with major depressive disorder but the episodes of hypomania or mania are distinct. Comorbidity with personality disorder, substance abuse, and anxiety disorders are however very common (Freeman, Freeman, & McElroy, 2002; Hendrick, Altshuler, Gitlin, Delrahim, & Hammen, 2000; Kawa et al., 2005; Vieta et al., 2000).

Research suggests that accurate assessment and diagnosis is therefore vital (Wolkenstein, Bruchmüller, Schmid, & Meyer, 2011) to ensure that vulnerable individuals, such as the hugely over-represented and under-catered for Māori population, receive the attention they need and are not inappropriately or miss diagnosed (Royal Australian and New Zealand College of Psychiatrists Clinical Practice Guidelines Team for Bipolar Disorder, 2004). This is further examined under the heading *Diagnosis* below.

Etiology of bipolar disorder

Etiology is the study of causal effects of diseases, mental disorders and the like. Research has shown a strong biological component for bipolar disorder (Johnson, 2005), with environmental and social factors playing a role in the exacerbation of symptoms (Weinstock, Keitner, Ryan, Solomon, & Miller, 2006).

Bipolar disorder is seen by some as a clear biological disorder, however, research over the past 20 years has shown that psychosocial variables shape the outcomes of this disorder (Johnson, 2005). Within the highly vulnerable bipolar population, the presence of any psychosocial adversity, be it low social support or high life stress, threatens their physical or emotional wellbeing, and triggers or worsens mental illness such as depression, anxiety, schizophrenia and bipolar disorder (Johnson, Winett, Meyer, Greenhouse, & Miller, 1999; Kendler, Kessler, Walters, & MacLean, 1995; Power, 2005).

While there are a number of theories for the origins of bipolar disorder, this review focuses briefly on a *diathesis-stress model*. Diathesis can be conceptualised as a predispositional factor (i.e., genetic, cognitive, or interpersonal) or a set of factors that make an individual susceptible to mental illness/psychopathology (Ingram & Luxton, 2005). Thus, the diathesis-stress model suggests that the interaction between predisposing factors and environmental stressors influences the development of mental health disorders (Moreno et al., 2012; Weinstock et al., 2006).

Although the diathesis-stress model provided innovative avenues for research (Urosevic et al., 2008; Walker & Diforio, 1997), it has not been established that psychosocial stressors are etiological factors. It is important however to be aware that Māori and other disadvantaged groups are more likely to experience stressors associated with low socio-economic status and poor mental health. The inter-relationship between those factors requires further exploration, specifically in the context of Māori, their whānau, and their journeys.

Lapsley et al. (2002) identified a series of themes surrounding participant's perceived origins of mental health difficulties. Although not solely focussed on bipolar disorder, the narratives utilised in their study which involved a total of 40 people (20 Māori and 20 non-Māori) provide a framework for understanding the journey of mental health for a group of people living in New Zealand. The majority of the group identified aspects of their past during childhood or adolescence as contributing to their mental fragility. Participants spoke most often of the impact of abuse, loss, abandonment and lack of love, and feeling different, and within these themes, participants were able to provide detail from their lived experiences. Similarly, Wells et al. (2010) note the negative impact of childhood adversity in specific relation to the development of bipolar disorder in New Zealand.

Other researchers also describe the contribution of negative life events to the onset and recurrence of bipolar disorder (Urosevic et al., 2008) and mental health (Taitimu, 2008) symptoms. Further research by Lapsley et al. (2002) emphasised how stressors and critical incidents, such as those encompassing shame and failure, reactivating previous trauma, and suicidal behaviour dictated the onset of a period of being mentally unwell.

Factors associated with relapse

Research suggests that individuals experiencing significant negative life events were found to take three times as long to recover from an episode of bipolar disorder than those without such events (Johnson, 2005). Striving for significant goal attainment (which in itself could be viewed as a significant life event) was also seen to trigger the onset of manic symptoms (Johnson, 2005). With these factors in mind, identifying low and high level stressors and coping mechanisms is crucial to managing the course of bipolar disorder.

Families with high expressed emotion may also be associated with an increased tendency to relapse in bipolar patients (Miklowitz, Goldstein, Nuechterlein, Snyder, & Mintz, 1988). Expressed emotion is a term that describes the affective attitudes and behaviours (i.e., criticism, hostility and

emotional over-involvement) of relatives toward a family member with a psychiatric illness and is seen as a reliable predictor of relapse.

Diagnosis

It is vital that the assessment and diagnosis of bipolar disorder are accurate (Wolkenstein et al., 2011) to ensure that individuals receive the appropriate medication and help, and are not further disadvantaged. Around two-thirds of patients diagnosed with bipolar disorder experience delusions which often accounts for misdiagnosis of schizophrenia (Cosgrove & Suppes, 2013). Of particular relevance to Māori addiction rates is that delusions and grandiosity is also common in substance abuse disorders (Knowles, McCarthy-Jones, & Rowse, 2011).

Understanding the way in which Māori present and the significance of that for clinical assessment and care is critical. It is important not only in relation to the effects and contributions of specific cultural variables, but also in relation to the validity of standard Western approaches to diagnosis and classification for Māori. The issue of how mental health clinicians interpret psychiatric phenomena was identified as being particularly relevant when diagnosing mood and psychotic disorders for Māori (Taitimu, 2008; Tapsell & Mellsop, 2007; Wharewera-Mika, 2012).

The impacts of bipolar disorder

Bipolar disorder significantly impacts on multiple aspects of peoples' lives. Studies show that bipolar disorder is associated with high rates of divorce and relationship dysfunction (Moreno et al., 2012; Rowe & Morris, 2012), difficulties with parenting, schooling and education, erratic work performance (McPherson, Dore, Loan, & Romans, 1992), and troubles with daily roles and responsibilities (Dean, Gerner, & Gerner, 2004; Merikangas et al., 2007).

Studies have also associated bipolar disorder with increased levels of substance abuse - including nicotine, alcohol and drug-dependence (Leventhal & Zimmerman, 2010; Vanable, Carey, Carey, & Maisto, 2003), and high rates and risks of suicide and/or self-harm (Angst, Stassen, Clayton, &

Angst, 2002; Oquendo & Mann, 2001). Among affective disorders, bipolar disorder has the highest rates of premature mortality as a result of suicide (Kupfer, 2005; Merikangas et al., 2007) particularly for those who have made prior attempts (Grunebaum et al., 2006); however, not all bipolar patients commit or even attempt suicide during their illness (Gonda et al., 2012).

In later life, episodes may be further apart and shorter in duration, and manic symptoms less problematic; however, depression, suicidal risk, drug and alcohol abuse and relationship dysfunction continue to impact on optimal wellbeing (Ketter & Wang, 2010). The experiences of an ageing bipolar population must not be overlooked as they can contribute significant detail about their pathways to relapse and recovery (Angst & Sellaro, 2000).

Women with bipolar disorder

Research suggests that women who are mentally unstable are vulnerable and are at higher risk of physical and sexual abuse in comparison to males (Curtis, 2005; Hyun et al., 2000). Studies have identified that of the 16% of adults presenting with disorders such as depression, bipolar or anxiety related disorders in New Zealand, 20% of those presenting are women, and 12% men (Ministry of Health, 2012).

Women have a different course of symptoms for bipolar disorder in comparison to men (Zappert & Rasgon, 2010). While men are more likely to experience bipolar I, women tend to experience bipolar II (with predominant depressive episodes) more frequently (Arnold, 2003; Freeman & Gelenberg, 2005; Leibenluft, 1997). Women also experience more depressive episodes, and less manic episodes over the course of their illness in comparison to men (Arnold, McElroy, & Keck, 2000; Curtis, 2005; Kawa et al., 2005; Marangell, 2008; Nivoli et al., 2011; Tondo & Baldessarini, 1998), and may also show higher rates of mixed mania (Arnold et al., 2000; Freeman & McElroy, 1999; Marangell, 2008), and medication-induced mania (Burt & Rasgon, 2004; Leibenluft, 1997).

Furthermore, the effects of certain anti-depressants on women with bipolar may result in rapid cycling (Curtis, 2005; Leibenluft, 1997; Tondo &

Baldessarini, 1998), a sudden shift in mood state, or mixed mood states (Marangell, 2008). Rapid cycling is the occurrence of four or more episodes within a twelve month period (Curtis, 2005), and a mixed mood state is the presence of any or several depressive symptoms during periods of mania (Arnold et al., 2000).

There are certain factors unique to women that require special consideration during the course of the illness, treatment, and recovery (Freeman & Gelenberg, 2005). The impacts of bipolar on women may potentially influence family planning, parenting capabilities, gestation, delivery, and breastfeeding (Moreno et al., 2012), however, there are mixed findings as to whether or not menopause (Leibenluft, 1997) and reproductive cycles (Freeman & Gelenberg, 2005) have an effect on the course of bipolar in women.

Rasgon, Bauer, Glenn, Elman, and Whybrow (2003) comment that in bipolar disorder, "the premenstrual and menstrual phases of the cycle have been associated with increased rates of suicide attempts, increased severity of suicidal intent, and increased rates of psychiatric hospitalization" (p. 48). Pregnancy, childbirth and the postpartum period, breastfeeding, and menopause are also critical periods in women's lives (Zappert & Rasgon, 2010). Another study found an increased risk for depression in menopausal aged women with bipolar disorder in comparison to men of similar age range and younger women (Marsh, Ketter, & Rasgon, 2009). Further research is required to understand the direct impact of hormonal transitions on the course of bipolar disorder (Marangell, 2008; Marsh et al., 2009).

Blehar et al. (1998) found that of 186 women who were interviewed about their reproduction experiences, two-thirds reported frequent premenstrual mood disturbances, and around 20 percent of postmenopausal women reported severe emotional disturbances during the menopausal transition; furthermore, almost half reported severe emotional disturbances in relation to childbearing, with close to one-third reporting symptom onset during pregnancy. Despite the risks involved with pregnancy for women with bipolar disorder, these risks do not discourage them from wanting to bear

children (Curtis, 2005). The effects of bipolar disorder and medication on women's reproductive cycles, foetal development, breastfeeding and symptom presentation is variable, highlighting that more research is needed (Viguera, Cohen, Baldessarini, & Nonacs, 2002).

Women with a mental illness may find it difficult to manage relationships within the family as well as parenthood, and on rare occasions may pose a threat to the wellbeing of their child/children by their hallucinations or delusions (Friedman, 2011). As a result women with severe mental health conditions (including bipolar disorder) may experience having their child or children removed from their care, which for some women can be detrimental to their health and mental wellbeing (Montgomery, Mossey, Bailey, & Forchuk, 2011).

There are many instances in which child welfare services tilt towards removal "without adequate understanding of the difference between being mentally ill and being dangerous" (Friedman, 2011, p. 1). For example, a study found that mothers with serious mental illnesses who lived with at least one of their offspring experienced significantly less stressful life events compared with those who did not have their children in their care (Montgomery et al., 2011). Dyall et al. (1999) also identified that women felt safe and secure in knowing that their children would not be removed from their care as a result of their mental illness, as their children were also a source of wellness.

Impact on whānau and tamariki

Bipolar disorder can have devastating consequences for individual sufferers and their whānau. Research suggests that bipolar disorder is highly correlated with increased levels of familial dysfunction creating less cohesion and greater levels of distress (Moreno et al., 2012). The impact on whānau members needs further documentation, however, Lapsley et al. (2002) identified the commonly expressed impacts on participant's relationships with their children, and for some participants, they felt a sense of having

failed their child or children, as well as a general difficulty to make and maintain friendships.

Research has shown that a non-optimal rearing environment with existing psychosocial stressors such as abuse, harsh and critical communication style, deprivation, drug and alcohol abuse, violence, sexual abuse, and neglect has a negative impact on children (Robertson et al., 2013), and is associated with the development of mental disorders in children (Adrian & Hammen, 1993), with certain individuals more susceptible than others (Mason & Beavan-Pearson, 2005; Walker & Diforio, 1997).

Children of parents with affective disorders tend to experience various challenges as a result of the combination of maternal stressors, environmental stressors, and personal stressors. The negative events that children experience at home affect their ability to acquire knowledge and learn new skills, and may also influence the pathways they choose to take (Adrian & Hammen, 1993; Moreno et al., 2012).

The use of family interventions have proven successful to minimise the levels of environmental stress that may impact on children's wellbeing (Moreno et al., 2012). It is important to understand however that for Māori, the circumstances for tamariki and whānau members generally, are such that that additional supports are needed to prevent the interrelated impact of unemployment, poverty, mental health issues, suicidality, drug and alcohol addictions, substandard housing, and unplanned, or unsupported pregnancies (Blakely, Collings, & Atkinson, 2003; Butterworth, Leach, Pirkis, & Kelaher, 2012; Cram, 2011; Robertson et al., 2013).

Individuals with bipolar disorder who have in place strong support systems experience less depressive symptomatology over time (Johnson et al., 1999), however, those who are surrounded by hostile and critical others are more likely to experience more depressive symptoms, have a poorer response to treatment, and experience higher relapse rates (Rowe & Morris, 2012; Walker & Diforio, 1997; Weinstock et al., 2006). This literature could further

be aided by identifying the roles of whānau that support or hinder the recovery process.

Pathways of recovery

Recovery is an ongoing journey of healing, transformation and reclaiming a positive sense of self and one's roles in life, rather than being a consumer in the mental health system (Mental Health Commission, 2001). Recovery does not always mean that people will return to full health or retrieve all their losses, but they may well continue to lead happy lives in spite of them (Mental Health Commission, 1998). Being active, involved in meaningful activities, and physically fit is integral to the recovery phase and the maintenance of wellness. It is an active process in which whānau support and involvement is essential (Dyall et al., 1999). It is also about autonomy and self-determination where "each person with mental illness needs to define for themselves what 'living well' means to them" (Mental Health Commission, 2001, p. 1).

A study conducted by Robertson et al. (2013) provided insights into the lived experiences of women dealing with violence, their attempts to protect themselves and their tamariki, and their experiences of a whānau ora wellbeing programme. In their study, the loss or weakening of whānau ties was a common theme, however, the importance of having a strong well connected whānau was highlighted as being an essential protective factor for women dealing with violence and abuse (Robertson et al., 2013, p. 1). Furthermore, the outcomes of their study found that the distinctive needs of women included 'feeling safe', 'having sustainable housing', 'being financially independent', 'having successfully addressed drug and/or alcohol abuse', 'improved physical, psychological, and emotional health', 'reconciling with whānau members', and 'feeling more competent and better resourced as a parent' (p. ii).

The term recovery features principles and aspirations such as 'social and occupational functioning', 'self-determination', 'social inclusion', 'healthy social relationships', 'hope and autonomy', 'understanding, supporting and

strengthening identity', 'living free from stigma and discrimination', and an emphasis on 'social and personal responsibility' for recovery (Keyes, 1998; Lapsley et al., 2002; O'Hagan, 2001; Provencher & Keyes, 2011; Ryff & Singer, 1996).

Contrary to the 'life sentence' given to bipolar patients, the recovery-focused mental health literature argues that wellness is achievable for even the most intractable conditions (Lapsley et al., 2002; Mental Health Commission, 2001). Definitions of recovery are varied and reflect the need to consider wellbeing from the perspective of the person in need. Although the term recovery supposes that one has 'recovered' and is 'living well', what is clear is that recovery refers to the episodic nature of mental illness and shifts thinking away from a 'chronicity paradigm' - where mental illness is seen as permanent and where individuals or groups are blamed for their mental health status (Ramon, Healy, & Renouf, 2007, p. 109).

Lapsley et al. (2002) noted that in keeping with policy documents and lived experiences for consumers, recovery stories should include the multiple influences on peoples' lives:

> *Our research waka and the subject it conveys inevitably demands that stories of recovery from mental ill health be viewed and investigated in the fullness of their social, economic, political, spiritual and emotional environments. These environments are essentially bicultural, even in some instances multicultural, and sometimes monocultural. Rarely do they involve only Māori* (p. 1).

They also emphasised that the recovery approach is compatible with Māori mental health models in that, "*balance is sought between the body, person, whānau, and the environment and ecologies within which they exist*" (Lapsley et al., 2002, p. 2).

The recovery approach has underpinned New Zealand's approach to mental health service delivery for over a decade (Mental Health Advocacy Coalition, 2008). Recovery is impacted on by environments in which people are isolated from communities, power is used to coerce people and deny choices,

and where people with mental illness are never expected to get better (Mental Health Commission, 1998). Indeed, some argue that the term recovery is overused and sets unrealistic expectations for consumers, particularly if those expectations are not met (Sterling, von Esenwein, Tucker, Fricks, & Druss, 2010).

In the context of being Māori, to be healthy is to be mentally, physically, socially, and spiritually well (Durie, 2001, 2004). Te Whare Tapa Whā (the four cornerstones of health) model developed by Sir Mason Durie provides a tool for culturally appropriate assessment and treatment of Māori with mental illness (Durie, 1994). This model and its emphasis on taha whanau (family/social health), taha tinana (physical health), taha hinengaro (psychological health), and taha wairua (spiritual health), show what are seen as key areas for engaging and supporting Māori through their mental health journeys (Durie, 1994, 2001).

This model forms a unified approach to health services and can be useful for understanding various types of health issues (Rochford, 2004). When all four elements are equally understood and maintained, the total health and wellbeing of whānau Māori will thrive. Tapsell and Mellsop (2007) also highlight the works of Durie in advocating for the importance of culture and cultural connectedness in assessment; most importantly for those who strongly identify as being Māori or feel dislocated or disconnected from their identity.

The Mental Health Commission (2000) reviewed literature and engaged four whānau Māori in their stories of mental health hindrances and recovery factors, with all participants emphasising the importance of such a model in addressing important cultural aspects of wellbeing, whilst also addressing mental health. Narrators in their study spoke about the importance of whānau connectedness, of life experience in relation to te ao Māori, and the importance of learning how to bridge the lapses between one's own sense of identity, as well as acknowledging different frameworks for viewing mental health (Mental Health Commission, 2000).

Mitchell and Romans (2003) reported that individuals experiencing bipolar disorder showed differences and experienced confusion between the explanations of medical and spiritual advisors. This further advocates the importance of assessing for religious and cultural standpoints and understandings of mental health in order to provide the best type of care for any mental health consumer (Mitchell & Romans, 2003; Taitimu, 2008; Wharewera-Mika, 2012). Various other assessment and treatment models seen as having a holistic focus (e.g., Te Whare Tapa Whā), would also likely aid in the utility of both assessment and treatment for Māori (Taitimu, 2007).

Treatment

Bipolar disorder is typically treated using medication to reduce symptoms and prevent relapse and psycho-social strategies such as self-care or self-management plans. Although symptom relief is important, studies show that an emphasis on social and functional recovery is needed for service user empowerment and greater collaboration among professionals (Jones, Mulligan, Higginson, Dunn, & Morrison, 2013).

Lapsley et al. (2002) highlighted shared experiences for many individuals in terms of assessment and treatment when experiencing mental health problems. Although, their research is not limited to those with bipolar disorder, it offers useful concepts for considering our indigenous journeys through New Zealand's mental health systems. Most of their participants reported hospitalisations (often more than once), visits or consultations with General Practitioners, and utilising community treatment settings. Five participants chose alternative methods of treatment, outside of traditional mental health services, such as self-help and using alcohol/drugs. Around half of the participants noted their experience of hospitalisation as negative; and many noted few opportunities for individual therapeutic work. Those who did experience a therapeutic process found that this was mostly of benefit to them (Lapsley et al., 2002).

The Royal Australian and New Zealand College of Psychiatrists (2004) explored treatment and assessment recommendations for those with bipolar

disorder. Their review identified that treatment, both medical and psychological, should aim to restore the patient to full health, and the ability to lead a meaningful life. Specifically, this review presented evidence regarding the efficacy of a shared approach to treatment, utilising both medication and psychological therapies, especially when the patient is showing significant improvements. Furthermore, this review recommends outpatient psychiatric input wherever possible, and implied some contraindications of inpatient treatments, in-line with the reporting of Lapsley et al. (2002).

Mental health services

Mental health systems each have their own unique culture and are managed and run in a way that supports their organisational values, rules and expectations. For many mental health consumers, the process of negotiating through health services, particularly as a newcomer in unfamiliar surroundings, can be quite a difficult and daunting experience (Barnett & Lapsley, 2006), even more so when coming to terms with the experiences that led them to be there in the first place.

Support services identify individual's assets, strengths, and areas of health and competence in order to support those endeavouring to manage their mental illness as they regain a meaningful and constructive sense of membership within the broader community (Davidson, O'Connell, Tondora, Styron, & Kangas, 2006). Research indicates the need to incorporate culturally appropriate practices to better cater to the Māori population (Dyall et al., 1999) as culture plays an important role in health and health care (Mauri Ora Associates, 2006).

The health status of the New Zealand population has showed significant improvements as a result of better facilitation and access to health care, as well as advances in the availability of medical treatments (Dye et al., 2012; Ministry of Social Development, 2010).

Mental health service providers are encouraged to allow for consumer input in the decision making process (Walker & Dewar, 2001). This alongside the

incorporation of Māori mental health frameworks, for example Te Whare Tapawhā model (Durie, 1999, 2001), and Māori health strategies such as Whānau Ora (Durie et al., 2010; Ministry of Health, 2002a) can work together to meet the needs of Māori coming into the mental health system (Neilson-Hornblow, 2009).

Whānau ora

Health and disability sectors are responsible for recognising that health and wellbeing are influenced and affected by the 'collective' as well as the individual and also need to understand the vital importance of working with people in their social contexts, not just with their physical symptoms (Ministry of Health, 2002a). The whānau ora framework, encourages and supports the use of holistic Māori models and approaches to wellness, as are the aspirations of Māori to self-manage and determine their own solutions and pathways (Ministry of Health, 2002a). Holistic approaches to mental health service provision means that mental health needs will not be viewed in isolation, but rather looked at in terms of all needs fundamental to wellbeing.

The Government's expectation for Māori health development is *Whānau Ora: Māori families supported to achieve their maximum health and wellbeing* (Ministry of Health, 2002a). The inter-connection of strength, support, belonging, security and identity play a central role in the wellbeing of Māori individually and collectively (Ministry of Health, 2002a). The positive, meaningful and supportive interactions within the whānau comprising kuia, koroua, pakeke, rangatahi, and tamariki are also a source of wellbeing for Māori (Ministry of Health, 2002a), creating nurturing and fostering relationships which encourage progression. While whānau ora is reinforced by a philosophy of collective wellbeing, it explicitly recognises and encompasses the diverse needs of all population groups across the lifespan.

Although conceptualised as an individual process focused primarily on the attainment of individual autonomy, recovery for Māori must be conceptualised within the broader context of whānau ora, with an emphasis

on inclusiveness, collectiveness and interdependence (Durie et al., 2010). Whānau ora recognises that pathways to wellbeing and recovery for Māori needs to be focused on building identity and whānau capacity (Durie et al., 2010). Similarly, the journey of recovery for Māori with mental health conditions encompasses the recovery of autonomy or empowerment that is inclusive of whānau, hapū, and iwi (Milne, 2001; Wharewera-Mika, 2012).

Responding to the diversity that characterises what it is to be Māori is an important challenge. Whether this diversity relates to socioeconomic circumstances, cultural affiliation or differential access to Te Ao Māori, no two Māori journeys will be the same. In terms of mental health service delivery, being Māori will always be relevant, but not in a way that can be presumed (Durie, 2001).

Summary

This chapter provides a comprehensive background on the socio-historical positioning in which Māori (and other indigenous peoples) have experienced substantial deprivation through colonisation, and exposes the extent to which many Māori suffer from, and are over-represented in, all negative health statistics. It also sets the context from which to understand bipolar disorder and the impact it has on women, their whānau, and child-rearing practices; however, due to the scarcity of qualitative research on experiences of mental illness, in particular bipolar disorder in wāhine Māori, the literature review was limited to what is relevant and available.

The research discussed in this chapter, and in particular that offered by Lapsley et al. (2002), provides a starting point for my research to examine and gain a greater understanding of Māori women's experiences of bipolar disorder and their pathways to recovery.

The research to date shows a clear association between social, psychological and biological factors on the emergence, course, and diagnosis of bipolar disorder. However, a thorough understanding of why Māori women have higher rates than non-Māori women is necessary. Those rates suggest that

personal, social, political and economic forces are still impacting on Māori in a way that requires further exploration.

Chapter Three: Method

The primary focus of this study is to explore the life pathways and experiences of wāhine Māori (Māori women) who have been given a diagnosis of bipolar disorder (also previously known as manic-depressive disorder) at some point in their lifetime. This research project is part of a larger project running concurrently that sits with the Māori and Psychology Research Unit (MPRU) at Waikato University. While the larger project places a focus on 'whānau' experiences (both male and female) of bipolar disorder, this stream of the project looks at the experiences and impacts of bipolar disorder pertinent to wāhine Māori specifically.

The method of analysis is wholly qualitative informed by kaupapa Māori theory and narrative psychology. The following sections will provide a brief description of the processes involved in this research.

Kaupapa Māori research

This research employs kaupapa Māori methodology (Smith, 1997) and repositions western techniques (such as narrative inquiry and thematic analysis) to be useful to Māori needs and aspirations (Smith, 1999; Walker, Eketone, & Gibbs, 2006). Kaupapa Māori refers to a *by Māori, for Māori approach* where Māori participants are positioned as experts, and where structures of social oppression through unequal health status is challenged (Pihama, Cram, & Walker, 2002). This study therefore seeks to explore not only the barriers that wāhine Māori are facing in relation to access to health care and support systems, but also the sources of their determination, aspirations and wellbeing in spite of such barriers.

Kaupapa Māori research is concerned with the method of inquiry rather than the method used to produce and analyse data. The method of analysis may well draw upon Western methodologies, however certain kinds of qualitative research, for example oral histories, narratives, case studies and interviews "fit more comfortably within a Māori way of doing" (Walker et al., 2006, p. 336).

Kaupapa Māori research methodology allows for Māori to explain their experiences within a culturally-defined theoretical space (Pihama, 2001). The principle of mediating socio-economic and home difficulties (Smith, 2003) is addressed by ensuring that tino rangatiratanga (self-determination), and tikanga Māori are integral to the thesis methodology (Mane, 2009; Smith, 1999), and by being "committed to a critical analysis of the existing unequal power relations within our society" (Bishop, 1999, p. 2).

Narrative inquiry

Narrative methods of investigation were utilised in this study as a means of attempting to understand the lived experiences of wāhine Māori with bipolar disorder. Narrative inquiry is a form of qualitative research motivated by one's desires to gain an understanding of the other's perspective (Bresler, 2006), and can be used as a means of "uncovering the experience of illness" (McCance, McKenna, & Boore, 2001, p. 350), and in this case, recovery pathways also.

Narrative inquiry typically begins with participants responding to "more or less structured interview questions; by engaging in conversation or dialogue; or by telling stories triggered by various artefacts" (Clandinin & Huber, 2010, p. 437). As a narrative inquirer, this method requires an attitude of empathic understanding and listening (Clandinin & Huber, 2010), while also maintaining an attentiveness specifically in the views of the participant (Koivisto, Janhonen, & Vaisanen, 2003; Todd, Deane, & Bragdon, 2003).

This method of inquiry enabled wāhine to share their stories and focus on their own 'unique' and 'specific' experiences, which for them are very real, without asking them to think in general terms (McCance et al., 2001). Through the narrative-storying method wāhine are able to "give meaning to their experiences of suffering and dislocation" (Lapsley et al., 2002, p. 6), and ultimately reflect on the steps in which they took to start their recovery journeys.

Ethical approval

The ethics for this research was part of a larger ethical approval process completed alongside the MPRU. Ethical approval for the project was obtained from the Psychology Research and Ethics Committee at the University of Waikato (see *Appendix A*), and the Multi-region Ethics Committee (NTY/12/06/052); and support for this project was also gained from the Waikato District Health Board (WDHB) Māori Research Committee, and the Lakes District Health Board (LDHB) Research and Ethics Committee.

The LDHB requested that consultation be made with cultural advisors from local iwi governance boards to ensure that the project was supported in the Te Arawa region. The General Manager (Māori Health) of the LDHB arranged to meet and discuss the project with local iwi governance boards regarding my requests; and after a period of approximately three months, ethical approval was obtained with the full support and endorsement of *Te Rōpū Hauora o Te Arawa* and *Te Nohanga Kōtahitanga o Tuwharetoa*.

Resource development

Interview schedule

A comprehensive set of interview questions had been developed beforehand for the larger bipolar project, thus my job was to shorten the interview schedule and align it to the specific areas my project wished to explore. The finalised version of the interview schedule was piloted with my first participant (whom was aware of this) and was adjusted to correct any errors. The final schedule was used as the basis for all further interviews (see *Appendix B*). The interview schedule aimed to elicit a coherent narrative of the experiences of bipolar illness, initial engagement with health and support services, and pathways to recovery. Thus there were no strict questions to follow, rather the schedule was a guide to ensure specific areas were covered.

Research flyer

A research flyer/poster was developed to be displayed in various health organisations, DHB's and on the University campus. Posters included the title

of the study, the ethical approval committees, researcher contact details, and a brief description of what the research entailed (see *Appendix C*). The research posters invited wāhine to share their stories and experiences of bipolar disorder, the various supports they had received, and the tools they had discovered which aided them in their recovery. The posters encouraged wāhine to make contact with my supervisor (Dr Waikaremoana Waitoki) or myself if they were interested in participating in the study.

Participant information sheet

A participant information sheet had been previously developed by the larger bipolar project (MPRU) which I adjusted slightly to suit this study (see *Appendix D*). The information sheet described the background and objectives of the study as well as participants' rights (e.g. the right to withdraw from the study under any circumstances). Wāhine were also informed that all information provided by them will be viewed only by those involved in conducting the project and will remain confidential.

Participant consent forms

Consent forms were also developed to ensure that wāhine understood fully their rights, and what was required of them. Consent forms included researcher contact details, a brief statement of agreement; participant demographics including name, age, iwi/hapū affiliation, and a space for their signature and the date (see *Appendix E*).

Recruitment of wāhine

This study was open to wāhine Māori of all age groups who had at some point in their lives received a diagnosis of bipolar disorder and who are 'currently' living well (wāhine were able to manage their illness and continue to lead active lives). Research posters were distributed throughout the Te Arawa and Waikato communities with the support and assistance of organisations including the WDHB, the LDHB, Te Ngako Community Mental Health Service, and Supporting families in Mental Illness (Rotorua). Research posters were also displayed throughout the University of Waikato Campus, and advertised

in the July 2013 issue of the Ohinemutu Informer (Rotorua), and on the social media networking website Facebook.

The process of seeking wāhine to participate in this study was ongoing and lasted a period of six to seven months. Once initial contact was made with the wāhine, the information sheets were distributed via email for them to consider prior to our initial meeting. For those wāhine who did not have email addresses, information sheets were handed out and explained at the interview.

Ngā wāhine: Participants

A total of 12 wāhine took part in my study; 7 of whom responded to the advertisements, and 5 of whom were referred to me by whānau and friends. Unfortunately one wahine had to withdraw during our interview as she was no longer in a 'well' state and wished to discontinue her involvement. Her interview data has since been erased.

All wāhine have been given a pseudonym to protect their identity and keep their information confidential. They all had diverse tribal affiliations however their exact place of origin was not discussed. Four wāhine were interviewed in Rotorua, and the remainder were interviewed in Hamilton.

The ages of each wahine ranged from early-twenties to mid-sixties, however, the majority of wāhine were over the age of thirty. Eight wāhine had at least one child, and most were not in a relationship (single=6; in a relationship=4; unspecified=1).

For those wāhine who did work, their jobs were centred around supportive roles within their organisation; three wāhine were unemployed at the time of the interview; and three did not mention their occupation.

The table on the following page presents demographics for each of the wāhine who took part in this study.

Table 1: Participants demographics

Pseudonym	Age	Relationship Status	No. of Children	Occupation
Niwareka	61	Single	3	Mental Health Support Worker
Tania	56	In a Relationship	2	Unemployed
Hine	65	Divorced	8	Unspecified
Mapihi	22	Single	0	Student Mentor (Student)
Pua	23	In a Relationship	0	Mental Health Support (Student)
Tui	47	In a Relationship	0	Unemployed
Huia	49	Married	2	Works & Part-time Student
Tina	44	Single	4	Mental Health Worker
Hera	51	Unspecified	1	Unspecified
Awhi	47	Single	3	Unemployed
Aroha	20	Single	1	Unspecified

Research process

It was required that each wahine take part in one one-on-one interview with me for this research, with no time restrictions on the length of the interview. Once wāhine agreed to take part, the interview process and interview options (e.g. date, time, and location) were discussed with them. Wāhine had the option of choosing a suitable time and location for the interview to take place. Interviews were carried out in a number of different settings including their homes (no=8), their workplaces (no=1), or the researchers office (no=2).

Going into this research, protecting the *mana* (power, authority or prestige) of the wāhine was at the forefront. One of the most important guiding principles in kaupapa Māori research is to ensure that participants are respected and that their mana remains intact throughout the entire research process (Smith, 1999). An important factor to note was the participant's role in this research. Without participants, there would be no findings. The role of the participant as the expert in their field was acknowledged and respected throughout the interview and research process.

A critical aspect of the interviewing process was *whakawhanaungatanga*: allowing time and space to build and establish relationships (Mead, 2003). This took place at the outset of each interview, where we, the wāhine and I, engaged in general conversation, getting to know one another, and setting a comfortable atmosphere for the interview to take place. As a researcher, conducting the interviews in the participant's 'space' whether it be home or work helped me to engage in conversation with them about general topics such as art work, collectables, picture frames, or job roles within their workplace. I felt it was essential that a relationship was established before wāhine shared with me their personal stories; as Jones, Crengle, and McCreanor (2006) explained:

> *In order for a research project to achieve the best possible outcomes, those sharing and collecting information must be able to fully trust those who are ultimately responsible for the analysis, interpretation, reporting and dissemination of that data* (p. 68).

It was also important for me to keep in mind that I must manaaki the wāhine, which means looking after and treating them with kindness and respect (Mead, 2003). As researchers, we are inviting people to take part in our project, therefore they deserve to be cared for and appreciated for their contributions. This means getting informed consent, giving participants the ability to opt out, and offering koha as a token of gratitude for their participation (Jones et al., 2006). The following section describes how this process was acknowledged.

The interviews

At the beginning of the interviews, wāhine received both verbal and written explanations of the research project. Questions were also invited for clarification of any uncertainties pertaining to the research project. Once the wāhine were satisfied with the information given, consent forms were handed out for them to sign, followed by the commencement of the interviews.

The interviews were conducted according to a semi-structured interview format, with prompts and guidelines to follow in the interview schedule. Wāhine were encouraged to share their experiences as they felt necessary, and to include any information they thought was relevant. The narrative-storying approach sought to understand the experiences of wāhine Māori with bipolar disorder including:

a. Life before the diagnosis: I wanted to know what life was like for participants before the bipolar illness took over their life.
b. Life changes and events leading up to diagnosis: I wanted to know what types of events precipitated the bipolar diagnosis.
c. Experiences of diagnosis and engaging with mental health service providers: I wanted to know how participants felt about their diagnosis, and what it was like initially accessing mental health services.
d. Experiences of living with bipolar disorder: I wanted to know about the impacts that bipolar disorder had on participant's lives.
e. Help-seeking and support seeking patterns: I wanted to know how participants accessed support, and what some of the barriers may have been if they did not.
f. Recovery pathways: I wanted to know what assisted participants in returning to a state of wellness and what helped them to manage their illness.

The length of each interview varied from fifty minutes to two hours. All interviews were recorded using a dictaphone and transcribed verbatim. Transcripts were then sent to the wāhine to be reviewed for accuracy. Wāhine informed me once they were satisfied with their transcripts, which then allowed for the preparation of narrative summaries followed by the thematic analysis process.

Wāhine were provided with copies of their narratives for review and comment which they could retain as a written account of part of their life-history. Each wahine also received a $40 (NZD) Pak' n Save grocery voucher as a koha for their contribution.

The following chapter provides a brief description of the analysis process followed by a detailed presentation of the findings from the interviews.

Chapter Four: Presentation of Key Findings

As researchers, it is important to acknowledge any theoretical positions and values in relation to the research, our position as cultural members and as cultural commentators, and to recognise that the worldview of researchers provide the instrument of analysis through which the data "emerges" or is "created" (Braun & Clarke, 2006; Sanchez-Jankowski, 2002, p. 80). With these views in mind, it is important to show an empathetic understanding (Stiles, 1993) of the participants' worldviews and their voices imbedded within the narratives.

Analysis Process

The results that are discussed in this chapter firstly used a thematic analysis process to extract key findings from the interview transcripts of each wahine. In order to facilitate more meaningful outcomes to this research, those findings were then organised into categories that relate directly to the research question.

This research sought to gain an understanding and an awareness of the life pathways of each wahine involved in this study, and how such life pathways and experiences subsequently led to a bipolar diagnosis. This research also sought to determine the extent to which health services and health professionals are responsive to the needs of wāhine Māori with a mental illness. Priorities, issues, and information gaps within their experiences are also identified, while attempting to understand from the participant's point of view how these issues may be better addressed.

Thematic analysis

This methodology was adopted to readily identify the themes and trends in the narratives of the wāhine interviewed. It is a tool that identifies, organises and describes patterns or phenomena (Boyatzis, 1998), and works both to reflect reality and to unpick the surface of 'reality' (Braun & Clarke, 2006, p. 81). The thematic analysis allows researchers to "...capture something important about the data in relation to the research question, and represents

some level of patterned response or meaning within the data set" (Braun & Clarke, 2006, p. 82).

The interview transcripts were analysed and extracts from each interview were organised into categories that related directly to the research question. These key findings and events as expressed by the wāhine were ordered in common sequences, and a total of twelve categories were generated for the first part of the analysis. These categories included:

- Experiences leading up to diagnosis
- Experiences of mania or depression
- Triggers or signs of an episode
- Explanations of diagnosis communicated by health professionals
- Experiences with Mental Health Services and medication
- Whānau support or lack of support
- Impacts on relationships with whānau
- Impacts on relationships with partners/work colleagues
- Impacts on self
- Impacts on children and parenting capabilities
- Help-seeking patterns and key supports
- Pathways to recovery and management

Further investigation into the above categories made visible several common themes that were occurring throughout participant's journeys before diagnosis, during the illness and through the recovery process. As part of the thematic analysis process, the proposed themes and results were reviewed by my supervisor to check for consistency, irrelevant themes and errors.

The next process required a re-examination of the categories created which involved reading over all material concerning each of the major categories, and then coding that information into common themes. As this process progressed, categories were added, changed, refined or integrated. This process assisted in the identification of consistent themes across the wāhine interviews, as well as the similar (or unique) experiences of living with

bipolar which had a large impact on their lives. Once the initial coding was completed, new categories were formed, and a narrative sequence was developed in order to present the findings.

From my analysis, narrative sequences of the journeys and experiences of each wahine have been shaped into five key sections including:

- Origins of illness in the past;
- The onset of the bipolar disorder diagnosis;
- Experiences of mental health services;
- Consequences of bipolar disorder; and
- Pathways to recovery.

Within each section, examples and quotations from the interviews are utilised to amplify and highlight the various stages and themes which emerged throughout the analysis.

Section One: Origins of Illness in the Past

This section details a range of influencing factors associated with the mental health experiences of the wāhine involved in this study. The analysis exposed three distinctive yet interwoven aspects which are examined to reveal some of the contextual influences which impacted disturbingly on the pathways of each wahine. These aspects and themes are explored below as *mental illness within the whānau*; *childhood and adolescent experiences*; and *significant events - contextual factors*.

Pre-existing problems and the lack of support for whānau were predominant concerns of the wāhine interviewed which gradually emerged as the wāhine began to share their experiences. Each wahine described a range of experiences that reflected their vulnerabilities, setting the context for a later diagnosis of bipolar disorder. Their life pathways indicated that mental illness was something that was unavoidable, as they had each experienced a range of physical and psychological trauma that predisposed them to later problems. This was largely a result of having not received adequate support in the first instance.

A precursor to the development of bipolar disorder was evident across most wāhine. As some of the comments show, unresolved issues were possibly the primary concern rather than bipolar disorder itself. Many wāhine had previously engaged with mental health services prior to their bipolar diagnosis, however, others experienced symptoms of mental ill health but were not referred for further psychological help at the time.

> *My first suicide attempt was at age 14, my second attempt was at 23, and my third was somewhere into my 30's. Each time I was just put in hospital and then sent home. I was never ever sent to a psychologist for help (Niwareka).*

These associated problems are addressed under the relevant category following.

Mental illness within the whānau

More than half (7) of the wāhine described a history of mental illness within their whānau and had associated their experiences of bipolar disorder with a genetic predisposition. Niwareka and Tania felt that their genetic vulnerability alongside their negative childhood experiences had set them on a preordained path of mental illness:

> *I would say I had the potential for bipolar disorder as a result of my past experiences as well as the environmental stressors that surrounded me. My grandmother had bipolar, my brother had depression; two other females in the family have bipolar. It seems to be much worse with the females in our family. I think my daughter has bipolar too (Tania).*

Tania talked about a potential to develop bipolar disorder that could have been viewed as a genetic disposition or the result of social factors. Her views suggest that while she understood that bipolar disorder was present amongst the wahine in her family, the cause was not known. Meanwhile Awhi, Tui, Pua and Aroha had made references to whānau members with bipolar disorder and other mental illness diagnoses:

> *My mother had mental illness most of her life. I'm not sure what she was diagnosed with...so it's not a big shock in our family, there are about three of us, my mum, my brother, and me (Awhi).*

Hera said that her daughter also has bipolar disorder, is a heavy drug and alcohol user and has had her children removed from her care. She felt that her daughter's drug and alcohol abuse and parenting issues may have been the result of her inability to be a parent herself when she was hospitalized for long periods. Tania was also worried about her daughter who is following a similar life path to hers; and Tina also commented that her daughter has been previously admitted into the mental health service youth and adolescent ward at the age of 13.

Although an experience of familial mental illness was common across wāhine, many of them were not aware of the existence of mental illness within their

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whānau until they were diagnosed themselves. As noted earlier, the presence of a genetic predisposition was only part of the origin story. Unmet need associated with childhood and adolescent trauma, anxiety, depression, suicide and 'not fitting in' were significant features in the narratives collected. These themes are presented below.

Childhood and adolescent experiences

The majority of wāhine were able to pinpoint specific experiences or circumstances during childhood and adolescence that they associated with mental illness. For some of them there was no single event in their lives, other than noting a particular disposition (for example anxiety or not fitting in at school) or that there was an absent parent in the home, while others endured repeated and sustained abuses.

All wāhine had described at least one unaddressed psychological issue or unmet need during their childhood or adolescence. Some of the themes related to life prior to a diagnosis of bipolar disorder, and these tend to suggest that for some wāhine their pathway to unwellness was not unexpected. Their stories highlight that there was limited support available.

Unmet needs

Some wāhine expressed feelings of vulnerability, anxiety, and loneliness growing up and while in school. Tania's sister Marama said that Tania was an emotional child and would always cry. Marama said that she had witnessed her stepfather murder her father.

> That could be why the family didn't want to support her (Tania) because they had a whole lot of their own crap in their closets. They hadn't dealt with their own troubles (Marama, sister).

Tui said she was *"overly emotional about a lot of things"* and began to isolate herself during high school. Huia said that she had suffered from major anxiety as a child which caused her significant psychological distress, and Hera, Mapihi and Aroha recalled some form of bullying or isolation while in school which they believed had an impact on their mental wellbeing.

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Mapihi was sexually violated by a home intruder during a summer break in high school and this had impacted on her confidence, esteem, and grades in high school. She was eventually diagnosed with *major depression* and regularly engaged with health services and the crisis team. She felt that regardless of her traumatic experience, she was always going to be *"that way"*. Although she received counselling from the Accident Compensation Corporation (ACC) she felt belittled and treated like a child by the counsellor.

> *She wasn't really good…she just used standard ways of dealing with trauma, like by using toys to illustrate your pain. But for me, I felt like I was more intelligent than that. I could articulate pain without using animals and without using words like I FEEL SAD or I FEEL MAD and things like that. So the whole mental health system didn't give me enough credit (Mapihi).*

Prior to a bipolar diagnosis, several wāhine had sought assistance from mental health services due to symptoms of ill health from earlier trauma and experience. Most wāhine went on to develop chronic and acute psychological difficulties. As young wāhine Huia and Mapihi were diagnosed and treated for *major depression*, and Hine, Tina and Awhi had been diagnosed with postnatal depression. Hine said that *"through that not very nice experience and having a baby, and lack of sleep and stuff like that, I think it aggravated things"*. Tina's diagnosis of postnatal depression was immediately followed by her bipolar diagnosis. She also said that she was depressed following the loss of employment and shortly after, she experienced a negative reaction to her medication which resulted in a manic episode.

Awhi was the only wahine diagnosed with bipolar disorder as an adolescent. She became stressed because of relationship problems, and she started hearing voices and becoming paranoid. She was also smoking marijuana and drinking heavily.

> *In my teen years, when I was about 16, the paranoia started, it was terrifying sometimes, it was like you'd go into places and it was quite scary. You'd think people could hear what you were thinking about.*

Awhi was working when she became unwell. Her boss took her to the mental health service where she was diagnosed with bipolar disorder.

> *I kept on drinking a lot, mostly drugs really that led to a lot of smoking marijuana, that triggered it off. They put me into hospital and gave me some medication and then yeh.*

She said that she did not have much support and that her friends abandoned her. Awhi did not talk much about her childhood; however alcohol was a significant feature throughout her life and impacted on her ability to get well.

> *Four times I've slipped up in the last 7 years on alcohol, because I used to drink and drink full on for 10 years and hearing voices and getting paranoid, I was paranoid for years, it drove me crazy (Awhi).*

Some wāhine experienced such high levels of dysfunction in their upbringing that their causal influence could not be overlooked.

Wāhine who had engaged with mental health services prior to their bipolar diagnosis received mostly pharmacological treatment, others were isolated and unsupported, and some chose to minimise their contact with peers. Tui said that in hindsight there were signs that something was happening:

> *I was starting to isolate myself a bit in the last 2 years of high school. I think my family might have put it down to me being shy or something. I still had mates, but I'd isolate myself a bit. And I went nursing for a while when I was 19 before I went to Europe, and I was just overly emotional about lots of things, and I think it was sort of…talking with my brother, looking back, he could see things that were starting to creep in from about 16 onwards, then fully blown at 22.*

Tui's isolation could have been due to normal developmental factors; however, she felt that this was the point where she noticed that she was different to others. She became unwell following her OE (overseas experience) in Europe when she was 21-22.

A few wāhine spoke of experiences of mental ill health during adolescence/early adulthood which were not fully examined at the time.

When Huia began to feel unwell she went to seek help but said that it was a difficult process trying to convince the services to put her in with a specialist:

> *I was telling them that I need to see the specialist and that I'm really unwell, but that was actually before I flipped, before I went into my mania. It just took forever to get help.*

Wāhine described a range of experiences and dispositions that, in their view, were either not dealt with properly at the time or not dealt with at all. Aroha added that while in the service, she found it *"scary"* going into group therapy:

> *I think there's one other girl my age and everybody else is at least in their 30s or 40s, and it's like they haven't even heard of this or had any help, until they're too far on (Aroha).*

Four wāhine spoke of suicidal behaviour and self-harm behaviours during times of pressure and struggle. Niwareka had made three serious suicide attempts at age 14, 23, and again in her 30's but she recalled that there was no follow up after each attempt – "*each time I was just put in hospital and then sent home. I was never ever sent to a psychologist for help…my stomach was pumped, and I was discharged with no follow up*".

Three wāhine described their suicidal and self-harm behaviours as calls for help, unable to communicate what they were going through. Mapihi explained:

> *Help seeking was cutting my wrist, sort of because, well now people know I'm sad, like someone acknowledge this please, someone acknowledge that it's real*".

Aroha also added "*those are all cries for help, it's all saying that something's not right here and that I need to fix it, and you're trying to fix it on your own*". The narratives thus far expose the depth of vulnerabilities experienced by wāhine and their whānau. Their stories are expanded below.

Vulnerable families

One third of wāhine spoke of exposure to extreme hardship during their childhood that included *physical and emotional abuse* from parents, foster parents, and step-parents, and a lack of support when life began to spiral out of control. Other negative childhood experiences included, caregiver mental health issues, exposure to alcohol abuse, controlling parents, high CYFS (Child, Youth and Family Services) involvement (foster homes), and sexual assault.

Hera described her father as a "*control freak*" who had a *"mental attitude and torturing way of talking to mum".* Hera's first bipolar episode occurred after she had "*rumbled with him*" and ran away from home. Hera's story highlights a situation similar to other wāhine where a reaction to a stressful event precipitates excessive alcohol consumption over a period of days. As a result, Hera spent 3 days drinking and not sleeping. She said that she woke up in Tokanui Psychiatric Hospital and has since spent most of her life in and out of mental health services.

> *They told me I had manic-depressive bipolar disorder. I had no idea what it was. Eighty-five, 87, 89, 91, 93; I was in there for 3 months, 96, 97, I was in there a lot longer.*

Having an unstable home environment during childhood was mentioned in a few of the interviews. Both Tania and Niwareka were removed from the parental home as children. Niwareka lived in more than 30 foster homes after being removed from her mother's care at age 2 as a result of her mother's mental illness.

> *I endured mostly sexual abuse, physical abuse, and emotional abuse in all of those homes (Niwareka).*

As a result of the constant shifting, she felt as if she had lost her identity *"there was no record of my life"* she said. Her story shows a long history of mental health concerns that were untreated and aggravated by her personal circumstances. Similarly, Tania described a history of abuse that went

unchecked. As a young wahine, Tania had several negative encounters with her foster families which resulted in her running away:

> *I ran away a lot after being sent to CYFS. The cops would find me but I'd just run away again. And I'd tell them too. I just got sick of all the abuse and all of the hidings. Anyway, I got put back into CYFS, the doctor put me on medication. I was sleepy, and I'd cry a lot. I was a mess. Our step father was a paedophile and a murderer, and he was a rapist.*

Tina shared a similar story of early childhood abuse which affected her developmental pathway. She said that she was sexually abused and beaten as a child which contributed to what she says was severe trauma:

> *…My mother's response to things was to bash. My sisters couldn't stand up to it. My mother said I was a nutcase. I was going through counselling at the time. I chose to take the perpetrators (of the sexual abuse I experienced) to court. So mother used my mental health as an excuse saying, "she's mad, she's got a mental illness".*

The blame and abuse Tania, Tina and Niwareka were exposed to as children continued into adolescence and adulthood where they entered unstable and abusive intimate relationships.

The effect of pre-existing stressors on the wellness of each wahine across their life-span was noticeable. These effects, as well as the impacts on their whānau will be explored further in *Section Four*: *Consequences of Bipolar Disorder.*

Significant events – Contextual factors

Several subthemes emerged within the context of *precipitating factors* and *adulthood* indicating that pre-existing factors had yet to be dealt with. Upon finding themselves outside the family home, wāhine had autonomy to make decisions whether they were right or wrong.

Many wāhine experienced *multiple* stressors which caused the *"balance to tip"*. Most of them were able to recall the critical incident which triggered

their first episode, however some wāhine said that particular incidents triggered later episodes. For some wāhine, the use of drugs and alcohol offered them the illusion of happiness and temporary relief which resulted in unanticipated effects, causing major problems for them. And for some, living in abusive relationships was often the cause of mental illness. A critical point for many wāhine occurred after they left home, had a relationship breakup, had children, or experienced stress at work.

Drug and alcohol use

The use of drugs and alcohol by some of the wāhine became a form of self-medication to relieve stress or to escape from painful thoughts and feelings when under pressure. As noted earlier, Hera's mental health issues started in her early teens. She was frequently in and out of services and eventually became a heavy drinker. She was assessed and treated for an eating disorder and she was constantly self-harming:

> *I think it wasn't until my mum started going to my bedroom, finding stashes of alcohol hidden everywhere and stashes of pills everywhere and razors and that kind of stuff, I think it was then that they kind of freaked out and thought, no wonder she can drink all the time and I was stealing my parents alcohol.*

As a pathway to wellness however, most of the wāhine described no longer using drugs or alcohol, or at least having managed their consumption.

> *I try and keep in contact with those that don't drink and do drugs and that because I don't want to go back to that drinking world because it will only bring back my illness a lot more (Awhi).*

Wāhine became aware of the effects of substance abuse, and in their determination to get well; they took the appropriate steps to distance themselves from the use of substances to ease or relieve their stresses.

Intimate relationships

This theme reflects the impact that intimate relationships had on each wahine. Some stories clearly show that abusive, controlling and manipulative

partners were often the cause of mental unwellness; while others were not capable of being in a relationship because of their mental health issues. Other relationship effects were the end of a marriage or partnership. A reminder at this point in the analysis is that most wāhine have yet to be diagnosed with bipolar disorder.

Abusive relationships

Six wāhine described relationship difficulties most commonly involving abuse, rejection or a relationship break-up. Tina described her first bipolar episode as the *"longest"* and the *"strangest"*. At the time she was in a violent relationship – "*I was in an abusive, violent relationship. It affected my babies and me being pregnant. I was suicidal, I started cutting"*. She felt that this was a reaction to trauma rather than a mental illness – *"If I was in a loving relationship (or not in an abusive one) would I be like that? I don't think so"*.

Hine became pregnant at 18 years old and was married to Walter when she was 19. She wondered whether getting pregnant at such a young age and having a husband who was physically and emotionally abusive to her contributed to her mental health issues. *"I just felt this almighty whack…I'd never ever been hit by a man".* Walter continued to abuse her physically and emotionally.

> *I had a lot of negative stuff coming at me and it done nothing for my self-esteem. Only 1 year after we were married, we were in Hamilton and all I heard was "I want a divorce, you're effed in the head". All this negative stuff and I thought, this isn't love, it was so cruel! I was 19 at that time. I mean, perhaps it has a bearing, but that's just for me, it was so personal. But I kept on trying, you just don't give up, you always have hope that things will improve. So I stayed with him.*

Hine and Walter were married for 26 years before he left her. They had 8 children, and 2 miscarriages. Hine said that Walter 'did his own thing' and that at times she felt like a solo-mother. Walter also had multiple extra-marital affairs. Hine had 3 psychiatric admissions during her marriage, and

was diagnosed with bipolar disorder when she was 38 years old. She described her 30's as being the most difficult years:

> *I had more kids to care for, and just the home environment, and relationship more than anything else and trying to cope with the kids.*

Hine's story highlights not only abuse concerns but also the effects of unstable relationships. Unfaithful partners had a particularly devastating effect on vulnerable wāhine who, as noted earlier, were still struggling with mental health issues. While not considered 'abusive', the consequences for these wāhine produced similar effects.

Unstable relationships

This theme relates to the relationship experiences of some of the young wāhine in this study who presented with low self-esteem, self-harm, fear of abandonment, and drug and alcohol abuse. Aroha, Pua, Hine, Niwareka and Awhi were young wāhine who became unwell when there were problems in the relationship such as infidelity (real or perceived) or when the relationship had ended.

Aroha felt that her life had been heading *"downhill"* for a while, but it was the *"bad breakup"* with her boyfriend that affected her wellbeing:

> *I was really low, like not wanting to get up, not motivated, crying all day… starting to hear things and see things. I'm like, was that really there?! But I was having problems because he was too busy talking to his ex, so I was like, well if you're going to go back there then just go back, and just leave me alone.*

Pua described multiple stressors leading up to her first episode however, she felt that her relationship break up and the passing of her friend had been large contributors.

> *I was diagnosed in 2010, and I was admitted into the intensive care unit in hospital, but before that I was studying full-time at uni, I was studying full-time at Te Wānanga o Aotearoa, I was working full-time, I was*

working on releasing my album, and then I had a relationship break up and my best friend passed away. I stopped eating and sleeping for like 5 days, and I was heavily self-medicating, smoking marijuana, and then that led to psychosis.

Niwareka also described multiple stressors that had contributed to her becoming unwell, however it wasn't until her destructive relationship breakup where she realised that the *"balance had tipped"*.

Each story shows the significant impact relationships can have on the mental wellbeing of those with indications of mental unwellness and when there are multiple stressors there is eventually a tipping point. However, even though there were some examples of difficulties for wāhine within differing types of relationships, there was no clear thread to suggest that it was the mental unwellness that was the causative factor for the difficulties.

Childbirth

This theme relates to childbirth as a significant life event that precipitated mental unwellness. Of the eight wāhine in this study who were mothers, it appears that pre-existing mental health concerns were present for some, and that child birth precipitated a diagnosis of bipolar disorder or postnatal depression. Awhi, Hine and Tina were each diagnosed with postnatal depression following the birth of their children.

I think I had postnatal depression way back in 1969, but I didn't understand what was happening and I couldn't talk to anybody. But through that not very nice experience and having a baby, and lack of sleep and stuff like that, I think it aggravated things. I was trying to tend to the baby, but for me it was that, trying to look after my baby, but not really looking after myself (Hine).

Hine struggled to understand what was happening to her emotionally. She sought help from her parents, and together they went to see the family doctor who put her on medication for postnatal depression.

> *I didn't know anything about postnatal depression. Pania was my 3rd*
> *child and I wasn't supposed to have any babies after her.*

Hine and Tina lived in abusive relationships and had histories of child abuse and trauma. Their stories reflect a cycle of abuse that was not addressed for many years. Despite Tina's abusive upbringing, mental health issues were not formally noticed until she was in her early 20s. She recalled dealing with trauma-related issues such as flashbacks of her childhood abuse and that she lived with a partner who was emotionally and physically abusive to her. Tina's abusive relationship ended when her baby daughter was 3 days old. At that time, she had 2 other children under the age of 5.

> *I couldn't hold the baby...I spent hours just staring into space. Panic*
> *attacks, flashbacks of stuff. That's what I saw as unwell. I felt detached,*
> *numb...I realised that I wasn't ok. I cried a lot. I went to a doctor after I*
> *had baby and was diagnosed with postnatal depression. I never*
> *experienced a period of wellness – wellness is the opposite of all that.*

Tina entered another relationship and became pregnant with her 4th child. She said that she was aware of the risk of postnatal depression and told her GP. At that stage she was living alone with no other family around.

> *I was hospitalised after baby was born and diagnosed with bipolar*
> *disorder. The children went with their dad. I couldn't understand the*
> *diagnosis. I moved back to Wellington. I was with the community mental*
> *health team.*

While the responsibility of raising children was a protective factor for some wāhine, three of the wāhine found childcare to be a major stressor that they associated with their *"tipping point"*. It should not be assumed that the inclusion of childbirth as a possible origin of bipolar disorder illness suggests that the consequences of birth are the precursor for the illness. Rather, its inclusion is to examine the impact of the event on wāhine who might be predisposed to that illness. This will be expanded upon later.

Employment and study

As a precipitating factor, this theme relates to life events that become increasingly stressful. Life events refer to normal, expected routine situations that became too difficult for wāhine to manage. The type of situations the wāhine described included unrealistic deadlines set by employers, large workloads while studying, and the termination of employment. For some of them the work environment was tied to their wellbeing and was seen as a place of safety and stability.

For wāhine, the pressure of work, or situations beyond their control, combined with relationship difficulties led to their mental health crisis. Wāhine often described maladaptive coping patterns that fuelled their problems, such as having employment terminated, working longer hours, not sleeping, or drinking and taking drugs.

Niwareka said that she was *"one of the best in her workplace",* but as a result, more pressure was put on her to achieve higher targets:

> *I had hit 100% of the target for 3 years running. The downside however, was that I was rewarded by having the goal post raised, and with MSD and bipolar, this was the worst thing to do…In the same period I was going through a relationship break up.*

The relationship break up combined with the increased workload proved unbearable for Niwareka and had led to her second serious suicide attempt.

Tina said that she had been working as a consultant for 5 years without taking any breaks. When she finally did take a break, her contract ended without any notice. Shortly after, she became depressed and sought help from her GP who prescribed her a new antidepressant. Tina had a *"manic reaction"* to the medication which lasted for 3 days:

> *The psychiatrist said that I had reacted to the drug – called it a citalopram that created a spike. They saw that I had epilim, zopiclone. That's when they said that I had bipolar.*

A work-related stressor occurred when Huia began a church mission for 16 months. Early into her service Huia's anxiety escalated, and she said that the stress of it all had tipped her over. At that time mental illness was not openly discussed as it is now.

> *It was so important to do the mission. I had to keep going. All I needed to do was stop for a little while...but at that time they didn't know anything about mental illness. They talk about it naturally now. People didn't know. It was very frightening, because I was getting sick. My vision was blurred. I was so miserable and I knew I shouldn't feel that way. I was usually so happy.*

Huia said that she became depressed and could not be left on her own; she was eventually sent home – *"I didn't know what was happening and I didn't know how to manage it. I used to cry all the time. I was frightened, I was absolutely frightened"*. A feature of Huia's illness was related to the amount of pressure she was under. As a married woman with 2 children, she decided to try studying, but the workload became unmanageable for her. She was determined to complete them but said:

> *I had been struggling all my life but I was determined to try and get somewhere. I studied part-time then I went full-time. At that point I started to break down. I was losing it. I was stressed trying to meet deadlines. I was very, very, stressed and I couldn't function.*

Although she completed her diploma, she moved on to further study but explained that that was when she *"tipped over"*. Huia became acutely unwell and sought help from the mental health service. Unfortunately, the team did not believe she was unwell and refused to help her. It was several weeks before she received help and that was only after her husband rang the service and she refused to leave the reception area. Her experience is similar to other wāhine and will be described later.

Tui had spent over a year living overseas. When she came home she struggled to resettle and was overly concerned about her weight and what she was going to do with her life.

> *I didn't know what I wanted to do with my present I was always thinking about the past when I was overseas doing this and that. So I think the reality of it all made me get a bit unwell I think. I was now back in NZ, had to get a job, didn't know what I wanted to do, all sorts of things…I had also put on a lot of weight too.*

Her family noticed she was acting strangely and worried that she might hurt herself. Tui said that she was taken to a mental health service for assessment and remained there for a week. Tui did not think that she was managed well and that she should have stayed longer:

> *They noticed straight away, strange behaviour from about a month before leading up to when I was admitted, I was also psychotic, thinking people were persecuting me, I was getting paranoid. Just thinking people were out to get me.*

Like other wāhine, Tui was discharged before she was ready and she refused to take her medication (Tina also refused for many months) believing she was capable of managing on her own. A common finding among wāhine was that they enjoyed feeling the feeling of being elevated, particularly after periods of deep depression. Tui said that *"the doctor was spoiling my buzz. I was hearing all these good voices. Everything was wonderful and a lot more exciting than it normally was".*

Within a few months, her illness worsened to the extent that she committed a violent crime and was hospitalized for several years. She said she does not remember the event at all but believes it to be true. Her diagnosis was changed to paranoid schizophrenia.

Other wāhine mentioned study as a major stressor which triggered their illness. Mapihi's first episode was brought on by a heavy workload while at university. She described having little support during her time there and it was not until her 3rd year at University where she began to experience changes in her mental state:

> *It seemed so huge that it was a mountain I couldn't climb. I couldn't see how I could climb it, and I didn't have a strategy for how I would do that. But the more I thought about it, the more unwell I started to get…I realised I hadn't slept for a week, because if I slept, or if I ate anything then I'd feel guilty that none of this work was getting done.*

Mapihi took the initiative to go and see a counsellor because she wasn't coping. Due to a previous episode of depression, the counsellor referred her to a psychologist where she was subsequently given a bipolar diagnosis.

As mentioned earlier, Pua was studying full-time at two different tertiary institutions while also working full-time at a Kōhanga Reo (childcare centre). Pua's friend had passed away in the same period, and she was also experiencing a relationship breakup. She said she was admitted to hospital after 5 days of not eating and sleeping, and self -medicating with cannabis. She was sectioned under the Mental Health (Compulsory Assessment and Treatment) Act and had a diagnosis of bipolar disorder.

> *I thought I was hearing my ancestors, I thought I was Papatuanuku, I thought I was the Māori Moses too, I thought I was seeing demons and angels. It was like erratic thinking, one hour I'd be here, and another hour I'd be there and I'd just chop and change.*

All of the stories related in the employment and study theme above have a common thread to assist in better understanding and developing future research and treatment for sufferers of mental illnesses. It is readily apparent from the experiences related by the wāhine affected that any dormant periods of their illness became simply triggered. Their recalls of the triggering mechanisms are further examined later.

Summary

It is relevant to note that each wahine described how they came to be involved in the mental health system. Some of them received a bipolar disorder diagnosis at their first admission while others spent years, even decades in and out of services before they were diagnosed.

The delineation between psychological and psychiatric problems is necessary as participants described, in detail, the context for their episodes of mental illness and psychiatric admissions. Furthermore, the evidence for bipolar disorder was unclear as the stories showed considerable premorbid (pre-existing) mental health concerns and situational stressors that contributed to ongoing difficulties. These stories show that pathways to mental illness must be understood so that the appropriate care can be provided.

The next section examines the period when wāhine were first diagnosed with bipolar disorder and their mixed reactions to that diagnosis, where some wāhine felt that it was either incorrect, too early, or that it came too late.

Section Two: The Onset of the Bipolar Disorder Diagnosis

This section looks at the significant events, contextual factors, and the triggers which precipitated the mental health crisis and the bipolar diagnosis. It also places a focus on the way in which information about participant's experiences was communicated to them by health professionals.

Many wāhine described complications in their experiences with health professionals, and the process of assessment and diagnosis. Two wāhine had been presenting with symptoms of bipolar disorder during adolescence and early adulthood, however, it wasn't until they were into their mid-30s (Hine), and mid-40's (Niwareka) when they were diagnosed with bipolar disorder, or manic depressive disorder as it was referred to.

For many of the wāhine, some of the symptomatic presentations led directly to a bipolar diagnosis during adolescence or early adulthood (16-23 years), however, for some of the wāhine, the process of diagnosis was not so simple.

> *When just a diagnosis of chronic depression didn't work, they thought they'd look at schizophrenia or something like that, which was ridiculous because I don't hear voices in my head. I was just sad and that's what was frustrating for me. I felt I had insight into who I was and how I felt, but they were overruling it with what they would call their professional opinion (Mapihi).*

Aroha also went through several psychometric tests and questionnaires in attempt to understand what was going on for her, however, it became problematic as she was only 13 years old at the time.

> *I just kept being told depression until I got admitted the first time they said we want to look at personality disorders. They said they don't usually diagnose when you're that young because they put it down to behavioural problems.*

A predominant theme across the stories that evoked the attention of others was that wāhine posed an actual or perceived risk to themselves or others. Several wāhine spoke of suicidal and self-harm behaviours during times of

pressure and their inability to cope with the demands of work, relationships, study or childcare. Others told stories about '*bizarre'* behaviour that was concerning and out of character. Some wāhine described their first visit to a mental health service, while for others the visit was one of many. Niwareka, Tania, Tina and Hine's stories are similar**,** where multiple admissions were a feature of their lives and that living with mental illness had been taking its toll on them and their whānau.

Risk to self and risk to others

Niwareka's many suicidal attempts as noted earlier which went well into her 30s were eventually assessed when she was committed to the inpatient unit in Rotorua where a psychiatrist diagnosed her with bipolar disorder.

> *I was disappointed that I was still alive. It was as if all of those years of anger had just come out. I was determined that if I was released that I would go home and "finish the job". The pills hadn't worked and I was so angry, but I was determined to either shoot myself or drink weed killer. I was asked to volunteer to go into the ward but I wouldn't because I thought that there was nothing wrong with me, so I was committed.*

Tania started seeing a psychologist when her children were taken from her by the Child, Youth and Family Services (CYFS). Her mother and sister notified CYFS after they learned that she was living in a bus in a motor camp.

> *So it was about, the year 2000 or something, I was finally diagnosed with bipolar and by that time CYFS had taken my children. We were left at home by ourselves as children, all six of us; yet my mother was quick to judge me and call CYFS to report me. My family all knew that I had been diagnosed with bipolar but they never told my sister. She [Tania's mother] told CYFS that the whole family had tried to support me and help me with my living situation, but that wasn't true at all.*

As noted earlier, childbirth and childcare were major triggers to unwellness for most wāhine. After her second child Hine was diagnosed with postnatal depression and really struggled – *"through that not very nice experience and*

having a baby and lack of sleep and stuff like that, I think it aggravated things".
Hine's second child was born with a cleft-pallet and required "*around-the-clock*" spoon-feeding. It was not until her mid-30s that Hine was diagnosed with bipolar disorder; by that time she had five children.

Tina also struggled to care for her new born baby and was also diagnosed with postnatal depression. She explained that she was hospitalised after her child was born and she was diagnosed with bipolar disorder – *"the children went with their dad. I couldn't understand the diagnosis".*

Awhi's situation was similar to Tina and Tania. Awhi was diagnosed with postnatal depression after her first child was born. Over the years, she lost all her children:

> *I took her [Awhi's daughter] up there when I was in hospital and they said "we can't have her here", so CYFS said "we'll take her for three days" and I never got her back. For years I just kept on drinking and the illness got worse. This was about 2001 when that happened. I was on medication at the time but I can't remember what it was…But it is sad losing my daughter; I was screaming and went through all sorts.*

Awhi's daughter was placed in foster homes while her other two children lived with their father; a decision she was grateful for.

> *When I looked after her down South, it was freezing cold, but she never ever caught a cold, but then I get up here and I find out she's been through 7 homes and she's had glue ear, all these colds and you know it hurt really bad realising that she went through that. But she's good now. She's been with this family for about 7 or 8 years, and they're religious so that's good.*

Tina recalled suicidal behaviour and cutting herself while in an abusive and violent relationship but said *"looking back, is that mental illness or is that trauma? If I was in a loving relationship, or not in an abusive one, would I be like that? I don't think so". She* was given a diagnosis of bipolar disorder in her twenties after she was admitted for postnatal depression (see earlier

narrative under *childbirth*). She said she struggled to understand what this meant and what a diagnosis of bipolar II might lead to:

> *When they gave me the diagnosis I asked what it is and they told me that it has highs and lows…I remember thinking, I don't believe you guys? Yes lows, but I'd never had a high. Then they told me I was bipolar 2. They didn't explain. I asked, well is there a 3, 4, or 5 that goes after that?*

Tina described herself as 'rebellious' for the first year of her diagnosis and refused to take her medication. She felt that each time she experienced a 'manic' phase it was directly after her anti-depressant medication was changed. Her experience was similar to Huia's. Several stories highlight the risk of a spike in behaviour when wāhine took medication for the first time, or when the dosage changed.

Experiences of bipolar disorder

During the interviews, the wāhine were asked to describe their experience of bipolar disorder. This section looks at the symptoms of mania and depression, and how wāhine reacted to those experiences. Generally, they felt that they were unable to control any given situations, and that even simple daily tasks became difficult to comprehend. One quote in particular that stood out was from Niwareka:

> *My whole life is like surfing. I can never guarantee whether I am going to be on a high or a low. Some days I'd be driving to work and would have a real euphoric feeling, like something really exciting is about to happen, but then the next day driving to work I would have that sort of feeling that someone close to me has died, and there's no reason to it, that's just the way my life goes. I may even be at happy occasions or social events, yet I can't shake the feeling of being so down, and likewise at funerals or sad occasions, I may all of a sudden feel euphoric, and am unable to truly connect or feel sad emotions…These states are totally unrelated to what's going on in reality.*

The wāhine were also asked to describe experiences of mania and depression and the type of effect this had on their well-being. Some of them had full understanding of their episodes and the triggers, while several were still finding it difficult to understand their illness and the experiences they were going through.

Experience of bipolar disorder: Manic episodes

Experiences of mania were described by some as *"exciting"* and *"amazing"*, and by others as *"scary"* and *"terrifying"*. They were most commonly characterised by racing thoughts, high creativity, hearing voices, irrational choices, over spending, promiscuity, and overworking within their work place.

> *The euphoric feelings are exciting for me, it's just like geez something GREAT is about to happen. It's as if you've won lotto and you're just waiting for someone to tell you. It's not very frequent though there are more lows than highs (Niwareka).*

Niwareka went on to explain that once she was out of her manic phase she was able to *"sit there and have time to reflect"* which she found pivotal to recovery. Huia's description spoke of the difficulty to connect and relate to people and her difficulty with being put in situations where something had to be figured out:

> *It's like you're in a different sphere, and it's like you've got people all around you, but you don't feel any connection to them, it's like you're literally in a different world, but you can see everything happening around you, but there's no substance to it.*

Most wahine described experiences of paranoia, hearing voices and seeing things before the illness was identified. A negative reaction to medication resulted in Aroha hearing voices – *"it made me quite schizophrenic and I was hearing voices and I thought people were coming to kill me".* For Awhi, paranoia started after heavy alcohol and drug use, and for Tina, she explained that the voices were *"driving her mad".*

Tania experienced rapid shifts in her moods, she was constantly switching from highs to lows, racing around doing the gardens, going on shopping sprees, binge drinking and then feeling regretful about it. Most of the wāhine (8) described grandiose thoughts and risky behaviours, things that were not considered *"the norm"* for them, but after they had acted out, they were unable to comprehend how they could have done such things, as Hine said *"I just took the risk and did it",* and Huia also said *"I didn't even know I was doing it".*

> *I thought I had to do these certain things I have these visions of things that you have to do, they say its grandiose ideas...your mind is just racing and its unrealistic...you just can't believe it, it's just impossible for you to comprehend, you don't have logic, you don't have reasoning skills, you have nothing, because everything that you're experiencing is against the normal human feelings and everything I had felt in the past (Huia).*

Experience of bipolar disorder: Depressive episodes

Typically, once experiences of mania had ended, wāhine described slipping into deep depression feeling *"really low, not wanting to get up, not motivated; crying all day" (Aroha)*. For many wāhine, these periods involved a lack of motivation, excessive sleep, drug and alcohol abuse, feelings of hopelessness, sadness, emptiness, and in some cases thoughts of suicide.

> *Inside your body there's no comfort, there's just emptiness, total complete emptiness, a fear of being on your own, and just frightened (Huia).*

Pua alongside a few other wāhine felt that their depressed states were somewhat associated with their prescribed medication.

> *Most of the time I was in a depressed state, the medication was so heavy, I felt like I had bricks in my head, I couldn't think, I couldn't function, but I just thought that was my lot, this is my life you know, and it was horrible (Huia).*

Reaction to the experience of bipolar symptoms

Many of the wāhine had experienced distressing situations and disturbances to their normal mental state, and their physical and emotional wellbeing. These disruptions had a substantial impact on their self-control, eliciting *"fear", "agitation", "confusion",* and *"distress".* The majority of these impacts were due to a lack of understanding of the mental illness.

> *I didn't know what was happening and I didn't know how to manage it. That was my first time...Instead of saying that there was something wrong, and that I needed to deal with it, I just kept on blaming myself, telling myself that I wasn't good enough, because I didn't know anything about the illness...I used to cry all the time, I was frightened, I was absolutely frightened (Huia).*

Many wāhine were unable to explain the things they were doing and were not given any information once they had engaged with mental health services.

Huia had felt for a long time that she was unwell and after doing some research into her symptoms, she tried to explain to the doctor that she had bipolar disorder, but he wouldn't believe her, she was instead diagnosed with chronic depression.

> *He said you can't have it [bipolar] because you couldn't be doing the things that you are doing if you have bipolar. You couldn't be looking after your children, you couldn't be going to school, you couldn't have a relationship, you know and because most people don't.*

Being diagnosed with a mental health condition, many of the wāhine produced numerous reactions, and most commonly they did not accept their diagnosis. Some wāhine felt a lot of shame and guilt, while others felt that they had merely gone through a *"rough patch"* as Niwareka put it. The next section examines the encounters wāhine had with health and support services and the impacts the treatments they received were having on their well-being.

Section Three: Experiences of Mental Health Services

This section focuses on encounters with mental health services; help-seeking in times of crisis; diagnosis complications; and the way in which information was communicated to wāhine during the diagnostic process. It also explores the positive and negative aspects of the mental health services that wāhine were engaging with, as well as key support systems that were present during times of need.

Help-seeking in times of crisis

Many of the diagnostic processes were intertwined with hospitalization following the critical incident. Several of the wāhine (5) were able to see for themselves that something was not quite right throughout their experiences of mental ill health, while others were unable to reach out for support and seek the necessary help and guidance. Three wāhine spoke of self-harm and/or suicidal behaviour as a means of seeking help or letting people know that they were in need of help.

> *When I went to the GP to tell him how I was feeling, he just gave me sleeping tablets. I told him I didn't think I needed them, and that I just need to work my way through this, but I was never referred for talk therapy or anything. It was as if I had to attempt suicide to get help (Niwareka).*

The inability to communicate was a large factor in women not seeking help. They felt somewhat unable to express the experiences that they were going through as they also did not understand what was going on. There were various reasons that the wāhine felt unable to communicate. Mapihi disliked people showing sympathy for her, therefore she kept much of her troubles to herself. Huia, Awhi and Aroha were unable to express what was going on for them, and Hine was afraid of betraying her husband by telling her whānau about the abuse. Each time Niwareka felt pressured and stressed, she said that she would reach out to a couple of friends and ask if they were free to talk. When her friends said that they were too busy, she took that to mean that she was unworthy of their time and help. She said:

I felt as if I was saying to my friends "please help me". Well when I had time to reflect up in the ward, I remembered the actual words I had said, and not one of them would have realised that I was calling for help. I was very good at masking what was going on and no one could tell anything was going on with me. I thought I was reaching out, I thought I was screaming for help, but when I looked at how I was doing it, no wonder they didn't know what was going on. I wasn't actually saying the words.

These communication difficulties became invisible barriers preventing the wāhine from seeking the necessary help from their whānau and their social groups. However, as time went on and wāhine became more aware of themselves and their own personal triggers, self-determination became more prominent. They gradually built their own confidence to communicate more effectively and seek the appropriate help.

Once you've said it, it takes the power out of it. So it's good to let people know when you're low (Niwareka).

Many of the wāhine understood and emphasised the importance of *"speaking out"* and *"being vocal"* about letting people know when you are unwell.

Type of information communicated

Once diagnoses had been made, several wāhine described a lack of information which left them with very little understanding of their bipolar illness. Of the eleven wāhine interviewed, only two had received a clear explanation of what their diagnosis was, and two wāhine could not recall the period they were diagnosed.   Pua and Hine explained that at the time of explanation, they were unable to comprehend the information as they were still feeling the effects of their episode and the medication. For Hera and Awhi there was no explanation given at all, and for Tina the explanation was unclear. When Mapihi was first diagnosed with bipolar disorder after being sectioned, she recalls not really understanding what this meant nor was this communicated to her effectively. She felt as if *"medication is the only way out".*

There was no one within the profession who could say it to me in a way
that I understood, and for me, it sounded like it was doom and gloom,
like I had reached the end of the road and that I was never going to get
better…he didn't even talk about like, what's a way through for me and
can I do anything that's not just medication or am I just always going to
be stuck in an institution? It made me think that like heaps of my people
are getting admitted into institutions and they don't know why, no one
gives them a reason (Mapihi).

Tina also did not understand her diagnosis. When the doctor explained the highs and lows, she said *"I remember thinking, I don't believe you guys? Yes lows, but I'd never had a high…then they told me I was bipolar 2. They didn't explain any further".*

Similarly Hera explained that she hadn't received any information about her diagnosis:

They told me I had manic-depressive bipolar disorder I had no idea what
it was. No-one has ever given me any information, nothing to read. Even
in the last 10 years, I haven't been told about it. Not until my doctor
explained it to me recently. I suppose one could go on the computer and
see what they've got.

The wāhine who did not understand their bipolar diagnosis were less inclined to be able to help themselves or to seek the appropriate help. They struggled their way through experiences that they could not comprehend or make any sense of, which diverted them from a path to wellness. However, the wāhine who did have an understanding of their illness, whether it be from the health professionals or learning over time, were more equipped to manage themselves and identify triggers or signs of unwellness, and to seek the appropriate help.

Discussions around the experiences of treatment and therapy following the bipolar diagnosis drew both positive and negative emotions for wāhine. Health organisations provide a variety of services, and each has their own unique approaches to practice and treatment when working with clients.

These varying methods of practice may or may not suit the needs of each client, whether it is due to the culture of the organisation, the method of treatment used, levels of cultural competency, or perhaps the practitioners approach to engaging with, and treating clients.

Treatment concerns

Once wāhine became engaged with various health services and professionals there were an array of reactions to the treatments and the services they had received. They spoke of very little talk therapy and a heavy reliance on medication. One wahine stated:

> *The difference between people who don't live well with bipolar and those who do is that they're in residential care and they're over-medicated and under-talked... Without the talking there's no healing, and medication only numbs it" (Tania).*

Many of them also described feeling like they were *"just a number"* when engaging with mainstream mental health services. Many of the wāhine mentioned concerns around the way staff communicated with them as if they were children, and how they were treated as if they were not normal.

> *Sometimes staff out there would treat you as if you're not like them, like you don't need a husband or you don't need a partner, you know you're not well for this, you're not well enough for that (Tui).*

Predominantly, wāhine felt as if they weren't being acknowledged as real people, rather, they were just another patient coming in that required their services – *"maybe some more personal questions so that they could make me feel as if I was a person, they didn't know me, I was a stranger...nobody asked what my home life was like or what I had been through"* (Niwareka). This had a large impact on the way wāhine engaged with the service and how willing they were to participate in the treatment plans offered. Mapihi explained that within the mainstream services they did not acknowledge the importance of *"our Māoritanga"* and dimensions such as *"taha wairua, taha whānau, taha*

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tinana, taha hinengaro". Several wāhine spoke of this disconnection when discussing their own encounters.

In the Māori health organisations however, this was not the case. The staff and the services offered were responsive to the needs of the clients entering the organisations, allowing them to complete their treatment and rehabilitation within a culturally safe environment with important cultural values. Tina felt that they were more *"respectful"* of clients and that the Māori elements and aspects were pivotal to her determination to get well, she describes her determination as *"therapeutic".* Many wāhine spoke highly of the values instilled within the Māori services and the types of things that made them significant.

> *In the mainstream ward, everyone is treated the same. At Whaiora, we had karakia. We had meetings. You could talk to the staff and ask them anything. To me that ward was a good ward for the Māori. You could feel the wairua in that ward. They were sweeties (Hera).*

Wāhine who engaged in Māori services enjoyed interactions with the staff – *"they would even come in and eat with us, you know we were all whānau members to the staff, everyone was treated the same...The staff were good...they just treated you like you were one of their own you know"* (Tui). The true essence of whanaungatanga was instilled within their practices which played a large part in the positive development and rehabilitation of these wāhine.

Wāhine also mentioned the '*hassle'* of going through numerous health professionals and practitioners to receive the services they needed, Tania described it as *"inconsistent".* It became difficult for some of the wāhine as they started opening up to a professional from one service, and then suddenly having to move on to another service or another psychologist, or a psychiatrist. Those wāhine initially had to build a trusting relationship with the service and the person whom they were in contact with, which had taken time and courage to do so. Having to move on to another health professional

meant building trust with another and it was distressing having to *"tell your story over and over"*.

> *I had probably been to like 6 or 7 different therapists in all. And by the time I'd find someone I clicked with I moved on, I never had anyone for more than a couple of months…it gets exhausting (Aroha).*

This process involved being put on waiting lists, as well as miscommunication and frustration for the wāhine. Some described it as *"draining"* and *"time-consuming"* which led to exhaustion and a decline in their willingness to participate. Some wāhine found it very difficult to see specialists due to the waiting lists, Huia said that it *"just took forever to get help"*.

Hera recalled her experience of being in a rural psychiatric hospital where she was raped during times that she was paralysed from medication. She described being in a vulnerable state and being taken advantage of by a staff member, she said he did it to whoever he wanted – *"he just helped himself, he did it to anyone"*

Some wāhine also felt more comfortable with workers who had experienced some form of trauma in their past so that they were able to relate to them. Aroha felt that *"it's hard to have a doctor there that's never gone through anything like you have in their whole life and they've got a degree to show for it"*, instead it was much easier for her if it was someone who really understood the impact of similar negative experiences.

Generally wāhine described their initial encounters with health services as *"scary"* and *"horrible"* because of the environment – *"it was very much a prison, barb wire on the fences, they'd lock me in the room every night with all of the lights off, no windows, no handles on the doors"* (Pua). Often wāhine described looking around at the clients in the ward who were talking to themselves or who were in a very unwell state and thinking *"I'm nothing like that"* or *"I'm not that bad"* which left them wandering why they were being placed in these wards and institutions. Several wāhine also described what they saw as mistreatment at the time or *"physical putdowns"* as Hine put it:

They must have jabbed me with something to calm me down, it was
horrible, like belittling, humiliating, like physical put downs, but later in
retrospect, that's how they were able to help me.

Pua however felt that the wards had made her worse because of the
environment alongside the Pākehā nurses whom she felt she could not relate
to. She said:

The only person I did relate to was a Samoan nurse, because I think she
respected me on a spiritual level as well which I didn't have with the
Pākehā nurses. They didn't quite understand what I was going through,
I felt like the Samoan nurse believed me, that what I was going through
was real (Pua).

Encounters with health professionals and services involved mixed feelings
and reactions for wāhine, but it was evident throughout narratives that they
were more likely to participate and receive the appropriate help, guidance
and support when engaging with either kaupapa Māori services, or
Māori/Pacific Islander staff. Although kaupapa Māori supports were pivotal
in journeys toward recovery, many of the wāhine also described immense
support from whānau, close friends/work colleagues, and also from their
partners, which will be discussed following the next section.

Section Four: Consequences of Bipolar Disorder

This section explores the findings relative to the immediate and ongoing consequences that bipolar disorder had on the lives of the wāhine interviewed, as well as the key supports in place during times of need. It highlights consequences on work and study, and relationships with friends, partners, whānau and tamariki, while also placing focus on the personal and emotional impacts which were detrimental to the mental wellbeing of each wāhine.

Impact on work and study

Very few of the wāhine described how having bipolar disorder had impacted on their ability to work and study. The wāhine who did discuss this however touched on experiences of being unable to secure a stable job, unable to study, being too unwell to work, and being unable to attain workplace insurance.

Having bipolar disorder caused significant distress for Tui while she was working. Tui was unable to cope with the demands of her various work places while staying on top of her mental health issues. She described two work situations where she just became too mentally unwell to continue working and had to quit.

Awhi however spoke of the difficulties in trying to attain employment, explaining that it became *"quite limiting"* to get a job and *"hold it down"*. She explained that *"you can't do normal things in life, because you have to have medication just to keep you stable".* Awhi continues to struggle to find employment but she remains determined.

After Niwareka was diagnosed with bipolar disorder, she continued to work within the mental health profession supporting whānau who were dealing with mental illnesses. While working she explained that most days she would be fine, but some days she could not take the pressure but said *"I just have to push through those times and fake it"* which left her *"extremely drained"* afterwards and had a significant impact on her health. She also described difficulties in being able to receive insurance:

> *Because bipolar disorder had been put on my file, it had affected my professional life where I was unable to get income protection insurance…Insurance of any kind became more difficult for me to attain.*

This was a barrier for Niwareka because she knew that she was a committed employee, and regardless of her bipolar diagnosis, she never missed a day of work until she was admitted to hospital.

Study for many of the wāhine tended to be more about their own determination and perseverance to achieve a goal or an aspiration. Many of them spoke of study after their diagnosis in a positive light. It was about "*personal development"* and showing themselves and others that they did still have the skill and ability to reach and achieve their goals.

Before Pua became unwell she was studying full-time at University, studying full-time at the wānanga, working full-time at a Kōhanga Reo (child-care) and also working on releasing her own music album. After she was diagnosed with bipolar disorder, the University would not allow her to go back until she was *"completely in the right place",* however the wānanga allowed her to continue her Bachelor of Māori Visual Arts from home.

> *They were very supportive, the tutors even came to my house to help me when I needed help. I got one-on-one time and I finished my degree in the four years.*

Although she wasn't allowed back into university, she managed to complete her degree in weaving with sufficient support from the wānanga, and she was very thankful and appreciative of that, she said:

> *I really think that weaving was a big part of me getting better again…The support, and actually having to sit there and use my brains through pulling things together.*

Study for Pua was a positive experience in her recovery, and although she was unable to continue her degree at university during that time, she is now re-enrolled and working towards completing her degree in psychology.

Social and intimate relationships

Many of the wāhine described difficulties in maintaining friendships and relationships, mostly after they had been diagnosed with bipolar disorder. Tina, Awhi and Tania became more and more distanced from their friends as a result of the shame, guilt and stigma attached to bipolar disorder. Tania described feeling *"socially inadequate",* and Tina just stopped ringing friends because of embarrassment she felt after she had done something *"out of the norm".* Both Huia and Hera felt unable to connect and relate to people, and Pua*,* who was once a *"social butterfly",* became very withdrawn and kept to herself as a result of being bound to her home for two years.

Niwareka began to feel *"socially-phobic"* not wanting to attend any social occasions which involved a lot of people:

> *I would always decline any kind of invitation to socialise. However, it was important for me to ensure I had some contact with people and stay connected even though it was difficult for me.*

She also felt that she was unable to maintain close relationships as she found them *"suffocating",* in particular when she was in a romantic relationship she explained that she would fall in and out of love very fast, *"it doesn't last long"* she said.

There were many instances where wāhine were unable to engage in certain social situations and wanting to isolate themselves from the world. However, the importance of having contact with another person who was trustworthy and who could be a solid support was noted by the majority of the wāhine as being beneficial to their recovery and the management of their illness.

The following sections look at how having bipolar disorder impacted on these wāhine on a personal level, as well as how it impacted on their relationships with whānau and children, child-rearing, and study and/or employment.

Personal impact

During the initial stages of bipolar disorder, wāhine experienced disconnection and often spoke of feeling *"isolated"* or wanting to *"isolate"* themselves from others. Many of them felt *"shame", "guilt", "embarrassment", "self-doubt"* and very low *"self-esteem"* during periods of unwellness. Tina explained:

> *I hated myself, I walked with my head down and shoulders hunched. I didn't look at anyone in the eye. All I saw was illness and ended up with me self-harming. I stopped ringing friends. I didn't want them looking at me in disgust.*

These feelings were associated with the stigma attached to mental illness, as well as the manic and depressive episodes that had occurred in their past and the consequences of those episodes. Tania experienced a lot of derogatory remarks from people who found out that she had bipolar disorder including several negative reactions and comments. She said that *"everyone was too busy pointing the finger at me instead of understanding my mental illness".* This was something that Tania also experienced with her whānau and their lack of support.

Some of the wāhine felt that having bipolar disorder impacted on their ability to act or react appropriately in certain situations, and some also felt unable to read certain situations and body language which was difficult for them. Many of them also described intense paranoia which left them frightened and unsure of what to do because they did not have an understanding of what was going on for them, while others described feeling *"flat"* a lot of the time or feeling *"like a zombie"* as Pua put it. They associated these feelings of drowsiness with the amount of medication they were taking at the time; however paranoia tended to disappear when they were on the appropriate medication.

The impact of bipolar on some of the wāhine was very draining, and in most instances they just did not want to socialise. However, occasionally they would *"put on a mask"* as some wāhine described it and just *"play happy"*.

This caused a further loss of energy for those wāhine and had a significant impact on their health.

The personal impacts of having bipolar disorder were quite significant for wāhine, and for a long time had hindered their ability to live positive, healthy and well lives. Their perseverance with the process of learning about and really understanding the illness and also understanding themselves really helped them to push through barriers of *"self-doubt"* and *"low self-esteem".* It was the enabling element that assisted them to pursue their goals and focus on their aspirations to live well.

Impact on relationships with whānau

Mapihi had a close relationship with all of her whānau, however she explained that the *"sympathy"* was too overwhelming for her. As a result, she began to hide things from her whānau and did not tell them about the stress and pressure she was experiencing.

> *They'd look at me like I was just damaged, but I already felt those feelings for myself, I didn't really need anybody else to feel that for me. I couldn't even be strong for myself at the time so it was very hard for me.*

Her whānau would talk about her illness behind her back but not with her which she felt also hindered their relationship, she felt that there needed to be more communication about what she was going through.

Several wāhine also recalled making bad judgements and getting into a lot of trouble both with the law and with whānau. These bad and impulsive decisions occurred in particular while wāhine were in their manic phases. Their actions were often frowned upon by whānau members but they explained that they just had no control over what they were doing. In coming out of their mania, they were left feeling *"confused"*, *"embarrassed"*, and for some *"worthless"*. For example Tui had been hearing voices telling her that people were out to get her which led her to commit a violent crime. She said *"when I got well I couldn't understand how I could have done such a thing".* As a result of her actions her whānau had somewhat distanced themselves from

her unsure of how to support her – *"it's been pretty hard even for my mother and father because after doing such a thing they must have been nervous at first, even though I am their daughter"* she explained.

As mentioned earlier with Tania, her whānau were not supportive and had notified CYFS of her behaviour and living conditions, and this lack of support further distanced Tania from her whānau.

Impact on child-rearing and relationships with tamariki

Having bipolar disorder can have significant impacts on women who have the additional task of raising and caring for children. Eight wāhine in this study had children, and just over half of them were single mothers at the time of the interview. One of the questions put to the wāhine was in regards to how bipolar disorder has impacted on their ability to raise and care for tamariki, and also how has it impacted on their relationships with their tamariki. The two major themes emerging here were the *need for support* to raise their tamariki, and tamariki as a *source of strength and well-being*.

Some of the wāhine felt the need to be on their own so that they could figure out and really understand what was going on for them, and although they did feel like they had let their children down, it was in the best interest of their children and for their recovery. Huia explained that she had a *"short fuse"* when it came to raising her children *"especially while on medication"*. She was quick to react and take her frustrations out on them, but she now realises that this was a normal part of parenting and that there will always be good and bad days, with a mental illness or not.

Many of the wāhine spoke of unfavourable consequences for themselves and for their children. Five of the wāhine felt that raising children was very stressful especially while trying to manage their mental illness and keep themselves well.

Hine identified her children as helping her through in terms of maintaining a focus and also providing practical help. She explained that she was putting all of her attention on caring for her children, but this was detrimental to her

own health and wellbeing. It also put a strain on her older children as at this point she did not have the support of her husband, and her older children were providing her with that support.

> It's been very trying for my kids I think. Sometimes I felt like a big hoha, like a burden. When I've been sick or in hospital, they've taken our responsibility to look after the rest of the kids while he's off doing his own thing in Wellington, his fling. I just think that that's just so unselfish, it's just their love.

These types of actions strengthened Hine's relationship with her children and her many moko, all of which she attributes to her recovery process.

Some of the wāhine described weakened relationships with at least one of their children as a result of a manic or depressive episode. Children who did not understand their mothers' illness were more inclined to direct a lot of anger, hate and blame toward them. Tania has had a bad relationship with her daughter since her daughter was 19 years old. Her daughter blamed her for a lot of the things that went wrong during her upbringing and does not allow Tania to see her own grandson because of this broken relationship even though Tania had built a very strong bond with him. Tania was afraid for her daughter's health and was afraid that her daughter was showing symptoms of bipolar disorder.

> I'm just hoping that she sees a doctor who might be able to help her I just really don't want her to follow my path and end her life early.

Awhi acknowledged that she had made several mistakes while raising her children and to this day has minimal contact with them. Her son's partner had recently had a baby, her first moko, but she explained that the effects of the medication had made her *"drowsy"* and *"forgetful"* and on her moko's second birthday, she forgot to phone and wish her happy birthday. Since that day, her son has denied Awhi all contact with him and his children, something that has caused Awhi significant distress. Awhi did express her desire to *"reconnect"* and to *"find that bond"* again with her son.

> *His daughter is my first grandchild and I'd like to keep in contact with her.*

Her journey of recovery is fuelled by her self-determination to mend what has been broken and move forward positively and well.

A few of the wāhine were unable to raise their children due to other family members stepping in, or high CYFS involvement. Tina and Hera had at least one of their children removed from their care by whānau because they were unable to cope with the stress of looking after them. Tui did not have children of her own but could recall high CYFS involvement among the wāhine in the mental health service, she said *"all of them had kids, and 99% of them had the kid taken away, and the lucky ones they were given to an aunty or their grandmother or something, but it can be very sad"*. This was the case for Awhi where CYFS had taken her daughter away without properly informing her:

> *I had postnatal depression with my first daughter. I brought her up here and I was in hospital and they said "we can't have her here", so CYFS said "we'll take her for three days" and I never got her back. I've tried a lot of things to get her back. I went to all the appointments…but it never happened.*

Experiences of being watched over by CYFS and discrimination from CYFS, whānau, and other health professionals have provided many challenges in the lives of many of the wāhine. Tina described a long history of CYFS involvement:

> *CYFS was around me a lot when I was unwell in the early days… The father was really abusive and it kept making me unwell and I was making bad judgments. CYFs were constantly threatening to take the baby away. I fought that, I didn't want to lose my baby. I dug deep within myself. They weren't supportive. They policed me and my whānau. They didn't say which organisations could help.*

She explained that having a mental illness did not make her a bad mother, it just meant that she required extra support from others to raise her children.

She said *"if I had lost a limb I would have got more support. Would they have taken my babies if I couldn't catch up with them when they crossed the road?"* Although this made an impact on Tina's wellbeing, she was determined to keep her children and is still in close contact with all four of them.

Caring for children added extra strain on wāhine, particularly for those who were single mothers, or who were going through dysfunctional relationships. Having their children removed from their care was highly associated with their emotional vulnerabilities and their unstable life circumstances. The most important emerging theme here is that with the support from whānau and others, and self-determination, wāhine were able to overcome these challenges, particularly once they came to know themselves and what was possible for their whānau.

For Tui the impact of having bipolar disorder was quite negative in terms of being unable to bear a child. She was discouraged by doctors to have children and she explained that not having them was one thing that really upset her, although, she does see the positive side and enjoys time spent with her nephews.

> *I don't see it as such a big issue now, I've got 9 nephews.*

She further explained that it is not about *"not being well enough to raise children"* but that it was more about *"the support base when you have children…if you don't have support it's the hardest job out"*.

For many wāhine, caring and looking out for the wellbeing of their tamariki was a very significant aspect of their own personal wellness and recovery. Regardless of whether or not they struggled to care for their children, it was evident that they put their children's wellbeing ahead of theirs whenever possible, and with the strong support from other whānau members, they were still able to maintain those positive relationships. Without that support however some wāhine lost their bond with their tamariki, but it is an ongoing process for them to reconnect.

Much of the recovery process required wāhine to come to terms with these impacts and find a way to accept them and move on, even if it meant starting over again. At this point in their journey many of the wāhine discussed the process of learning as they made their mistakes, but accepting those mistakes and finding ways forward through self-determination to live well.

The following section identifies key supports that aided and guided wāhine to a place of wellness, where they were able to build up their confidence and regain autonomy over their lives.

Key supports

The public sector mental health services alongside key community support groups helped wāhine to overcome their initial struggles with mental illness through treatment, support and medication. Unfortunately most of them experienced mainly unfulfilling, and almost inadequate assistance from the public sector as related by the wāhine in the above sections.

For the majority of wāhine however, their greater recovery was highly enhanced through the *aroha* and *support* from the Māori health organisations, key whānau members, friends, and partners.

Whānau support

There were key characteristics about particular whānau members who assisted wāhine in their recovery, for example, values and behaviours such as *"accepting"* wāhine with their mental illness and treating them as *"normal people"*; support in the form of *"caring for tamariki"* during periods of unwellness; *"awhi"* and "*manaakitanga"* from whānau who cared for them in times of depression and stress; and most importantly *"aroha"* as Hine put it – *"knowing that I'm loved, by my whānau, children and friends...I just feel so blessed and rich in their love and in their presence"*. Concepts of *aroha* were evident in all stories of recovery, and it was important for the wāhine to have at least one key person who could be trusted and who *cared*.

Trusting others to seek help and support on their behalf was an important factor in the stories of the wāhine, because when times became difficult and

overwhelming for them, they were unable to reach out and seek help for themselves. Although all wāhine did not mention this explicitly, the call for others to step in and help was evident in their stories. Awhi offered advice for people who are supporting whānau with bipolar disorder and other mental illnesses:

> *You need to advise them and encourage them, and to be there when they're really stressed out going through a hard time. Because when we get unwell and we really need them, it's like whatever, but just to be there and go out of their way for us when were down. Most of all just to help them, give them hope, and to let them know that life is worth living for…it's kind of sad. Direct them into the organisations out there you know, there's a lot of people out there just at home doing nothing, even if the organisations reached out to those people at home, you know, there's no connection.*

Although most wāhine had identified a key whānau member who supported them through their recovery, all of them were also able to identify other whānau members who weren't so supportive of them and their illness. That at times actually hindered the recovery process. Some of the wāhine spoke of whānau members who would report them to *Child Youth and Family Services (CYFS)*; whānau members who were *"quick to judge"* their thought processes, behaviours and actions without understanding the bipolar illness; whānau members who were *"embarrassed"* of them during times of manic behaviours; and whānau members who *"distanced themselves"* and were not there in times of need. For example, Tania explained:

> *My family all knew that I had been diagnosed with bipolar so I don't see why they notified me to CYFS. They never told my sister [who now supports Tania]. My mother told CYFS that the whole family had tried to support me and help me with my living situation, but that wasn't true at all. No one supported me, the family did nothing, I've always been on my own.*

Tania already had a bad relationship with her family but this caused further distress on her health and wellbeing. A few of the wāhine described such situations where there was a lack of support and distance from certain whānau members, but overtime they spoke of being able to overcome this and surround themselves with positive and supportive whānau.

Support from friends/work colleagues

Wāhine also spoke of close friends and work colleagues who supported them in their goals and aspirations, and also in their daily tasks. One of the key things wāhine found important when receiving support from friends was that they needed to be *trusted*; they also needed to have an *understanding* of bipolar disorder; the friends needed to *understand them and their circumstances*; and most importantly, be able to identify their *triggers* and *signs of unwellness*. For example, when Niwareka would become overwhelmed with a heavy workload, she would start to get manic and overwork to the point of destruction, *"stress"* was one of her major triggers. But once she became aware of her triggers she was able to communicate them to key people within the workplace whom she trusted.

> *I have given my work colleagues my permission to seek help on my behalf if they can see me taking on too much work, or if I look like I am about to have a depressed episode or something.*

Very few of the wāhine spoke of friends as their key support person. However their friends' help, encouragement, and love were important aspects of their journey toward wellness. The majority of the wāhine appreciated the strong friendships they had, and those *"persistent friends"* who did not allow them to slip through the cracks as Mapihi put it, the friends who would visit even if it was only every so often.

Support from partners

Although many wāhine experienced abusive and negative relationships with partners, there were several of them who had experienced relationships that were encouraging, understanding and supportive of their needs. Tui felt that it was important to have a *caring relationship* and to have someone there

with you through recovery, and Huia expressed her appreciation for her *supportive* husband and his contribution to her recovery. Tania described her husband as her *"rock"*, because he understands her and he understands her illness:

> *My husband doesn't have a problem with it. I say I've got bipolar he says he's got a bad heart, so what.*

Wāhine who were involved in supportive relationships described the relationship as a source of wellness for them. Pua had experienced a destructive relationship prior to being diagnosed with bipolar but has since found a loving and supportive partner, she said *"he's supported me through my illness its actually made our relationship stronger, which I never thought I'd find someone like that"*.

Those wāhine however who were not in relationships still had a key support person in their life and did not see being single as a barrier to their recovery. For Niwareka, to keep well was *"to not be in a relationship"*, she explained that *"it wasn't a loss or emptiness, but it made me happy"*. This was a choice that she had made influenced by her past experiences of negative relationships, which she was happy with.

For many wāhine, whānau were their first source of support during the initial stages of bipolar disorder. This brought about unexpected opportunities for them to discover the positive and negative networks within their whānau. Ties were strengthened as support was offered and for many wāhine, their bonds with certain whānau members were enhanced. Although some whānau were quick to jump in and support the wāhine, there was a mixture of positive and negative impacts on relationships with various whānau members. When parents and other whānau members were supportive, their help was much appreciated and had made positive contributions towards the recovery of each wahine.

The following section discusses aspects of wellness and tools that the wāhine discovered throughout their journey which helped them to live well, and manage their illness.

Section Five: Pathways to Recovery

In this section, wāhine describe what wellness means for them and the process of becoming self-determined and motivated to get well and remain well. Recovery has been an on-going journey of healing and transformation, calling wāhine to reclaim their identity and positive sense of self despite the presence of mental illness and the clear psycho-social influences that impacted on their wellbeing. Wāhine wanted to live a life that went beyond being a consumer in the mental health system, where they could make significant contributions to their whānau and the wider community. Each wāhine drew together recovery strategies and the various types of supports that assisted them in their journeys.

Recovery and wellness

Recovery and wellness for wāhine meant managing their lives and reducing psychiatric symptoms, while also being able to set goals for themselves and their whānau and achieving them.

> *Intellectually, wellness for me is having my mental faculties about myself, clear and sound decisions for myself. Wellness is also being able to reflect. Physically, it's about being present in my body, being able to listen and feel my body, feel the sun being connected with Papatuanuku, being open to messages from my tupuna and recognising it. From a whānau level, we are happy, engaged, planning together, and sitting together. Un-wellness is the opposite of all of that (Tina).*

The importance of having *trusting*, *meaningful* and *nurturing* relationships was mentioned by more than half of the wāhine as being pivotal to recovery, and was associated with overall wellness.

> *The things that have made the most difference to me were when friends would say come and do something with us and I would usually say no, but they never gave me the chance to say no and that's probably a really good thing, because I would just isolate myself and make excuses for why I couldn't do something because I just didn't want to. So getting out*

and stepping out of my comfort zone is a good thing and having them persist. So it's cool to just have those persistent friends (Mapihi).

Wellness for wāhine was also about achieving a sense of self and knowing exactly what they enjoy and what makes them happy. Accounts of wellness often involved creative works and hobbies such as painting, jewellery making, weaving, singing and song writing, baking, and for Huia having her own home and creating a Māori atmosphere full of Māori designs. For wāhine to really engage in these creative works, it required focus and dedication. Taking the time out to focus on something that they enjoyed was pivotal to their recovery, *"you just focus...as simple as it may sound, it's really effective...those little achievements can lead to way bigger things"* (Hine).

Pua felt that weaving was a large part of her getting better again:

The support, and actually having to sit there and use my brains through pulling things together...it's therapeutic. It's the focussing, and doing something with your hands, creating things.

Pua continued on with her Bachelor of Māori Visual Arts after being diagnosed with bipolar disorder while she was still *"unwell"* and managed to complete her degree within the allocated four years. Over time, the work that she produced through weaving demonstrated her healing process:

In the year I was diagnosed I made a hieke, like a rain cape out of corn husk, and I died them all black, called one te pango o te pō because I was in that kind of state. And then the year after that I made a contemporary korowai out of rainbow emu feathers all different colours, and I called that te uenuku harikoa. Quite a bit of a transition, through that process I did heal, creating things.

Tamariki as a source of wellness

Most of the wāhine commented that wellness for them was the wellbeing of their whānau, and especially the wellbeing of their tamariki and mokopuna. Six wāhine expressed that their children were a pivotal aspect to their wellness and recovery.

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Hine and Hera loved to watch their children and mokopuna learn, grow and achieve, it *"took away the loneliness"* Hera explained, and Tania's bond with her grandson brought her extreme happiness. Niwareka said that looking out for the wellbeing of her son was *"part of the healing process"*, and Tui, although she was discouraged from having children, loved to spend time with her nephews.

Tina also felt that her children's wellbeing was important and decided that in order to care for them, she must address her own issues first. One of her daughters also suffers from bipolar disorder and was admitted to the mental health service at age 13. It was at that point that Tina realised she needed to be strong and well for her:

> *Her going into the ward really just knocked me and pushed me to fight the illness to awhi her. We both got discharged on the same day.*

Tina's other children also had an understanding of her illness and her triggers and were quick to support and encourage her to seek help when they could see that she wasn't doing so well. Through this support her relationships with her children became stronger and stronger overtime.

Bearing and raising a child can also be a positive new experience and a fresh start for some of the wāhine. Aroha was experiencing a lot of negative thoughts about her current life situation and was persistent in trying to take her own life. It wasn't until she found out that she was pregnant that she decided to focus on recovery for herself and well-being for her child. The thought of bringing a new little life into this world has made a huge impact on Aroha's determination to get well and be there for her child, she said *"I'm pretty much still only alive because I'm having a baby"*.

Motivation and self-determination

Wāhine spoke of their strengths and the positive interrelationships of their self-determination, supports, therapies, and personal resources. Within the theme of self-determination, they often described a point at which they

realised that in order to be well, some things would need to change, and that it was up to them to make those changes.

> *I stopped blaming other people for my illness and started realising what I can do to make things better by observing other people's behaviour. It just made me realise there are things that you can do that will make it worse, and there are things that will make it better, and it's up to you. You can't fix me, I'm the only one that can fix myself, I can reach out for your support, but you can't fix me (Niwareka).*

Wāhine had to reconcile with their past in order to start on their journey of recovery. The presence of supportive people and environments enabled them to begin making behavioural and lifestyle changes to help them through their journey. A focus on healthier living and eating featured in several stories, however some wāhine had to focus on rebuilding their self-esteem and confidence in order to progress forward.

> *I worked very hard at my health, that made me work very very hard at it, so I was very conscientious to eat the right foods and stuff to try and make up for that difference (Huia).*

Wāhine spoke of their experiences and their determination to further their education in the hope of being able to contribute to the field of mental health one day. Both Niwareka and Tania have worked in mental health services and have been able to share their journeys with whānau coming through the system. Through this work, they were able to gain a deeper understanding of themselves while being able to help others.

> *Through my work in the mental health system I was learning about who I was, I wasn't out of control anymore. I was getting a better understanding of what was going on you know, I'm down today, I'm up today, just in those circumstances I was able to just stand back and look at me (Tania).*

Pua has also begun on her pathway by setting up a mental health support group for University students:

> *Me going through the system, I saw things that weren't quite right and I thought in order to change that I'd need an education, and I love psychology, I love going to lectures. I plan to go as far as I can take it, like hopefully maybe a PHD one day (Pua).*

A large part of recovery was about setting goals and striving to achieve them. This featured significantly in many of the stories. Most of the wāhine had at least one goal or aspiration that they were able to focus on, and they were all determined to achieve it.

Maintaining wellness - Communication

Communication was highlighted by many wāhine as a vital component in maintaining their wellness. Having effective communication skills meant that they were able to seek help when they started to see signs of unwellness approaching. It was important for wāhine to *"be vocal"* when feeling unwell, "*that way I don't slip through the cracks, and people know"* as Tania explained.

> *What I have learnt is to actually ask for help and actually say the words...because if I verbalise it then I'm ok. If I wasn't able to verbalise it then I've got past being ok... Once you've said it, it takes the power out of it. So it's good to let people know when you're low, and being around people you can trust (Niwareka).*

In order to communicate effectively however required an awareness of the signs and symptoms of unwellness, and also having a management plan to avoid relapse.

Several of them highlighted the importance of caring for and putting your attention on others. Huia said *"helping others brings you joy"* and Niwareka explained that *"it deflects the downward spiral into poor me".*

Hine felt that humour played a large part in her recovery:

> *The humour, you have to have the humour to get through these episodes, you know and laugh at yourself, and with others too. That has been really helpful for me (Hine).*

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Acceptance

The first step to recovery for many of the wāhine was to accept the diagnosis and to accept the things that they couldn't have in life. This proved challenging for most, however once acceptance came, they were able to move forward and start creating a management plan.

> *I came to accept the diagnosis, the triggers, and what I can't have in life. I can't drink alcohol, I also had to manage my over working as that was a major trigger for me. I had to trust people around me to make sure that I didn't over work myself (Niwareka).*

Most wāhine wanted to be in charge of their wellness and create a management plan that works for them. Tina spoke strongly about wanting to determine her own recovery plan:

> *When I think about self-determination, I know doctors have a care-plan. For me, I want to get well. I know what I want. When I'm on new meds and I want to go to sleep, I'll go to sleep. If I want to walk, I'll go and I'll let you know. I'll determine my own way of getting well. Just let me do that (Tina).*

They expressed the importance of being aware of any triggers and warning signs that may precipitate the onset of an episode. Many of them mentioned triggers such as high stress levels, over-working, over-commitment, drugs and alcohol, and physical and verbal abuse; and warning signs for wāhine included fatigue and lack of sleep, racing thoughts, and rapid speech.

> *Stress is one of my major triggers, and it doesn't have to be major. It can be one small disappointment and I go straight to that mind-set of wanting to do something bad…When I start to think and talk fast, I realise that this is also a sign (Niwareka).*

Huia along with many others felt that being able to identify triggers and signs of unwellness played a large part in them being able to cope with the situations that faced them; she said *"it makes me feel good to know all of these things about myself now"*. With their awareness, and the support from

whānau and mental health organisations, wāhine were in a better position to take action to prevent their health from getting worse by avoiding stressors and contacting health professionals.

> *I guess my biggest trigger is sleep. So if I don't get a good sleep for about 3 days, I know that I've got to go to the doctors, and I need to talk about it with my GP, and sometimes I do take medication, like I'll ask for a sleeping pill and I know that if I just get that one sleep, if I can just shut my brain down, then I'll be okay for the next week (Mapihi).*

Through their experiences, wāhine gained a deeper understanding of themselves, and also learnt how to manage certain behaviours and impulses such as over-spending, drinking alcohol, and making irrational decisions. For example Niwareka would on many occasions make irrational choices but she said *"I have learnt to sit on the idea for a couple of days and if it is still a good idea after that, then I will act on it"*. Huia also expressed the need to pace herself and keep her life balanced in order to stay well.

The following chapter expands on the above findings and introduces a detailed discussion for consideration.

Chapter Five: Discussion

In order to understand how wāhine came to be diagnosed with and recover from bipolar disorder, a life-span analysis is essential. Such an analysis provides avenues to identify the priorities, issues and information gaps which occur in the experiences of wāhine Māori. This discussion is framed within the contextual themes of *whānau connection: supporting intergenerational wellness,* and *supporting whānau connection: pathways to recovery*.

A whanau-ora approach is used as it takes into account the importance of family and the need to address disparities that exist for Māori in wider social, political, educational and health sectors (Marmot, 2005; Ministry of Health, 2005; Robson, 2007); and in particular, the disparities that contributed to significant levels of unmet needs that occurred for each wāhine, and what is needed to overcome those needs.

Whānau connection: Supporting intergenerational wellness

Wāhine defined what they thought wellness looked like to them in the context of their own lives. Consistent with the recovery literature, wellness was not just the absence of mental illness, but more so the ability to live normal and fulfilling lives (Dyall et al., 1999; Lapsley et al., 2002; Mental Health Commission, 1998, 2001; Provencher & Keyes, 2011). Wāhine wanted to have trusting and nurturing relationships with whānau and intimate partners, to be employed and to have support from employers, to keep busy and contribute in some way to their communities, to live in stable accommodation, and to reconnect and remain connected with friends and whānau.

Whānau connection is about having stable, supportive and loving relationships with parents, siblings, intimate partners, tamariki and mokopuna. Wāhine experienced disconnection from their social environments and often spoke of feeling *"isolated"* or wanting to *"isolate"* themselves from others during the illness phase. It was apparent that many

wāhine required intensive support and ongoing care for basic needs such as providing adequate housing for their whānau, taking care of tamariki, keeping safe, eating, sleeping, washing, and keeping active.

The need for basic necessities such as shelter, safety and family support is critical to recovery, and to overall health and wellbeing (Dyall et al., 1999; Lapsley et al., 2002; Robertson et al., 2013; Wolkenstein et al., 2011). Research found that during periods of mental illness and instability, psychiatric survivors live in fear of losing their housing, their possessions, their lives, and of being hurt; they also start to lose control of their basic human rights (Forchuk, Ward-Griffin, Csiernik, & Turner, 2006). The ability of wāhine to hold onto and create relationships, identify supports, and seek help services while maintaining personal space and managing their illness is heavily reduced when everyday responsibilities become overwhelming (Brown & Anderson, 1991; Burt & Rasgon, 2004; Peace & Kell, 2001). Tania credits her wellbeing to the way her sister encouraged her to take small steps to achieving larger goals; while Hine credits her recovery to the immense help and support received from her older tamariki who took care of her younger tamariki when she was unable to.

Strong whānau connections were associated with faster recovery and longer periods between relapse for these wāhine. Consistent with Johnson et al. (1999), individuals who have in place strong support systems experience less depressive symptomatology over time. Similarly, research shows that being surrounded by negativity and hostility was more likely to be associated with increased levels of depressive symptoms, poorer response to treatment, and higher relapse rates (Rowe & Morris, 2012; Walker & Diforio, 1997; Weinstock et al., 2006), which was true for these wāhine.

Some wāhine felt *"shame", "guilt", "embarrassment", "self-doubt"* and very low *"self-esteem"*. These feelings were associated with the stigma attached to mental illness (Corrigan, 2004), as well as the need to fix damaged relationships. Highlights are that when wāhine were unwell, their whānau or social supporters took them to primary and secondary care services, their tamariki were looked after, they had homes to come back to, they were

encouraged to be hopeful, they had choices about how they wanted to live, and they were encouraged to adhere to treatment and medication. Tania's sister Marama was adamant that persistence and encouragement were needed to help whānau live well:

> *You need to advise them and encourage them and to be there when they're really stressed out going through a hard time. Most of all just to help them, give them hope, and to let them know that life is worth living for...it's kind of sad.*

Consistent with the literature, being in a supportive relationship provided stability and reliability which was hugely protective for many wāhine (Robertson et al., 2013; Torrey et al., 2005).

A significant finding was that wāhine lacked support to be mothers, and faced a constant risk that they would lose their tamariki. Some wāhine described how they struggled to be mothers, while others unfortunately had their tamariki taken from their care and were unable to see them again. CYFS failed to appropriately inform Awhi that her daughter was being taken into their care, instead they explained to Awhi that they would look after her daughter for the few days Awhi was in hospital; however, Awhi never got her daughter back – *"I've tried a lot of things to get her back. I went to all the appointments...but it never happened".*

Such concerns are detrimental to recovery and mental wellbeing and in some cases prevent wāhine from seeking help and support from government agencies (Montgomery et al., 2011). However, consistent with Dyall's (1999) findings, wāhine felt secure and safe knowing that their tamariki were not at risk of being taken away from their care.

Support to be a mother

Wāhine were asked to give details about their perception of the impact of mental illness on their ability to parent their tamariki. Two areas for discussion emerged which included: *the need for support to raise tamariki* and *tamariki as a source of strength and well-being*. Wāhine consistently

spoke of their tamariki as pivotal to their wellness and recovery. However, when wāhine were unwell, they needed support to keep their tamariki safe and secure, to continue with school, and to provide appropriate information about parental mental illness.

The importance of keeping whānau together is evident. Although at times, tamariki and whānau were seen as stressors, they were also seen as protective factors as wāhine tried to improve their personal wellbeing to benefit their whānau. When wāhine were well, they needed to have their tamariki returned to them and appropriate supports put in place. These findings are consistent with whānau ora literature and research outlining the importance of support for parents with mental illness (Durie et al., 2010; Ihimaera, 2007; Robertson et al., 2013). Support to be a parent involved being in loving relationships, having access to education, being free from neglect and abuse, having appropriate housing and other necessities for tamariki, and having access to appropriate and caring social and health services.

Some wāhine talked about their experiences of being the child of a parent who had mental health concerns, while others talked about having their children taken from them. Awhi said that she turned to drugs and alcohol to manage the stress of having her child taken away and not returned. Tina's description of her history of CYFS involvement highlight the stages where she could have been helped, and show a lack of collaboration between services as well as a lack of caring support.

> *CYFS was around me a lot when I was unwell in the early days... The father was really abusive and it kept making me unwell and I was making bad judgments. CYFs were constantly threatening to take the baby away. I fought that, I didn't want to lose my baby. I dug deep within myself. They weren't supportive. They policed me and my whānau. They didn't say which organisations could help.*

Several wāhine who are now grandparents have turned to their mokopuna in the hope that they can shelter them from the effects of their parents'

psychological issues; the issues they blame themselves for causing. After over 45 years of institutionalisation, Hera talked about how important her mokopuna and parents are to her wellbeing. After losing her children, Hera is determined not to let her mokopuna grow up exposed to their parent's substance use or family violence. Like other wāhine, her journey of recovery is fuelled by her determination to mend what has been broken and move forward positively and well.

Addressing unmet needs

The life-span approach to this study highlights how unmet needs impacted on wāhine to the extent that psychological issues were perpetuated from childhood into adulthood and on into the next generation. Consistent with previous research, wāhine who experienced physical, sexual and psychological abuse within their early-life or relationships described a life-time of stressful situations and events not only for them, but also for their children, partners, parents and siblings (Adrian & Hammen, 1993; Lapsley et al., 2002; Moreno et al., 2012; Robertson et al., 2013). Some wāhine now in their late 40s, 50s and 60s talked about their mental health issues as tamariki, adolescents, parents, and grandparents.

The effects of sexual abuse and family violence were evident for many wāhine. Niwareka described a life of foster care, neglect, and sexual and physical abuse which was not addressed despite being involved in child protection services since she was 3 years-old, and the mental health system as an adult. She experienced hardship and stress for almost her entire life until she was able to leave an abusive marriage. Tania also had similar experiences and the intergenerational effects of unmet needs have transferred to her daughter as she witnessed family violence, and experienced unstable living environments. The literature is extensive as to the effects of childhood adversity on healthy developmental pathways (Adrian & Hammen, 1993; Blehar et al., 1998; Freeman et al., 2002; Gluckman, Low, & Franko, 2011; Spataro et al., 2004).

The section above describes the relationship between positive and supportive whānau connections and addressing unmet needs to recovery. Barriers to recovery for wāhine were the absence of whānau and social connections and the absence of opportunities to engage in meaningful, productive, creative and restful pursuits due to illness. In the following section, maintaining wellness is described in the context of healthy and stable relationships. Although it is recognised that systemic, external, and institutional issues are significant influencing factors on Māori mental health, the focus here is on the importance of whānau.

Supporting whānau connection: Pathways to recovery

When wāhine experienced healthy personal relationships they were better prepared to incorporate wellness strategies into their lives. On the other hand, unhealthy relationships contributed to illness and aggravated stress levels which reduced their ability to live well in other aspects of life. Consistent with the literature, opportunities to live balanced lives where wāhine could reconnect with life and engage in leisurely pursuits were protective elements (Kartalova-O'Doherty & Doherty, 2010; Lapsley et al., 2002).

When external and internal factors to achieving wellness were optimal, wāhine were able to reconnect and enjoy their family and personal relationships. The external factors that contributed to and maintained wellness for wāhine were access to stable and appropriate medication, access to prevention and early intervention services, access to information, access to talking therapies, treatment for co-existing mental illness, access to kaupapa Māori services, and being productive, creative, and able to contribute in meaningful ways.

Access to stable and appropriate medication

Wellness for some wāhine was related to appropriate and stable medication. Huia described a sudden shift from a depressed state into an extreme high after her psychiatrist prescribed her *"an enormous amount of pills".*

> *I woke up in the morning and it was like going from dark to light. It had*
> *an instant impact on me. I could feel again. I could taste. I was so*
> *excited. But then I went straight into this mania. I didn't know. I thought*
> *I was ok. You can imagine the elation that I felt. I thought I had lost my*
> *life, then straight into being really happy. But I was really aggressive*
> *(Huia).*

Consistent with the literature, it is not uncommon for wāhine to experience medication induced mania (Burt & Rasgon, 2004; Leibenluft, 1997) as a result of taking inappropriate medication or incorrect dosages. Wāhine benefited most from services that gave them the right medication, provided detailed information about medication and their effects, were careful about dosage and combinations, monitored compliance, controlled for medication side-effects, and treated wāhine as valued, autonomous members of society.

Access to prevention and early intervention services

Wāhine benefitted from services that prevented or addressed their illness and unmet needs in a timely and appropriate manner. In terms of early intervention, wāhine benefitted from services that respected their self-autonomy, confidentiality, and those who offered clear explanations about the services available to them. Several wāhine described how difficult it was for them and their whānau to access services during the initial stages of becoming unwell, a finding that is consistent with previous research findings (Barnett & Lapsley, 2006). For some wāhine it was about protecting their children from being taken away, and for others it was about not knowing how to articulate what they were experiencing (Jansen, Bacal, & Crengle, 2008; Lapsley et al., 2002; Montgomery et al., 2011). The stress and anxiety associated with not being seen placed wāhine, their whānau, and members of the public at risk and at a disadvantage.

Access to information

An undeniable gap for wāhine was the lack of information offered to them about bipolar disorder. Information and resources that are accessible provide hope and optimism, is realistic, and promotes autonomy, which was needed

at all stages for wāhine. Basic information about the development, course, co-existing disorders, consequences, assessment, and treatment of bipolar disorder would have enabled wāhine and their whānau to understand the nature of their thoughts and behaviours.

Some of the wāhine felt that health services lacked an appreciation of Māori models of mental health. Tina described being cautious about her cultural beliefs because she knew they would be used against her – "*the doctor asked me if I spoke to my ancestors, "damn straight I do" I said, but that's not being ill".* Wāhine benefitted when they felt safe talking about their cultural worldviews and perspectives on illness.

Access to talking therapies

Only three wāhine were offered psychological therapy for bipolar disorder. Others saw a psychiatrist, a nurse, or a counsellor. However, in general, medication was the primary treatment offered. A difficulty with medication alone is that although bipolar is considered to be a biological disorder, it is also known that the course and expression of bipolar disorder is affected by a range of bio-psycho-social and environmental variables (Johnson, 2005; Kessing, Agerbo, & Mortensen, 2004); however, the bio-medical model of mental health is still privileged.

Co-existing mental health issues such as substance abuse, anxiety, depression, relationship difficulties, postnatal depression, suicidality, trauma and post-traumatic stress disorder were prevalent across the wāhine and required ongoing support. Given the extent to which co-existing disorders occur with bipolar disorders (Baxter, Kokaua, et al., 2006; Kawa et al., 2005), wāhine benefitted from a shared approach to treatment utilising medication alongside psychological therapies, talking therapies and/or occupational therapies (Royal Australian and New Zealand College of Psychiatrists Clinical Practice Guidelines Team for Bipolar Disorder, 2004).

Access to kaupapa Māori services

For unknown reasons, wāhine did not access mainstream community health services. Their perceptions of mainstream psychiatric services ranged from

'good, ok, and beneficial' to 'unsafe, dehumanizing, and lacking an understanding of Māori worldviews'. Māori service providers however offered wāhine an opportunity to engage in support services that encompassed several cultural aspects such as karakia, kaitahi, aroha, and manaaki, with staff who were able to engage with wāhine on a more meaningful level. Inpatient, community, and community-residential kaupapa Māori services were used by wāhine at several stages in their journeys.

Consistent with the literature, the unique features across kaupapa Māori services for wāhine were that services emphasised inclusiveness, collectiveness and interdependence, they felt comfortable and cared for, they felt that they could be Māori and that their worldview and culture was understood without the need for explanation, they felt that they were valued as Māori, and that the services were accessible (Durie et al., 2010; Dyall et al., 1999; Lapsley et al., 2002).

Recommendations by the Mental Health Commission (2000) emphasised the need for kaupapa Māori approaches and services in order to enable Māori to return to states of wellness and achieve their best life potentials (Mental Health Commission, 2000; Wharewera-Mika, 2012). Furthermore, these services must have Māori staff who feel confident and able to practise from a kaupapa Māori standpoint, and are supported within their work environment to do so (Mental Health Commission, 2000; Wharewera-Mika, 2012).

Being creative and productive

Research is yet to be conducted on how fostering and preserving creative and productive traits can enhance and improve outcomes for individuals with bipolar disorder (Galvez et al., 2011; Murray & Johnson, 2010), however, creativity and productivity were some of many factors key to maintaining wellness for the wāhine in this study. Wāhine appreciated opportunities to paint, make jewellery, weave, attend church, sing and write songs, bake, and complete home projects, as it allowed them time to focus on something productive and creative.

Huia's wellbeing was enhanced by having her own home and creating an atmosphere filled with Māori designs as she felt that she did not grow up valuing her Māori identity. Huia's sister had helped her to purchase her first home which Huia said helped her to overcome a sense of failure about not owning a home. Wellbeing for Huia, like other wāhine, incorporated eating healthy meals, exercising daily and part-time study. Pua's wellbeing was enhanced through many creative works including singing, song writing, and weaving. The work that she produced through weaving demonstrated her own personal journey of healing:

> *In the year I was diagnosed I made a hieke, like a rain cape out of corn husk, and I died them all black, called one te pango o te pō because I was in that kind of state. And then the year after that I made a contemporary korowai out of rainbow emu feathers all different colours, and I called that te uenuku harikoa. Quite a bit of a transition, through that process I did heal, creating things.*

Wellness strategies for wāhine also included being able to study, be employed, maintain a household, exercise and eat well, and to look after their whānau, which are all consistent with previous literature (Dyall et al., 1999; Mental Health Commission, 2001; Robertson et al., 2013). Being able to engage in meaningful activities provided wāhine with a sense of purpose, hope, and a positive view of life.

The consequences of a life-long mental illness for many wāhine meant that they were limited in their ability to earn a consistent wage to purchase food, a car, and household items, to pay a mortgage, to pay insurance, to pay education costs for their tamariki, to pay rent or to pay medical expenses. For example, all wāhine received a complimentary groceries voucher valued at $40.00 for participating in this research. All wāhine were very appreciative, and Hera said that the voucher was equivalent to a week's shopping for her.

Unmet needs: Substance abuse/self-medication and risk

A developmental progression was evident in the stories about substance use. For many wāhine, substance abuse began in late childhood or early

adolescence and continued on throughout adulthood. Awhi drank alcohol and smoked cannabis for many years to escape from her thoughts:

> *Four times I've slipped up in the last 7 years on alcohol, because I used to drink and drink full on for 10 years and hearing voices and getting paranoid, I was paranoid for years, it drove me crazy.*

Most of the wāhine gravitated to substances to escape from the psychological effects of anxiety, trauma, stress, depression, sexual and physical abuse, dysfunctional relationships, cognitive distortions (e.g., shame, guilt, hopelessness), or 'to fit in' with peers. Only two wāhine said they did not use substances at any time in their lives.

A pattern emerged in the stories that showed the chronicity of unmet needs for wāhine. Niwareka had made three serious suicide attempts at age 14, 23, and again in her 30s but she recalled that there was no follow up after each attempt – "*each time I was just put in hospital and then sent home. I was never ever sent to a psychologist for help...my stomach was pumped, and I was discharged with no follow up*".

Risk refers to the impact of unresolved needs for wāhine or their whānau. In many cases, wāhine responded to the stressors in their lives with little or no support and often with extreme consequences. Risks included suicidal ideation and behaviour, unsafe sexual activity, drug and alcohol abuse, physical and emotional abuse, and risk to others. Huia's comments reflect the view of other wāhine who sought relief from the effects of chronic and acute depression and distress.

> *I understood why people wanted to die. Now I understand why people want to commit suicide. Inside your body there's no comfort. There's just emptiness, total complete emptiness, a fear of being on your own, and just frightened.*

Many of the wāhine in the study not only had significant childhood difficulties, they also lived with abusive partners or families, or both. All of the wāhine who were diagnosed with postnatal depression, except Huia, experienced

emotional, physical and psychological abuse from their partners. Some also had unfaithful partners who openly flaunted their infidelities.

Some of the wāhine experienced multiple stressors which caused the *"balance to tip"*. Consequently, some were incarcerated, hospitalised, had their tamariki removed from their care, or diagnosed with additional disorders. In hindsight, wāhine recognised that substance use only provided limited relief or further aggravated the problem.

The findings highlight the importance of addressing unmet psychological needs at earlier points in life (Baxter, 2008). The indicators for psychological risk are well known (Baxter, Kingi, et al., 2006; Wharewera-Mika, 2007), however, these wāhine fell through the system and were not helped early enough to prevent further damage. The effect of drugs and alcohol was extensive and intergenerational, preventing wāhine from engaging with mental health services, exiting abusive relationships, building lasting relationships, and maintaining employment.

Diagnostic issues

An issue of diagnostic reliability arose during this study as it appeared that for some wāhine, the features or indicators of bipolar disorder were more often related to intense reactions to environmental, social and psychological stressors, and substance use. These findings are consistent with the literature on the effect of such stressors and substance abuse on the exacerbation of bipolar symptoms (Weinstock et al., 2006). For example, Mapihi engaged in self-harming behaviour in attempt to seek help while being bullied and teased in high school *"because, well now people know I'm sad, like someone acknowledge this please".*

The trend throughout the narratives was that wāhine who were in dysfunctional relationships were diagnosed with depression, personality disorder, anxiety disorder and eventually bipolar disorder. Like other wāhine, Tina had a long history of hospitalization, however she also had unresolved sexual abuse trauma and she was living in an abusive relationship.

I was in an abusive, violent relationship. It affected my babies and me being pregnant. I was suicidal, I started cutting. Looking back; is that mental illness or is that trauma? If I was in a loving relationship, or not in an abusive one, would I be like that? I don't think so (Tina).

Diagnostic issues were common for wāhine during their reproductive years. Wāhine who were pregnant, post-natal, and who had tamariki were often diagnosed with post-natal depression or bipolar disorder. Tina struggled to care for her new born baby and was diagnosed with post-natal depression. She explained that she was hospitalised after her child was born and then she was diagnosed with bipolar disorder – *"the children went with their dad. I couldn't understand the diagnosis".* She said she struggled to understand what this meant and what a diagnosis of bipolar II might lead to:

> *When they gave me the diagnosis I asked what it is and they told me that it has highs and lows…I remember thinking, I don't believe you guys? Yes lows, but I'd never had a high. Then they told me I was bipolar 2. They didn't explain. I asked, well is there a 3, 4, or 5 that goes after that?*

Genetics, or unmet needs?

More than half of the wāhine described a history of mental illness within their whānau and associated their experiences of bipolar disorder with psychosocial stressors or a genetic predisposition.

The presence of whānau members with mental health and substance abuse issues could be viewed as widespread unmet needs. However, it appeared that for some wāhine, whānau history may have been used as evidence of bipolar disorder rather than further examining their backgrounds. Tania's comments highlight the potential socio-cultural pitfalls in diagnostic reliability. She said that the women in her family were the most affected by depression and bipolar disorder and that negative childhood experiences and environmental stressors set her on a path of mental illness.

I would say I had the potential for bipolar disorder as a result of my past experiences as well as the environmental stressors that surrounded me. My grandmother had bipolar, my aunty had it, my brother had depression; two other females in the family had bipolar. It seems to be much worse with the females in our family. I think my daughter has bipolar too (Tania).

The effects of intergenerational family violence, family mental illness and environmental stressors are clearly implicated in Tania's story and others like her. The narratives of all wāhine clearly show the lifespan trajectory – **wāhine Māori experiences of bipolar disorder are intergenerational experiences of unmet needs.** Pathways to recovery require assistance to resolve underlying and co-existing issues, and to reconnect whānau and strengthen whānau ties (Johnson et al., 1999; Mental Health Commission, 2000, 2012; Ministry of Health, 2002a; O'Hagan, 2001).

Limitations of the present study

One of the methodological limitations to this research is the use of only one one-on-one narrative interview per participant. The intention of narrative interviews is to invite participants to narrate freely with occasional prompts to trigger their memories (Hopf, 2004); however, it may be difficult to understand the life story and get the totality of a person when conducting only one single interview (Breakwell, 2000).

This research may have benefitted from the use of multiple interviews to gain a fuller understanding of the participants' experiences; or mixed methods such as symbolic interactions or visual methodologies (Denzin, 2004) to add to, and enhance the information gathered from the narrative interviews. One of the problems with the use of mixed methods however is that it can become time consuming for both the researcher and the participant as it requires multiple engagements; and the data can also become overwhelming in terms of quantity and analysis.

In terms of the small sample size, the focus and intent was to achieve an intimate qualitative research to best understand the experiences of the

wāhine who participated in the study. Their experiences are a reflection of how they as wāhine Māori have lived with bipolar disorder. The intention of the research was not to generalise the findings across all populations; therefore the size of the sample is not as important as it is to quantitative research.

Implications of the present study

This study reinforces the importance of understanding Māori mental health needs from a broader systemic perspective, while also recognising the potential factors placing wāhine at greater risk of developing mental health and addiction issues (such as poverty, inadequate housing, unemployment, and low education).

A **collaborative approach** from the primary and secondary health sector, the broader social, education and justice sectors, Child Youth and Family services, mental health and addictions sector, and Work and Income New Zealand **is necessary** in order to address unmet needs related to child protection, suicide risk, adequate housing and nutrition, employment, family violence, and drug and alcohol addictions.

This research also emphasises the need for wāhine whaiora to have access to parental mental health services that operate from a kaupapa Māori and whānau ora worldview; and that supports be put in place to eliminate the barriers preventing tāngata whaiora from accessing the supports and services they require. Wāhine and tāngata whaiora may also benefit from resource packs that provide a range of culturally relevant causal theories, and assessment and treatment options for bipolar disorder and other mental illnesses.

Future research on the topic of wāhine Māori with bipolar disorder should be conducted to address intergenerational experiences of unmet needs on wāhine and their whānau; to understand the impact of parental mental illness on tamariki; and to explore the effects of unresolved sexual and physical abuse and trauma on the life pathways of wāhine Māori.

Conclusion

This research has explored the experiences and life pathways of 11 wāhine whaiora who have been diagnosed with bipolar disorder at some point in their lives. Using a narrative inquiry approach that privileged kaupapa Māori perspectives, wāhine were prompted to share their experience of bipolar disorder and their stories of recovery. Their journeys showed the extent to which health services could have been more responsive to their needs as wāhine, mothers, wives, daughters, sisters, cousins and friends.

An exploration of the lived realities of wāhine produced a deeper understanding of the significant levels of unmet need and their impact on wāhine and their whānau. In actuality, the fragmented approach to providing health care for wāhine made their condition worse and shifted the focus away from broader systemic causes.

Key to recovery for wāhine was the importance of supporting them to reconnect and stay connected with whānau and friends (Ihimaera, 2007). Strong whānau connections and ongoing support facilitated faster recovery for wāhine and longer periods between relapse (Johnson et al., 1999; Mental Health Commission, 2000). Having supportive and trusting relationships also provided wāhine with stability and reliability, and emphasised the aroha existing within their relationships and within their whānau (Robertson et al., 2013; Torrey et al., 2005).

In keeping with a Māori worldview, whānau ora is paramount if we are to live a fulfilling life (Durie et al., 2010; Ihimaera, 2007).

Hutia te rito o te harakeke
Kei hea te kōmako e kō?
Kī mai ki ahau;
He aha te mea nui o te Ao?
Māku e kī atu,
He tāngata, he tāngata, he tangata!

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Appendices

Appendix A: Waikato University ethics approval

School of Psychology
The University of Waikato
Private Bag 3105
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Phone 64-7-856 2889
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THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

17 October 2012

Dr Moana Waitoki
School of Psychology
University of Waikato
Private Bage 3105
Hamilton

Dear Moana

Ethics Approval Application – #12:56
Title: Māori experiences of Bipolar Affective Disorder and pathways to care

Thank you for your ethics application which has been fully considered and approved by the Psychology Research and Ethics Committee.

Please note that the approval is for three years. If this project has not been completed within three years from the date of this letter, you must request reapproval.

If any modifications are required to your application, e.g., nature, content, location, procedures or personnel, these will need to be submitted to the Convenor of the Committee.

I wish you success with your research.

Yours sincerely

Dr Nicola Starkey
Convenor
Psychology Research and Ethics Committee
School of Psychology
University of Waikato

Appendix B: Interview schedule

<u>INTERVIEW SCHEDULE:</u>

<u>*Part A*</u> *- the aim of this interview is to identify in your own words the story of your journey with bipolar disorder.*

- When did you first become aware that you had Bipolar Disorder, and what happened next?
    - The beginning of the disorder
    - Perceptions about the background or cause
    - When it was recognised or when participant became aware
    - Help seeking patterns – who was involved
    - Reactions from whānau, friends, partners, children, employers, and so on…

The next part will look at detailed descriptions of your experiences -

- What was the course of the disorder? – What happened before it started?
    - Symptoms (thoughts, feelings, behaviours)
    - How long did the episode last?
    - What happened right after (consequences)?
    - What kind of encounters did you have with health services
    - Describe any assessment procedures
    - Describe any treatment procedures
        - How were you treated by others
    - What information were you given about the disorder?
    - What did/do you know about it?
    - What was the length of time with the disorder (number of episodes)?
- What do you think was the impact of the disorder on you, your whānau (& extended), and friends?

<u>*Part B*</u> *will look at the Recovery processes*

- What worked for you?
- What didn't work for you?
- What effect has the disorder had on your life?
- How do you manage the disorder? What helps?
- How do you think others view you as a result of this disorder?
    - What do you say to others?
    - What do you keep to yourself? (if anything)
- What do you think is important for Māori with Bipolar Disorder?
- What advice do you have for others with Bipolar Disorder?
- What advice do you have for service providers?
- If you could change anything in your journey what would you do?
- Is there anything you would like to add?

Thank participant, give koha, and discuss follow-up to check accuracy of transcript….

Appendix C: Research flyer

Bipolar Affective Disorder
Māori Experiences and Pathways to Recovery

Have you experienced Bipolar Affective Disorder at any time in your life? Or do you know of anyone that has? If the answer is yes, we would like to hear from you.

We would like to talk with you and ask you about your experiences of living with Bipolar Disorder as well as the type of support you received from health services, the community, whānau, or friends. We are interested in finding out what you think helped you in the difficult stages and beyond. If you are interested, or know someone who might be, text, email or phone using the numbers below:

Dr Moana Waitoki (Phd, Clinical Psychologist)
Cell: 027-5737-493   Email: moana@waikato.ac.nz

Pare Harris (Masters Student-Waikato University)
Cell: 021-466-574   Email: petkh1@waikato.ac.nz

Māori and Psychology Reasearch Unit (MPRU)
This research has been approved by the Waikato University Ethics Committee, Lakes District Health Board and Iwi Governance Committees, and the Northern Y Ethics Committee

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Your information is confidential **AT ALL TIMES**

Appendix D: Participant information sheet

Māori and Psychology Research Unit (MPRU)
Located in the Department of Psychology
The University of Waikato
Private Bag 3105
Hamilton, New Zealand 3240

THE UNIVERSITY OF
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Information Sheet for Participants

Wāhine Whaiora:
Māori Women's Experiences of Bipolar Affective Disorder and their Pathways to Recovery

Researcher contacts:

Dr Waikaremoana Waitoki, MPRU
University of Waikato,
Private Bag, 3105
Hamilton Ph: 07-856-2889
Email: moana@waikato.ac.nz

Parewahaika Harris, Masters Student
University of Waikato,
Private Bag, 3105
Hamilton Ph: 07-856-2889
Email: petkh1@waikato.ac.nz

Tēnā koe, you are invited to participate in this research study. Before you decide to participate, you may like to think about it and discuss it with whānau or friends. The researchers will contact you within a week to see if you are willing to participate. You are free to decide whether or not you wish to take part.

About the project

This research project seeks to explore the experiences of wāhine Māori who have been diagnosed with Bipolar Affective Disorder and their pathways to wellbeing. At present, there is little information about the lived experiences of Māori with Bipolar Affective Disorder and the type of support they receive or should receive. There is also little information that explains why Māori present more often than non-Maori to mental health services. We plan to interview and record the stories of 10-15 Māori women and to explore those stories to look for key themes that show how their journeys can inform future services.

Recruitment

We aim to interview people over the next 3-4 months and will recruit participants through Māori and non-Māori health service providers and community groups. It is important to know that we will not contact you directly. If you choose to be involved, you may contact Waikaremoana above,

or let your contact person know and he/she will provide us with your contact details. Your personal health records are not available to us, and we do not need to see them.

Participation
We would like to interview Māori who are managing their condition and are currently well. Your participation in this research is voluntary. We will organise a time and a place that suits you and invite you to bring a support person if you need one. When we meet, the interviewer will discuss the project, answer questions you might have and ask you to sign a consent form. With your permission, we would like to record the interview so that nothing you say is lost.

The interview is informal and we would like you to be as comfortable as possible. We expect that the interview will take around 90 minutes. The interviewer will ask you to talk about, in your own words, your experience with Bipolar Affective Disorder. You may stop at any time for a break.

If you decide that you do not wish to continue the interview, please let the interviewer know. There is no pressure on you to continue. Should you wish to conduct the interview at another time, you may do so. If you are not able to continue with the interview due to the effects of bipolar symptoms we will not conduct or continue with the interviews. I will assist you to access any support you require although it is likely that you may be withdrawn from the study.

Confidentiality
No material that could personally identify you will be used in any reports or presentations without your consent. If you wish to have your information made public and if you have provided details that could identify whānau, we will ask you to obtain evidence from them that they consent to their details being made public. All information held about you will be kept in a secure room and will not be accessible to anyone other than the researchers named above. After 10 years, the information will be destroyed.

Results
After the interview, we will prepare a summary report for you that documents your journey with Bipolar Affective Disorder. After you have read the summary report, you are free to change any part that does not suit you. We will provide another copy to you to check. You may also decide to withdraw your information from the study, if this happens, we will do that without pressuring you to change your mind. After you have seen and approved the report, we will analyse them according to the overall goal of the research. At this stage, most of what you have said will be blended with the

stories of others. Following that analysis, we will write the main findings of the research into a report.

The project will lead to the publication of scholarly articles in local and international journals, a report, conference papers and some educational materials. We will also deliver a community presentation to the referring organisation. You are welcome to attend this presentation and bring whānau or friends if you choose. If you would like to receive copies of the final report, let the interviewer know and they will organise this with you. There will be a short delay between the interview and publication of the results. The project is set to last for 12 months.

Ethical Approval

The researcher and interviewers are bound by and committed to following the standards established by the Code of Ethics for Psychologists Working in Aotearoa (http://www.psychology.org.nz/Code_of_Ethics) and the Health Information Privacy Code (1994). This study has received ethical approval from the University of Waikato Ethics Committee and the Multi-Region Ethics Committee, which reviews national and multi-regional studies, ethics reference number (NTY/12/06/052).

Thank you for your time and attention. Please feel free to contact one of the researchers if you have any questions about this study.

Appendix E: Participant consent form

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Consent Form for Participants

<u>Wāhine Whaiora: Māori Women's Experiences of Bipolar Affective Disorder and their Pathways to Recovery</u>

I have read the ***Information Sheet for Participants*** for this study and have had the details of the study explained to me. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time. I understand that I may use whānau or friends to help me ask questions and understand the study.

I also understand that taking part in this study is voluntary (my choice), that I am free to withdraw from the study at any time, or that I can decline to answer any questions in the study. I understand that if I withdraw, I will not be affected in any way. I understand that my participation in this study is confidential and that I will not be identified at any time without my consent. If I choose to identify details about my whānau, I agree to provide evidence of their approval.

I agree to participate in this study under the conditions set out in the ***Participant Information Sheet***.

Signed:_____   Date:_____

Name: _____

Age:_____   Iwi/Hapū Affiliation:_____

Project Explained by:_____

Researcher's name and contact information:

Parewahaika Harris, Masters Student, Department of Psychology, University of Waikato, Hamilton, petkh1@waikato.ac.nz; 07-856-2889

Supervisor's names and contact information:

Waikaremoana Waitoki, Department of Psychology, University of Waikato, Hamilton, moana@waikato.ac.nz; 07-856-2889

Linda Nikora, Department of Psychology, University of Waikato, Hamilton, psyc2046@waikato.ac.nz; 07-856-2889

Appendix F: Glossary of Māori terms and proverbs

GLOSSARY OF MĀORI TERMS

Aotearoa	*New Zealand*
Aroha	*Love*
Awhi	*To care for, to look after*
Hapu	*Subtribe*
Hieke	*A large coarse cloak of rough flax*
Iwi	*Tribe*
Kai	*Food*
Kāinga	*Settlements, Home*
Kaitahi	*To eat together*
Karakia	*Prayer*
Kaumatua	*Elderly Man/Elderly Woman*
Kaupapa Māori	*Māori ideology*
Koha	*A token of gratitude*
Kōhanga Reo	*Māori language preschool*
Koroua	*Elderly man, grandfather*
Kuia	*Elderly woman, grandmother*
Mahi	*Work*
Mana	*Authority, prestige, power, status*
Manaaki	*To support, to take care of*

Manaakitanga	*Hospitality, kindness*
Māoritanga	*Māori culture, practices and beliefs*
Moko/Mokopuna	*Grandchild/grandchildren*
Pakeke	*Adults/parents*
Papatuanuku	*Earth Mother*
Rangatahi	*Younger generation, youth*
Taha hinengaro	*Psychological health*
Taha tinana	*Physical health*
Taha wairua	*Spiritual health*
Taha whānau	*Family/social health*
Tamariki	*Children*
Tāngata whaiora	*People in the pursuit of wellness/with mental health needs*
Te ao Māori	*The Māori world, traditional Māori worldview (includes: language, customs, protocols, and the Treaty of Waitangi)*
Te pango o te pō	*A name given to Pua's weaving creation (the dark of the night skies)*
Te uenuku harikoa	*A name given to Pua's weaving creation (the delightful rainbow)*
Te Whare Tapa Whā	*The four cornerstones of health*
Tikanga	*Māori customs and protocols*
Tino rangatiratanga	*Sovereignty*

Tupuna	*Ancestors*
Wāhine whaiora	*Women in pursuit of wellness*
Wahine	*Woman*
Wāhine	*Women*
Waiata	*Song(s), to sing*
Waka	*Canoe*
Whaiāipo	*Partner, boyfriend, sweetheart*
Whakawhanaungatanga	*Process of establishing relationships*
Whānau ora	*Contemporary indigenous health initiative in New Zealand driven by Māori cultural values*
Whānau	*Family*

WHAKATAUKI (Māori Proverb)

Hutia te rito o te harakeke,
Kei hea te kōmako e kō?
Kī mai ki ahau;
He aha te mea nui o te Ao?
Māku e kī atu,
He tāngata, he tāngata, he tangata!

If the heart of the harakeke was removed,
Where will the bellbird sing?
If I was asked,
What was the most important thing in the world?
I would be compelled to reply,
It is people, it is people, it is people!

The above proverb reflects the Māori reference to the harakeke (flax) plant as a whānau unit.

The outer leaves are the tupuna (ancestors); the inner leaves are the mātua (parents); the most inner leaf is the rito or pēpe (baby). Only the tupuna are cut as the mātua are left to protect the pēpe.

Accordingly the proverb reflects that without the sound of children in the world (the next generation) mankind will not survive.