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**Women's Experiences of Medical Miss-Diagnosis:
How Does Gender Matter?**

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Abstract

Misdiagnosis is increasingly becoming a significant health risk. Women experience higher rates of misdiagnosed illnesses and health conditions compared to men. An androcentric, patriarchal medical system has historically under-researched female bodies and therefore has limited knowledge about recognising symptoms in women. This also extends to tests and treatments that have been developed on male bodies, making them inefficient and inappropriate for female bodies. Additionally, women have historically been positioned as 'emotional', 'weak', 'hysterical' and 'hypochondrial', meaning they are not taken seriously as legitimate patients and are considered unreliable symptom reporters. Collectively, the lack of knowledge, and negative prejudices against women, produce healthcare that ignores and silences them, and fails to diagnose and treat them appropriately. This thesis engages a qualitative feminist standpoint, using a narrative framework to explore women's experiences of misdiagnosis and how they make sense of it. The research draws on semi-structured interviews conducted with eight women aged between 26 and 57 years old, who had experienced a misdiagnosis of an illness that is equally likely to affect women and men. A descriptive inductive analysis approach was used to look for similar experiences in the narratives to inform categories and themes. This research found that a misdiagnosis is highly distressing and often leads to disparate health outcomes. The women described doctors lacking knowledge to make a correct diagnosis, or knowledge to treat their conditions. They needed to advocate for themselves when symptoms continued or worsened. The women experienced rude and sceptic treatment, adding to the burden of being unwell. It is recommended that future research continue to privilege women's voices in healthcare settings, and explore the misdiagnosis experience from the perspective of healthcare professionals to enable more transparent and collaborative healthcare for women.

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The Context

My interest in this research topic stemmed from my own experience with misdiagnosis. Although my symptoms were not 'typical' (I had no right-side abdominal pain), my general practitioner (GP) was confident about a diagnosis of appendicitis and sent me to the hospital. However, the emergency department doctor diagnosed me with an ovarian cyst and sent me home. Two weeks later, with symptoms fluctuating, I developed right side abdominal pain and my GP returned me to hospital care. I spent 24 hours in a critical decision unit being told that I was experiencing a gynaecological problem and would not need surgery. Finally, an ultrasound to confirm the cyst revealed a burst appendix and I was booked for surgery after all.

A one hour, key-hole procedure was scheduled, but once it began, they found that the infection was extreme. A specialist was needed to assist with the 15cm diameter mass. My surgery took approximately three hours and I was discharged from the hospital thirteen days later, after aggressive, intravenous anti-biotic treatment. This experience caused significant trauma for me and my family, and it raised a lot of questions around why it had happened. How had I been released from the hospital with a diagnosis of an ovarian cyst when my GP was so confident I had appendicitis? And why were the doctor's in the hospital so convinced that my illness was gynaecological from the outset, instead of considering all possibilities?

To make sense of my experience I started trying to answer my questions. I found that my experience of misdiagnosis and dismissal from a healthcare setting was unfortunately not unique. Abundant anecdotal accounts during the 1980's prompted feminist scholars to investigate the conditions in which misdiagnoses were occurring. Researchers directed attention to the doctor-patient relationship, medicine as a social institution, and sociocultural beliefs about women (Munch, 2004). It was thought that because women were repressed in patriarchal societies, it would be a logical step to suspect a patriarchal medical system in the repression of women within healthcare settings (Munch, 2004). Women described not being taken seriously, being treated as 'time wasters', with their symptoms misunderstood and funnelled into psychiatric

diagnoses such as depression, anxiety or hypochondria (Adams et al., 2008; Berg Gundersen, Sørli, & Bergvik, 2016; Katz, Seaman, & Diamond, 2008; McSweeney, Lefler, & Crowder, 2005). Women receive less pain medication than men during hospital stays (Hoffman & Tarzian, 2001) and women are diagnosed with asthma when presenting with identical symptoms and histories as men diagnosed with chronic obstructive pulmonary disease (Chapman, Tashkin, & Pye, 2001; Delgado, Saletti-Cuesta, Lopez-Fernandez, Gil-Garrido, & de Dios Luna Del Castillo, 2016). These examples represent the various forms of discrimination women endure in medical settings. Any delay in a correct diagnosis is difficult for the patient. It can result in psychological distress, family strain and social isolation, increased physical discomfort, and the worsening of the condition, potentially resulting in death (Berg Gundersen et al., 2016; Waldron et al., 2012; Wehbe-Alamah, Kornblau, Haderer, & Erickson, 2012).

Drawing from feminist principles that argue for social change and improving women's lives (Akman et al., 2001; Birns, 1999), this work aims to shed light on the problematics of misdiagnosis of biological illnesses for women that might otherwise be ignored, and draws attention to the serious implications of misdiagnosis on women's lives (Hornstein, 2013). This work engages a narrative approach that privileges silenced voices, allowing them to be heard in a way that is meaningful to their lives (Kim, 2016; Rickard, 2015; Squire, Andrews, & Tamboukou, 2013). I appreciate that inclusive research, such as this, can act as a catalyst for change in social arenas and influence attitudes and, importantly, healthcare policy.

To achieve these goals, this research specifically explores women's experiences with misdiagnosis of medical conditions that affect women and men equally (those which are not specific to women's bodies), to shed light on this devastating phenomenon and to explore how women make sense of their experiences. Illnesses that affect women and men equally are better able to represent a potential gender bias in a misdiagnosis experience.

The Androcentric Biomedical Health System

This chapter traces how Western culture is traditionally androcentric in nature, meaning women are explicitly and implicitly considered inferior to men, and treated accordingly. This means poorer outcomes for women across social spheres, such as healthcare and education. It will then discuss how women are positioned as second-class citizens in Western medicine, resulting in poorer outcomes with health and illness, and within healthcare settings. The chapter moves on to explore assumptions about women's bodies, symptom manifestations and emotional stability. It looks at the way in which women are dismissed from medical settings without diagnoses, with psychiatric diagnoses or incorrect diagnoses for their complaints. These misdiagnoses can have serious repercussions for women's health, resulting in delayed and incorrect treatments.

Gender and Power in Culture

Androcentrism, the social practice of privileging men over women, dominates Western medicine and cultures, reinforcing patterns of inequality, power (control, authority or influence) and vulnerability between genders (Munch, 2004; Parker, Larkin, & Cockburn, 2017; Verdonk, Benschop, Haes, & Lagro-Janssen, 2009). In this sense, gender does not exist in a vacuum. It is intimately entwined within socio-political and cultural contexts (Celik, Lagro-Janssen, Widdershoven, & Abma, 2011). Culture can be understood as shared customs, beliefs, values and traditions that are passed on through social learning, or learning from others (Triandis, 2010). Within particular cultures, what is considered 'normal' is determined by dominant groups (Cermele, Daniels, & Anderson, 2001; LaFrance & Stoppard, 2006). In Western cultures, this is (white) men. Women are consequently positioned as 'inferior', 'other to' and 'less than' men (Hare-Mustin & Marecek, 1998; Katz et al., 2008; Ussher, 2004), producing a power hierarchy whereby men are at the top and women below. Men in positions of power can be found in traditional heads of households, heads of businesses (Chief Executive), and heads of governments. Women have difficulty in reaching positions of power, domestically, professionally, and politically (Nicolson, 2004). Hence, it is imperative to understand the effects of gender and power in cultural locations to

understand health, particularly for women (Holmstrom, Kaminsky, Hoglund, & Carlsson, 2017; O'Hara, 2008; Rondon, 2010).

Western science began to dominate Western culture during the scientific revolution of the 16th Century Renaissance, shaping ideas, beliefs and values of the members of that culture in significant ways. For example, science produced knowledge that had power in shaping narratives and social order that positioned women, and women's bodies as inferior (Birke, 2004). Women were labelled and reinforced by science as 'abnormal' and 'weak'. Conditions like 'hysteria' (and all of its succeeding manifestations, see Ussher (2013)) and the idea that emotionality is pathological, underpinned the notion that women should be silenced, controlled and managed (Katz et al., 2008; Ussher, 2013). Science, which historically is the domain of men, was used to justify the non-education of girls and women during the 19th century and earlier, claiming that if women used their brains it would damage fertility (Nicolson, 2004; Ussher, 2004). Medical arguments, such as threats to fertility and physical fragility, were also used as justification for keeping women from politics (representation in government, having the vote), medical school and midwifery (Munch, 2004; Ussher, 2013).

Traditional ideas about the role of women in society and what makes 'good' women, are based on the ideas that woman have an intrinsic, and biological desire/urge to bear children (a sex-role), and that women are suited to this task because of 'feminine' personality traits (a gender-role), that include being empathetic and nurturing (Hare-Mustin & Marecek, 1998; Munch, 2004; Stoppard, 2010). Women are considered 'natural' stay at home mothers (Nicolson, 2004; Stoppard, 2010). However, looking at how the symbolic aspects of gender, those ideas or images that represent gender work in the larger context of culture, and the shared implicit societal beliefs about women, it can see that there is an assumption that motherhood is the kind of work women *should* be doing, by virtue of tradition and biology.

Jack (1991) delineates how women and girls are produced through socialisation within Western culture so that relationships become a salient part of 'the good woman'. The goal of relational intimacy requires prioritising the relationship and also often the

subordination of women's own needs – silencing the self and the internal voice to avoid conflict and risk of abandonment or rejection (Hare-Mustin & Marecek, 1998). This self-silencing, subordination and voicelessness acts to disempower women, and can be seen in workplaces and in health contexts, particularly where women feel like they are not going to be taken seriously or their credibility is questioned (Andaleeb & Millet, 2010; McSweeney et al., 2005; Wiklund, Fjellman-Wiklund, Stalnacke, Hammarstrom, & Lehti, 2016). This is a salient problem in medical misdiagnoses.

When focused on the cultural and societal constraints, biases and implications of gender, such as women being 'weaker', destined for motherhood, and secondary in relationships, explanatory efforts move beyond gender as something simply biological (AbouZahr, 2014; LaFrance & Stoppard, 2006). For instance, while discussing women's depression, Stoppard (2010) makes the distinction between viewing the source of depression as a result of female hormonal levels (biological sex) and the structural aspects of gender in society. These can include the burden of caregiving, the practice of putting other's needs ahead of their own, the violation of women's bodies, lower levels of education, and the gender pay gap and lack of power in, and availability of, employment opportunities, particularly gaining positions of power (such as Chief Executive positions, and heads of state).

The dominant patriarchal culture preserves patterns of behaviour of those with power that perpetuate and legitimise inequality within and across institutions and western culture (Beaumont, 2016). While some aspects of gendered inequality may have been addressed, such as the fundamental right to vote, Beaumont (2016) notes that new forms of discrimination and gender bias continue to exist (such as gender-based hate-speech and online harassment). Health inequities, particularly in relation to gender, is one area that consistently demonstrates a significant gender equality problem (Andaleeb & Millet, 2010; Celik et al., 2011; Morgan, Williams, & Gott, 2016). Such problems also exist in our healthcare systems.

Gender in Medicine

The biomedical approach to health represents the androcentric culture embedded within Western societies, as mentioned above. The female body is pathologised and the male body normalised (Marcum, 2015; Munch, 2004; Parker et al., 2017). Medical knowledge is based on male bodies and is extrapolated to female bodies (Marcum, 2015; Parker et al., 2017; Verdonk et al., 2009). However, women's bodies are different to men's; they have different hormones, hormonal cycles, genetics and physiology. Women's bodies have different health outcomes, including severity and presentation of illnesses and symptoms, and responsiveness to standard tests treatments (Ballantyne & Rogers, 2011; Celik et al., 2011; Wienclaw, 2013). Treating women and female bodies as equal to men and male bodies is not in the best interests of female patients, as doing so leads to poorer health outcomes (Chen & Standing, 2007; Payne & Doyal, 2010; Sanfey, 2005). However, while attention *is* paid to women and women's bodies in research, investigation focuses on what Wenger describes as the 'bikini model' of medicine – that is, women's reproductive health (menstruation, pregnancy, childbirth and menopause) receives a lot of attention (Ballantyne & Rogers, 2011; Verdonk et al., 2009; Wenger, 2004). This is a reflection of a culture that values women as child bearers, and has difficulty moving past this premise to prioritise other health needs.

Embedded within wider socio-political and cultural narratives, biomedical approaches often pathologise female bodies as deficient and in need of 'treatment' when positioned in comparison to male bodies. An example of this is menopause treated with hormone therapies, rather than as a normal developmental occurrence with female bodies (Verdonk et al., 2009), particularly as this contrasts male bodies that do not go through the same developmental phases. From this way of thinking, a power imbalance normalises male bodies and discriminates against female bodies. It also acts to normalise power relations that privileges the male above the female, which has been shown to be important during patient and doctor interactions (Foss & Sundby, 2003; Parker et al., 2017).

Women and men are treated differently by health care professionals, and women and men health care professionals behave differently when treating patients (Celik et al., 2011; Payne & Doyal, 2010; Ross & Lypton, 2014). Research by McSweeney et al. (2005) shows that women are treated negatively by their doctors, which includes being labelled 'time wasters' and treated patronisingly, when presenting to doctors with symptoms the doctors consider irrelevant. Andaleeb and Millet (2010) argue that this results in poor healthcare experiences and delayed health seeking behaviour, as well as women avoiding follow-up care and following treatment regimes, or preventing others from seeking help through negative word of mouth. In their study investigating everyday discrimination and healthcare utilisation, Fazeli Dehkordy, Hall, Dalton, and Carlos (2016) found their female patients assumed a socially sanctioned role that placed the physician in a position of authority, so they are taken seriously as an ill person. In this way, women manage the relationship carefully to get their needs met, placing power in the hands of authority figures, who are often men, perpetuating the submissive, passive women's role that places them beneath men (Holmes, 2016). In particular, ill women are not just exposed to, and are negotiating, the power of the expert doctor, but the power of gender in their interactions as well (Foss & Sundby, 2003; Morgan et al., 2016; Wiklund et al., 2016).

Women are frequently dismissed from medical settings without appropriate tests being conducted. For example, spirometry testing for Chronic Obstructive Pulmonary Disorder (COPD) is utilised more frequently in men than women, despite effectiveness for both genders (Chapman et al., 2001; Delgado et al., 2016). In some instances, failure to do so may be entirely appropriate, but this is not always the case. For example, while Nestler et al. (2017) found more men than women received a treadmill exercise stress test to test severity of coronary heart disease (CHD), this may be appropriate, as some research suggests the test is inefficient for women's presentations of the disease. By the same token, women being treated less aggressively than men for CHD might rightly reflect real clinical differences, such as lower lipid levels in women (Adams et al., 2008). These are good examples of tailoring medicine to the uniqueness of women's bodies, rather than simply receiving a standardised (on men's bodies) treatment or test.

Some authors have attempted to argue that differences in health outcomes between women and men are simply a result of patient behaviours. These authors imply that women experience different symptoms, fail to report symptoms, and describe symptoms more vaguely than men, making it harder for a clinician to come to the correct diagnosis (Alspach, 2012; Berg Gundersen et al., 2016; Saletti-Cuesta, Tutton, & Wright, 2016). Women's communication style, allegedly ambiguous and full of social context, during consultation with their doctor has also been used to dismiss bias in healthcare settings (Teunissen, Rotink, & Lagro-Janssen, 2016). Some authors claim gender bias disappears when underlying factors, such as differences in clinical presentation of illness, are accounted for (Bosner et al., 2011). However, if women experience different symptoms for some illnesses, then more stringent medical knowledge and diagnostic skills could identify differing symptom presentation between the genders, instead of producing misdiagnoses and disparate outcomes for women because they presented with different symptoms to men (Adams et al., 2008; Koyama et al., 2018; Ross & Lypson, 2014).

The diversity in clinical presentation of illness between genders is a primary issue for gender bias in healthcare, and misdiagnosis. Without an equal representation of the difference in symptomology, bias exists. O'Hara (2008) believes all health professionals should have knowledge and awareness of the ways in which sex and gender affects health. This would ensure adequate care is delivered to all patients and address gender issues when necessary (Foss & Sundby, 2003; O'Hara, 2008). However, this is difficult when the importance of sex and gender is excluded from medical training and not emphasised in professional practice.

Medical Education

Medical training programmes have historically not focused on gender specifically, nor included it as part of the curriculum (Sieverding & Kendel, 2012). Recognising this gap, in 2006 the World Health Organisation (WHO) initiated a review to integrate knowledge about gender (and sex) into medical curricula (van der Meulen, Fluit, Albers, Laan, & Lagro-Janssen, 2017). This directed medical committees and councils

around the world to undertake projects that address the effects of gender on patient treatment and care. It advocated for gender sensitivity in healthcare systems and required healthcare professionals to be competent in perceiving existing gender differences and biases, and to take these into consideration when making decisions or taking action, to eliminate misdiagnoses (Celik et al., 2011; Koyama et al., 2018). The ways in which gender matters needs to be deliberately and systematically incorporated into medical practice and policy (Celik et al., 2011; Koyama et al., 2018).

To date, despite worldwide attempts to include robust gender awareness in education, there has been mixed success (Marcum, 2015). Positively, Andaleeb and Millet (2010) found gender disparity was minimal in some Bangladesh hospitals because education levels of staff were broad. In most other instances where gender awareness had not occurred it was surmised this was due to resistance to additional course content, because unfortunately, medical training is already crammed without adding a gender component. There is also uncertainty about how to practically implement gender training, not enough time to dedicate to the issue, and institutional reluctance to change (Marcum, 2015; Risberg, Johansson, & Hamberg, 2011; van der Meulen et al., 2017). Celik et al. (2011) point out that much of the research in this area focuses solely on changing professional behaviour through educational activities without addressing institutional and structural power. This reflects pervasive attitudes of women as second-class citizens, so the impact of gender and sex in health settings is not considered a priority (Risberg et al., 2011).

Where gender is addressed, it is positioned within education programmes as women's domain, with more female educators engaged with gender-sensitive issues and discrimination than male staff, who generally are more dismissive of gender-related concerns (Bleakley, 2013; Risberg et al., 2011). Yet the interest and engagement of educators in health is important, particularly male educators, because they have power to exert change, and act as role models (Celik et al., 2011; Risberg et al., 2011). In a study by Risberg et al. (2011) male participants noticed women colleagues being questioned about the validity of their perspectives and practical experience much more than they themselves were. This is concerning, as the classroom is where respect

is taught and demonstrated, not just for patients but for women in general, including women students, educators and patients (Celik et al., 2011; Parker et al., 2017; Verdonk et al., 2009).

Often, gender is dropped as a priority in course programmes. Medical educators in Australia claimed good gender practice was not necessary as relevant knowledge about gender could be learnt at the bedside by observing the behaviour of educators interacting with patients (Verdonk, Benschop, Haes, & Lagro-Janssen, 2008). However, as Risberg et al. (2011) rightly point out, this surmounts to suggesting trainees can learn cardiac medicine by simply watching cardiac specialists interact with their patients. Those in positions of power are often unaware of the discrimination people who are marginalised endure in their everyday life. To suggest it is possible to be aware of unconscious and nuanced gender discrimination in a patriarchal culture is problematic, and merely reinforces the status quo.

It is vitally important to continuously challenge ideas about gender in medical training and to advance methods that help students develop the necessary skills to identify stereotypes and biases to help prevent discrimination and misdiagnosis, and to provide adequate healthcare for all genders whenever and wherever appropriate (Alspach, 2012; Marcum, 2015; Sieverding & Kendel, 2012). Verdonk et al. (2009) advocated for an inclusive curriculum that integrates gender and sex awareness across all compulsory courses, rather than specific gender and sex courses that students voluntarily participate in. However, they also acknowledge gender and sex awareness is difficult to implement as it requires the commitment of all involved, from policy writers to educators.

According to some, gender issues can be resolved spontaneously simply by the inclusion of women in medicine. For instance, Sieverding and Kendel (2012) argued that the increased numbers of women training as healthcare professionals will influence traditional medical thinking and culture. Such beliefs assume that female students can challenge gender-biased systems or gender-offensive remarks from peers and teachers (Risberg et al., 2011; Wienclaw, 2013). However, this ignores the

underlying institutional policies and attitudes that create gender power imbalances. Risberg et al. (2011) found their participants recognised attitude problems when it came to gender issues, even acknowledging themselves, as men and as educators, as part of those problems. Shifting problematic attitudes is difficult while there is denial that a problem exists, and unfortunately this belief, widely held among the medical discipline, also reflects wider cultural attitudes that treat women poorly (Risberg et al., 2011).

Research Trials

Women are underrepresented or excluded in clinical trials for many illnesses and conditions that affect both women and men, such as heart disease, stroke and chronic pain (Adams et al., 2008; Davidson et al., 2012; Worrall-Carter, Ski, Scruth, Campbell, & Page, 2011). Ironically, this trend occurs in part because it is assumed that cyclical hormonal changes in women's bodies act as uncontrollable confounds within a study. However, this ignores the way in which any biological difference interacts with an illness or condition, and any chemical treatments prescribed to treat it, resulting in unknown and potentially dangerous outcomes for women (Nieuwenhoven & Klinge, 2010; Sanfey, 2005).

Fear of experimental treatments on fertility or pregnancy, and higher rates of particular diseases in men, have also been used as justifications for why women were historically excluded from clinical trials (Verdonk et al., 2009), although this does not explain why women are excluded from other health and medical research projects, such as studies that measure peak athlete performance, but only with male participants. In this sense, women's bodies are controlled by privileging the reproductive body, and women as mothers, regardless of intention to have children or not. By the same token, conditions that are traditionally thought of as 'women's diseases', such as depression, reproductive health and hip fractures, continue to prevent inclusive knowledge from being produced by not including men in research (Nieuwenhoven & Klinge, 2010; Saletti-Cuesta et al., 2016; Verdonk et al., 2009). Conditions that are considered 'women's diseases' also attract less research interest and funding, perpetuating limited knowledge.

Importantly, any exclusion produces biases that affect how women are treated in healthcare settings. Bias can result in the assumption of no difference between women and men, where both genders are treated the same (alpha bias), or when a difference does not exist between women and men but they are treated differently (beta bias) (Alspach, 2012; Hare-Mustin & Marecek, 1998; Saletti-Cuesta et al., 2016). Smirthwaite and Swahnberg (2016) describe these in relation to healthcare as type A: exaggerating or constructing differences between women and men in ways that can endanger health and/or cause inequity in care; and type B: neglecting differences between women and men while making one the standard for both (typically men). Gender stereotypes essentially obscure the ability to observe and process salient clinical information because of preconceived or faulty beliefs about illness based on gender alone (Marcum, 2015). Continuing this, a doctor with such a bias is unable to consider specific characteristics of a gendered patient, that is, they are unable to see the individual, and wrongly incorporate the patient's gender into diagnosis and treatment (Marcum, 2015). Therefore, the clinician sees a stereotypical version of their patient that facilitates prejudice (FitzGerald & Hurst, 2017), and often leads to misdiagnosis.

Many countries around the world now legislate for the equal presence of women in health research (such as the National Institutes of Health Revitalisation Act 1993 - USA), recognising a prior lack of inclusion (Johnson, Karvonen, Phelps, Nader, & Sanborn, 2003; Liu & Dipietro Mager, 2016; Nieuwenhoven & Klinge, 2010). However, there are conflicting reports as to whether such mandates are being met. Ballantyne and Rogers (2011) claimed a review of inclusion of women in medical trials found, on average, that women represented the majority of research participants. However, on closer inspection, men were considerably more likely to have been recruited to non-sex specific research and women to sex-specific research. This was confirmed again more recently by Liu and Dipietro Mager (2016). Unfortunately, this does not resolve any bias, as findings from non-sex specific research are still likely to be inappropriately generalised to women. A fifth of cardio vascular disease clinical trials reviewed by Johnson et al. (2003) excluded women altogether, and those that did include women had fewer numbers of women participants than men. Despite legislation that aims for

equality between the genders, women are still excluded and discriminated against because of an androcentric culture that privileges men over women.

Not only do more women need to be included in research, but when they are, that research should be analysed for sex and gender differences and similarities (Davidson et al., 2012; Nieuwenhoven & Klinge, 2010; Worrall-Carter et al., 2011). Studies that fail to recruit sufficient numbers of both sexes or genders should acknowledge the limitations and reflexively outline why they were not inclusive (Ballantyne & Rogers, 2011; Morgan et al., 2016). Few currently do so. Results from the analyses of sex and gender differences and similarities need to be widely disseminated, with recommendations developed for sex-specific approaches to illness treatment, prevention, diagnosis and rehabilitation (Nieuwenhoven & Klinge, 2010; Worrall-Carter et al., 2011). To illustrate, Saunders-Pullman, Wang, Stanley, and Bressman (2011) argued more women are needed in early-stage Parkinson's research, however, because women are not diagnosed in a timely manner, they are less likely to be able to get into early-stage medical trials, perpetuating a knowledge gap. Here, accurate and early diagnosis is vitally important for inclusion of women in medical research that focuses on early stages of conditions, particularly as this could help improve accurate and early diagnosis for treatment.

Gender awareness is important in research and the policies that aim to resolve gender bias (Verdonk et al., 2009). Women need to be involved in both research and policy, not just as participants, but as collaborators, as they offer different perspectives, priorities, needs, interests and resources (Bleakley, 2013; Koyama et al., 2018; Verdonk et al., 2009). Verdonk et al. (2009) and Risberg et al. (2011) note that sex and gender awareness in a health context should include biological, reproductive and social issues – for women *and* men, such as societal and cultural expectations about practices of 'femininity' and 'masculinity'. This knowledge should be taken up while designing health research, health interventions, health system reforms, health education and health policies.

Ballantyne and Rogers (2011) note that the inclusion of women in research trials is important because the value placed on evidence-based medicine directly influences clinical practice guidelines and therefore, clinical care and the culture of medicine. If women are included in empirical based medical research, the results may influence new ways of thinking about and understanding women's bodies. Marcum (2015) and Verdonk et al. (2009) argue that a cultural change would significantly impact on gender disparities in healthcare settings. This would matter to diagnosis and treatment, as well as health research (Marcum, 2015). The culture surrounding medical education also needs to change. Ideally, any change should occur at the interpersonal *and* organisational level to support, not just a change in attitudes, but in working routines (such as diagnostic processes), policy and institutionalised discrimination (Celik et al., 2011; Chen & Standing, 2007; van der Meulen et al., 2017). A structural shift is particularly important in a biomedical model of healthcare that emphasises, prioritises and values positivistic research.

Misdiagnosis

Tracing the implications of gender and power, gender and medicine, and gender and medical education provides the context for understanding how misdiagnosis occurs for women within healthcare systems. In this section, the literature specific to misdiagnosis is unpacked and how the gender dynamics matter is explored.

Misdiagnosis is becoming an increasingly significant health risk. Research from the USA, represents a higher rate of misdiagnosis (26%) than surgical accident (25%) (for both genders), resulting in worse prognoses and outcomes (Neale, Hogan, & Sevdalis, 2011). Research shows that women bear the brunt of misdiagnosis, with 50% more women being misdiagnosed after a heart attack (University of Leeds, 2016), and 75% misdiagnosed after a stroke (Newman-Toker, Moy, Valente, Coffey, & Hines, 2014). On average it takes 4.6 years for women to be diagnosed with an autoimmune disease (American Autoimmune Related Diseases Association, 2018) and 7 years to be diagnosed with female-specific illnesses, such as endometriosis (Arruda, Petta, Abrao, & Benetti-Pinto, 2003). Any delay in diagnosis can be difficult for women as patients, because it results in psychological distress, family strain, social isolation, increased

physical discomfort, and the worsening of the condition, resulting in heavy illness burdens and potentially death (Berg Gundersen et al., 2016; Waldron et al., 2012; Wehbe-Alamah et al., 2012). In conjunction, with dismissal from a doctor's office, patients may doubt their symptoms and delay seeking further treatment (Andaleeb & Millet, 2010; Berg Gundersen et al., 2016), even in light of new or worsening symptoms. In this sense, the reduction of any diagnostic error is vitally important for the safety of women and their quality of life (Carnlof, Iwarzon, Jensen-Urstad, Gadler, & Insulander, 2017; Koyama et al., 2018).

Women themselves have reported a strong desire to have a diagnosis for experienced symptoms, and an explanation that did not involve 'over exaggerating' or being told 'it is all in your head' (LaFrance & Stoppard, 2006; Waldron et al., 2012; Wehbe-Alamah et al., 2012). Being told 'it's all in your head' implies women are manifesting symptoms psycho-somatically and feeds into women as hysterical hypochondriacs or attention seekers. Importantly, research has demonstrated that not knowing why they were experiencing particular physical symptoms increased anxiety, while knowing enabled women to more effectively cope with their illness (Levin, Mor, & Ben-Hur, 2003; Waldron et al., 2012). A correct diagnosis is not just salient for treatment of biological conditions, but for mental health as well.

The family doctor is paramount in healthcare, often as the first point of contact with the medical system. They act as the gate-keepers for referral to specialists services and potential treatment (Briones-Vozmediano, 2017; Waldron et al., 2012). Aotearoa New Zealand has a three-tier health system. Accident services, including medical malpractice, is covered by the Accidental Compensation Cooperation (ACC). District Health Boards (DHBs) plan, manage and provide health services for the people of their district, which includes primary care and hospital services (New Zealand Government, 2017). ACC and DHBs operate with funding generated through taxation. The third tier involves private healthcare accessed through health insurers, with premiums paid for by the policy holder.

As well as the physical outcomes of not gaining timely treatment, and the impact on personal wellbeing, there is a two-fold financial burden. The first cost is that to the patient for repeatedly paying for GP visits, which are not included in the free health care system in Aotearoa New Zealand (doctors set their own fees) (New Zealand Government, 2018). The second cost is situated within the healthcare system as misdiagnosis can lead to more expensive and prolonged treatments for patients that may have benefitted from less costly earlier interventions. In the USA, a lack of early diagnosis is estimated to have a \$750 billion economic impact annually (Britto, 2018; PinnacleCare, 2016).

Conclusion

Misdiagnosis can have serious repercussions for women and women's health. Women experience significantly higher rates of misdiagnosis than men. Western culture is androcentric and patriarchal. It has a history of treating women as second-class citizens with poorer outcomes for women in many spheres of society, including education, and health. Women have been historically considered weak, emotional, and biologically suited to the traditional roles of household management and child rearing. As an extension, Western science and medicine also adheres to an androcentric and patriarchal discourse, with men and the male body as the 'norm'.

A significant amount of medical knowledge is still derived from research that has male participants only, with the results generalised to women. This means medical tests and treatments are not specific to female bodies, which could result in poor health outcomes. Additionally, the absence of women in research means illness symptoms are poorly understood, as are their bodies outside of reproductive functions. Medical education programmes around the world struggle with gender sensitive courses; they are not considered important enough. Educators claim they do not have time to include gender in education programmes, which represents a failure to understand the value of inclusiveness.

Assumptions are made about women's health based on gender stereotypes, or simply being women. These assumptions, including a common misconception that physical

symptoms are merely manifestations of psychological problems, can mean women are dismissed from medical offices with psychiatric diagnoses, without diagnoses, or an incorrect diagnosis.

The current research project aimed to shed light on women's experiences of misdiagnosis and how women who have been misdiagnosed make sense of their experiences. It also sought to give women the chance to tell their stories about misdiagnosis, and have their voices heard because often the implications of misdiagnosis are overlooked or ignored. In the next chapter, the methodology and strategies used to achieve this are discussed.

Methodology

Feminist Research

This project engages a feminist approach to research. Feminism is an ideology that aims to define, establish and achieve political, economic and social equality of the sexes. A feminist approach to research recognises that feminist research is explicitly political, in that it should challenge wider social, economic, and cultural contexts that affect women's lives (Fish, 2009; Ussher, 2004; Wiklund et al., 2016). With feminist research there is no absolute 'truth' to be discovered, uncovered or revealed (as there is in quantitative ideology), and there is no limitation to the methodology that feminist research can be utilised with (Akman et al., 2001; Burns, 2004). Despite there being no definitive approach, there are, according to Akman et al. (2001), four core principles that guide a feminist methodology, namely: (1) recognising and validating the importance of women's experiences, (2) challenging traditional scientific inquiry, (3) acknowledging power imbalances between researchers and participants, and (4) representing the political nature of research. Additionally, feminist researchers should be aware of, and engage with, gender in research and analysis, and draw attention to how language around women is used within research contexts, as language can shape meaning (Akman et al., 2001; Rickard, 2015; Squire et al., 2013). These principles are easily adopted by feminist psychology as ways of exploring women's lived experiences. As explicated in the previous chapters, these features of feminist research are sorely lacking in medical thought, culture and research.

According to Fish (2009) and Parker et al. (2017), women's health became central to feminist movements and research throughout the world during the second wave of feminism in the 1960's (the second wave focused on equality for women beyond the first wave's goal of enfranchisement, such as in legal, workplace and family inequalities). While feminist research in health *is* being conducted, much of it focuses on issues that specifically affect women such as oral contraceptives, childbirth procedures, lesbian health, breast cancer, eating disorders or psychiatrics (such as personality disorders or depression), researched using qualitative methods. However, feminist research overlooks other aspects of women's health, such as much needed

quantitative research into women's bodies with diabetes and heart disease, drug therapies, threats to health and access to healthcare (Ballantyne & Rogers, 2011; Marcum, 2015; Verdonk et al., 2009). If feminism, and, by extension, feminist research, aims to improve women's lives (Akman et al., 2001; Birns, 1999), then research into women's experiences with healthcare settings is relevant.

Drawing from arguments by Morgan et al. (2016), in that a feminist approach to research does not necessarily fit a designated feminist perspective, such as intersectional feminism or liberal feminism, this project similarly does not adhere to one particular feminist research practice, but instead honours the four core principles offered by Akman et al. (2001) above. In this way, I acknowledge and examine the pervasive influence of gender on social life. This work focuses on the historical silencing of women's voices – as researcher and the researched (Morgan et al., 2016) – and aspires to, first and foremost, give women the chance to tell their stories of their misdiagnosis experience and have their voices be heard.

Reflexivity

Reflexivity is the process of considering one's own thoughts and actions in differing contexts, and is an ongoing critical reflection of their influence to the research process. It is considered an important factor in reducing the power 'gap' between researcher and participant, and is a feature of feminist qualitative research that does not attempt to exclude the subjective experience of the researcher (Akman et al., 2001; Holmes, 2016). In acknowledging feminist research principles, particularly around power (Akman et al., 2001), I was aware of my role as the researcher, and as someone who has experienced misdiagnosis. Who I am, of course, influenced every area of my research project, from the way I framed my research question to the research design.

I was mindful that because I had been through the literature around misdiagnosis and women in healthcare, that I had a much larger knowledge base than the women I was representing. In some instances, this positioned me as the 'expert' in the qualitative interviews. When participants appeared to be nervous about sharing their narratives, it allowed me to lead the process and conversation. Participants asked more questions

about the process and what would happen to their data. Others were more confident and direct, and asked few or no questions. In these cases, their narratives were much more succinct. Given my experience, and my gender, I was able to empathise with and understand my participants experiences. It may be that this helped them feel comfortable to open up and share their stories. It would seem reasonable to suggest a man conducting the interview may have elicited different answers, particularly in a patriarchal society.

I also acknowledge that my position as the researcher may have created socially desirable responses, such as politeness or compliance. Holmes (2016) has discussed the importance of social performance and impression management in participant interviews. Participants may answer questions they do not want to or give responses to questions they think the researcher wants to hear, as a way of acting in a 'pleasing' manner and managing the relationship between participant and researcher. This is particularly salient for women participants, who are traditionally socialised into compliant roles, where relationship harmony is prioritised (Jack, 1991). However, I did not sense that compliance occurred in the interviews. While I am not privy to the inner thoughts of my participants, I interpreted hesitations in response to questions were to think about the reply, rather than to weigh up how much to share. In only one interview did I get the explicit impression a participant was refraining from sharing some information. I did not push her to expand when she changed the subject, as I was more focused on being receptive to what participants wanted to share with me. However, this did not mean I refrained from asking any follow-up questions, even difficult ones, as this was an important part of the process in terms of producing knowledge about medical misdiagnosis for women.

While I initially wanted to know what the women's thoughts were about gender playing a role in their misdiagnosis experience, I did not explicitly ask about this until towards the end of the interview as I wanted to see if this was first raised by the participants. From there, a discussion of the literature often ensued, and I found in some interviews I was 'educating' these women and possibly providing meaning

(sense-making) to their experience. While I had knowledge and 'expertise' through the literature, I acknowledged the participant's as experts in their own experiences.

My experience with the literature and misdiagnosis also influenced the way in which I interpreted the participants narratives and analysed the data. However, I have endeavoured to be fluid, transparent and listen to what the narratives told me, rather than seeing what I wanted to see (Kim, 2016). In choosing which voices to include through the participants quotes, and in omitting others, I have presented a version of the narratives my participants shared with me, which may not entirely reflect the context in which they were shared (Kim, 2016). Certainly, another researcher would have analysed the interviews in different ways and made different choices around this research project, producing different interpretations (Kim, 2016).

As this project does not adhere to an objective research method, my subjective experience was not ignored. Importantly, as with my gender and lived experience, my ethnic identity as New Zealand European may also have influenced the interviews in unknown ways, providing familiarity and connection for some of the women. Given New Zealand's colonial past, and the history of negative outcomes for Māori in research, my ethnic identity may have produced tension for the Māori participant.

Ethical Considerations

As with a feminist approach, ethical practice for this project included reflexivity and following ethical principles as set out in Massey University's Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants (Massey University, 2015). The code is an expression of the basic human rights of respect for persons, autonomy, privacy and justice, which includes consideration of confidentiality, consent, truthfulness, conflicts of interest and minimising harm to participants and researchers (Massey University, 2015). This project was reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application SOA 18/32.

This work also drew from a commitment to biculturalism as recognised in the Treaty of Waitangi. The code of ethics in relation to psychological research in Aotearoa New Zealand requires researchers to be culturally aware and to practice in a way that supports and upholds the dignity and respect of Māori as tangata whenua of this land. While this study did not aim to focus explicitly on Māori or other non-European New Zealanders, nor did it plan to discuss ethnicity, as a European New Zealander, it was important for me to respect and apply tikanga Māori principles if necessary. To support my ability to engage with participants and conduct interviews in a culturally safe manner, particularly in recognising the importance of Māori participants in this research, I gained cultural supervision from an advisor at the School of Psychology at Massey University. I met with the cultural advisor to discuss the research aims and approaches, and to seek knowledge about the best way to engage with Māori participants in this space. My cultural advisor requested further contact after analysis to ensure Māori were represented appropriately. This was completed and considered satisfactory.

Narrative Research

While medicine prioritises quantitative empirical science (which produces objective 'facts' and 'truths'), and marginalises qualitative research (which looks at richer meaning and lived experiences) as mere additional analyses, qualitative research continues to gain momentum and merit (Morgan et al., 2016; Wilkinson, 2000). It is not to say that objective, positivist methods do not generate useful information, particularly in biological contexts, but they tend, as represented earlier, to reinforce existing and detrimental power relations between women and men (Akman et al., 2001; Munch, 2004). Qualitative approaches, particularly narrative research, encourage rich descriptions of personal experiences, and can therefore enable understandings of symptoms and the diagnosis-making process from the perspective of the patient (Berg Gundersen et al., 2016; Latz, 1994; Squire et al., 2013). Narratives about experiences can act as mirrors for a range of social realities (Rickard, 2015; Squire et al., 2013). Therefore, a narrative qualitative approach to this research project is appropriate and necessary. It also fits well with a feminist approach, as it privileges

the voices of those who have been silenced (Brinkmann & Kvale, 2015; Squire et al., 2013).

A narrative is an account of connected events, to form a representation of a story. These accounts can be written or oral and are contained in almost all forms of human communication, including in interviews and art. Providing a platform for sharing stories and experiences allows the possibility of exerting control over the meaning of those experiences, gaining a sense of closure, validation and being able to construct a story that re-establishes order (Akman et al., 2001; Latz, 1994; Rickard, 2015; Winskell et al., 2015). Narrative research, therefore, is an appropriate conduit for making sense of an experience. Sense-making can be defined as an activity in which information about a situation is deliberated upon to form an understanding and to generate insight (Pohl & Haider, 2017). It can be an implicit and contradictory process (Pohl & Haider, 2017; Squire et al., 2013; Winskell et al., 2015). Sense-making can also be seen as an interplay between inner dialogue and social contexts, where sense emerges over time and through multiple interactions, by recounting an experience when alone or with others (Dowding et al., 2016; Harrington, 2017; Wright, McCarthy, & Meekison, 2004). In this sense narratives are a way to organise human experience and social relationships.

Collecting the Narratives

Advertisement and Participant Recruitment

Participants were recruited through an advertisement that was distributed via Facebook (see Appendix A). Participants were also recruited through an information sheet that was circulated to the Massey University psychology graduate (psych-grad) mailing list on two occasions two months apart (see Appendix B). The psych-grad mailing list was a very effective means of advertising as most of the respondents were recruited through this platform. In most cases, a form of snow-balling occurred, in that a recipient of the psych-grad email passed the information on to a participant, who then contacted me. One participant was made aware of my study by a third party. The third party was aware of my research project and heard the participant discussing her

misdiagnosis experience at a fitness group. The third party passed on my contact details to the participant, who then contacted me.

After being provided with the study details, respondents self-identified for inclusion and contacted me via email expressing their interest; some also provided phone numbers as a way for me to contact them. At that point, I provided the information sheet to give fuller details about the study, participation requirements and rights (see Appendix B). If respondents expressed further interest or had additional questions, we continued to communicate via email or phone calls. A cell phone number was purchased solely for use in this study so potential participants could contact me and if necessary, protect my privacy, as required in my ethics application. This contact also served as an initial screening conversation to check their eligibility for inclusion in this research project. No participants who responded were excluded from this study. Three potential participants who initially contacted me did not respond to messages to make a time to meet for an interview and I decided to not pursue them after a four-week period of non-responsiveness.

Participants were eight women living in Aotearoa New Zealand, who had had a misdiagnosis experience in an Aotearoa New Zealand healthcare service. In qualitative research, saturation of data is influenced by the level of knowledge the researcher can gain from the interviews, such that, during the first interviews, there is a significant amount of new knowledge, but by increasing numbers of interviews the researcher starts to recognise the patterns in the experiences of the interviewees (Guest, Bunce, & Johnson, 2006; Hagaman & Wutich, 2017). That is, the more heterogeneous the group, the more interviews are required (Guest et al., 2006). Guest et al. (2006) found the basic elements for themes are present within the first six interviews, suggesting full saturation occurred at twelve interviews. In this research project, given recruitment techniques and time limitations, eight participants were considered sufficient to reach data saturation.

One participant identified as Māori, one participant identified as mixed-American, and six participants identified as New Zealand European or Pākehā. While this study does

not focus on the role of ethnicity in misdiagnosis experiences, the presence of Māori women in this project is significant as Māori voices have been historically absent from research in Aotearoa New Zealand. As such, sensitivity was given to participants' culturally specific experiences during the interview, as outlined above, while the analysis of this interview was discussed with the cultural advisor. Participant's ages ranged from 26 to 57 years old. Illnesses varied considerably, from acute (Hypokalaemia, breast cancer) to chronic (Trigeminal Neuralgia, Chronic Fatigue Syndrome, Sudden Sensorineural Hearing Loss, Motor Neuron Disease, Ehlers Danlos Syndrome, chemical sensitivity), and several women had multiple health issues or illnesses for which they had also experienced a misdiagnosis (appendicitis, Hashimoto's Disease, fractured coccyx) (for descriptions of the conditions see Index). The diagnoses are stated with each participant in the results section to provide context for their experience. Time to diagnosis ranged from a few days to 21 years; two participants considered themselves to still not have an accurate diagnosis (they named the current 'theory' of the illness they were experiencing) and this process was ongoing for them (their diagnoses are therefore disputed by them). All participants were proficient in English. Five of the participants indicated they had a tertiary level of education; three participants were current university students.

The Semi-structured Interview

One to one semi-structured interviews were conducted by me. Interview guidelines had been developed to direct the interview towards the narrative of participant's experiences with misdiagnosis (see Appendix C). My role as the researcher in these semi-structured interviews was to facilitate and encourage the participants to recount their experiences with minimal explicit prompting.

Once consent to participate was given, I asked demographic questions (see Appendix C), including ethnicity, illness, and time it took for a diagnosis. After setting the background for the research project by reading an introductory statement from the interview schedule (see Appendix C), I began interviews by asking participants to tell me their story of misdiagnosis. This often began with a chronological narrative from symptoms to diagnosis. For some of the women in this study, these were short stories,

that occurred over months and had finite endings. For the majority of the women in this study, their experience was ongoing to the moment we sat down for the interview. Further questions during the interview were to clarify details and focus the discussion on the research project's area of interest. Questions were a blend of open and closed and participants were able to expand on their answers freely. In some interviews, the interview guide was covered spontaneously by the participant, in others it was utilised more explicitly.

Three participants were interviewed in their homes and four were interviewed via online video calling such as Skype and Google's Hangouts. While video calling is face-to-face contact, it removes the context of the participant and researcher being in the same physical space, and raises issues around building rapport with the participant (Weller, 2017). I met one participant in a meeting room on Massey University's Manawatu campus, in the School of Psychology's building. For safety, I notified nominated contact people of where the interview was taking place, the time at which I was entering the participant's home and when I left. Interview duration ranged between 24 minutes and 1 hour 14 minutes. Before the interview began the participant was given a consent form to fill out and sign (see Appendix D). Consent was given verbally if we were speaking via a video link, but participants were emailed a consent form in advance, to read at their leisure. One participant signed the consent form, scanned it and emailed it back to me.

Each interview was audio-recorded on a Digital Voice Recorder. Two participants asked for their audio recordings to be returned. The resulting Mp4 files were transferred and stored on a password-protected laptop until the analyses were completed. The Mp4 files were then deleted. Consent forms were stored securely in the researcher's home until after the interviewing period was completed, where they were transferred to long-term storage at Massey University, Wellington Campus.

Three participants requested a copy of their transcript to review. This allowed the participants the opportunity to correct transcription errors and clarify any statements made or expand on the ideas they were trying to express during the initial interview.

Only one participant engaged with this process and returned their transcript to me with amendments. The other two participants did not make any amendments. All participants were then agreeable to the release of their transcripts for inclusion in this project.

The interview audio-recordings were transcribed verbatim, but pauses, repeated words and interjections, such as 'um' or 'like' were excluded. The decision to exclude was made to create a more coherent written narrative. I acknowledge that in transcribing an oral conversation to a written text, intonation, body posture, facial expressions and gestures are lost, and with it the context in which the live interview conversation took place (Brinkmann & Kvale, 2015), and the context of the stories as well. Where I felt laughter, pauses for thinking, eye-rolling or other non-verbal gestures were important for context, they were included in the transcript.

Confidentiality

Participants privacy was respected and protected through the removal of any identifying information being used in the write up of this study; pseudonyms were also utilised. This protection was also extended to any other people who were identified during the interviews, such as healthcare professionals or family members. No conflict of interest arose during the interviews regarding knowing any of the healthcare professionals or other parties that participants may have discussed. Consequently, I did not need to halt an interview or disclose a conflict of interest.

Follow-ups

All participants were agreeable to further contact from myself about the research project. It was unnecessary to engage with any further contact relating to the research project, other than to disseminate a summary of findings where requested. Participants were made aware they were welcome to contact me if they had further questions about the study or had anything they would have liked to add. One participant did this through amending her transcript. One participant did so by adding to her interview via email.

Data Analysis

Brinkmann and Kvale (2015) acknowledge that a narrative can be analysed in many ways, however it is useful to focus on meaning, social structures and the plot (the main events) of interview stories. They suggest beginning the analysis process by coding before interpreting the data for meaning. Drawing from their approach, and following a descriptive and interpretative analysis, I coded my data by looking systematically for emerging patterns in the narratives I had collected (Kim, 2016; Walsh, Holton, Fernandez, Levina, & Glaser, 2015). These patterns were derived from similar experiences between participants, or plots in the narratives, and were placed into initial and open categories, or, for example, by simply grouping together all the times participants mentioned they had been treated rudely by a healthcare professional. I also looked for experiences and events that matched with the literature review as outlined above, such as times they had not being taken seriously. This approach was most appropriate for my work, which was focused on the social meanings of the narratives, rather than structured plots or language which is typical of narrative analysis (Kim, 2016; Rickard, 2015; Squire et al., 2013). Instead, in wanting to privilege the voices of the participants, I chose to describe and interpret the narratives, and therefore adhered to no specific theoretical underpinning (Smythe, 2012).

I listened repeatedly to each audio-recording to gain a sense of familiarity with the narratives. During the interviews I took notes when participants mentioned ideas or topics that were in the literature. After transcribing the first few interviews, I went back and added these notes to the transcripts. When later interviews were transcribed, I did this process simultaneously, as repeated categories were emerging and becoming familiar. I then went back to earlier transcripts and added any new categories that had arisen as I gained more data and that were not from the literature. After all interviews were transcribed, and I had a greater sense of the categories, I started the process over again, thinking about the categories that fitted together as themes. This process is described by Kim (2016), as a way of looking at patterns in narrative data and forming them into categories and then themes. These themes will be discussed in the next section.

The Narratives and Finding Meaning

Medical misdiagnosis is a serious health risk, particularly for women, who experience significantly higher rates, and poorer outcomes. The experience of misdiagnosis is not well understood, and women's voices are often silenced in healthcare settings, as well as in research. Therefore, the participants narratives of their experiences offer valuable insight into the experience of misdiagnosis. Three main themes about misdiagnosis emerged from the women's narratives: contradictory dialogues, embedding agency in the misdiagnosis experience, and the culture of women in healthcare. These give voice to the experiences of the women in this study within healthcare settings, and explores how they made sense of their experiences. I now discuss these three narrative themes.

Contradictory Dialogues

The women expressed contradictory dialogues when they narrated their misdiagnosis experience. These were sets of contradictions that operate simultaneously (Colyar, 2012). Contradictions, as posited by Colyar (2012), are usually worrisome in Western cultures and empirical thinking that values a singular 'truth', or one way of thinking . However, contradictions enable the opportunity to explore two paths, with each allowing insight and innovation into experiences and processes that need to be shifted in some sense (Hagel, Brown, Samoylova, & Arkenberg, 2013; Squire et al., 2013). Such innovation may be beneficial to interactions and relationships between patients, healthcare settings and healthcare professionals. Colyar (2012) also believed an approach that allows for more than one dialogue to be respected, that is dialogic, is valuable, in that it allows a group of people to be heard from within their own experience, with all its complexity intact, rather than from reductive descriptions.

The contradictory dialogues in the participants narratives were demonstrated through the categories: positive experiences in a healthcare setting and negative experiences in a healthcare setting, the doctor as an expert and not having enough knowledge and

needing healthcare and refusing treatment. Each of these contradictions and how they mattered to the way participants made sense of their experiences are discussed below.

Positive and negative experiences

Often, the contradictory experiences seemed to be related to context for the women, who had a positive experience with one healthcare setting followed by a negative experience in another healthcare setting. This can be seen in having a positive relationship with their GP, followed by poor experiences with the specialist they were referred to. Inversely, this was also a poor experience with one healthcare setting, such as a nurse, dentist or Emergency Department (ED) doctor but a positive experience with another healthcare setting, such as a specialist. No participants described scenarios where they had all positive experiences or all negative experiences as they interacted with multiple healthcare settings. However, the majority of scenarios described were negative and distressing.

Five of the eight women in this study discussed having a positive relationship with their general practitioner (GP). This was established through having the same GP for many years. In some instances, this was over sixteen years but was mostly more than two years. Positive relationships were described as 'friendships', and GP's were seen as people and not just doctors, as the following quotes represent:

*I've been going to the same GP since 1997 so she's like an old friend really –
Bryony (Breast cancer)*

*I've had my GP for probably about fifteen, sixteen years. I like her very much as a
person – Zoe (Hypokalaemia)*

Participants also narrated a positive experience with specialists and other doctors who were not the primary caregiver, such as locum GP's, or GP's from other practices. These experiences included knowledge and supplying products for the women in this study throughout healthcare settings in Aotearoa New Zealand:

The ENT was amazing. He was a super lovely guy and obviously knows a lot about it – Cara (Sudden sensorineural hearing loss/Hashimoto's disease)

I get the product from a doctor. He sends it to me. I get it by mail. So, he believes in it – Amy (Pernicious anaemia/Motor neuron disease – disputed)

In healthcare settings, there is a heavy reliance, and trust, in doctor's acting with competence and reliability (Ceplak & Hlebec, 2012). Doctors are positioned as powerful authority figures, who patients are socially conditioned to trust. Here, trust is developed over time, through a series of experiences that reinforce the worthiness of a person, or that a person is trustworthy because they have consistently acted in ways that reinforce their trustworthiness (Donskoy, 2015; Puig, Erwin, Evenson, & Beresford, 2015). It seems the long-standing relationships with GP's as mentioned above also invoked an element of trust, which extended to other people within the healthcare system, and the healthcare system, more generally. The following excerpt depicts how Bryony experienced trust:

I wasn't that keen on the locum but the surgery, it's always been a good surgery. I trust the people who are in there so, yeah, I took her at her word – Bryony (Breast cancer)

Trust can also be established when the concerns of one party are taken seriously by another party (Puig et al., 2015). The women expressed positive experiences occurred with their GP's when they appeared to believe their accounts of their symptoms and sought to resolve them or find treatment solutions. Being believed, or taken seriously as a symptom reporter, is a significant issue in the misdiagnosis of women. For example, in a study about coronary heart disease in women, the participant's in McSweeney et al. (2005)'s study feared their symptoms would not be taken seriously, which impacted on their confidence to report their conditions and the ability to get diagnosed. The following two participants felt 'supported' by their GP's who were represented as people who warrant some 'faith' (as an element of trust) and 'goodness':

My GP who I do have some faith in, who has really stuck by me and said: 'I don't think it's in your head' – Piper (Chemical sensitivity – disputed)

My GP was really good. He couldn't do anything, so he kept referring me back to the hospital – Amiria (Trigeminal neuralgia)

For Amiria, even though her GP was unable to diagnose or treat her health issues, he continued to refer her to specialists and other healthcare providers so she could access appropriate medical care. He believed she was experiencing a significant health issue, one that he was unable to deal with.

Every woman in this study described negative experiences in healthcare settings. When negative experiences occurred, trust in doctors was diminished, as described here by Nicole and Amy:

Oh, trust in doctors. Which was already waning a bit by that point – Nicole (Ehlers Danlos syndrome)

If I hadn't done my initial research in the first place, I would be dead. So, I don't have much faith (in my GP) – Amy (Pernicious anaemia/Motor neuron disease – disputed)

All the participants had been spoken to rudely, disrespectfully, and treated with a lack of compassion by medical professionals. Negative treatment by healthcare staff, which included nurses and even administrative staff, added to the frustration and distress participants felt when entering a healthcare space, as Cara described:

He said I was surprisingly healthy for someone as large as me. At which point I picked my self-esteem up from the floor, put it in my bag and walked away – Cara (Sudden sensorineural hearing loss/Hashimoto's disease)

I guess my experience has been that people are always very polite but polite isn't the same as respectful. They were all nice to me, but one doctor had a yucky tone – Piper (Chemical sensitivity – disputed)

It feels very, very emotional. I don't think I cried so much in my whole life. One from the pain, but also for just dismissive attitudes and the lack of compassion – Amiria (Trigeminal neuralgia)

Each of these quotes demonstrated the impact of the negative interactions on the women's self-esteem and emotions. Six of the women in this study talked about having negative experiences with specialists in particular. They described specialists treating them in a way that left them feeling humiliated, not discussing their treatment or diagnosis with them, or not listening to them after describing symptoms. The physical toll of an illness can be distressing enough without added anguish from having to deal with those in the healthcare system – the very people who are supposed to help and care. The following narratives represent the significance of the emotional response:

I'm just absolutely shattered. I've been fighting, looked like a bitch, but actually I've just felt like crap. They just see the bitch but not the crap that's behind it. I don't want to be humiliated anymore. Not really getting anywhere. It's just too distressing. Feel totally hammered – Piper (Chemical sensitivity – disputed)

I left that endocrinologists office and went to my car and I sat, and I cried, because I thought - I just felt humiliated – Cara (Sudden sensorineural hearing loss/Hashimoto's disease)

He said to me: 'no, you are going to die. You are not getting better.' This is how he spoke to me. Pretty awful. And that was it! I walked out of the room. There was no support. There was no info pack. There was nothing. I drove home and I was in shock. I was really in shock – Amy (Pernicious anaemia/Motor neuron disease – disputed)

Here the women described feelings of distress at being ‘hammered’ and ‘humiliated’. To be told that your death is inevitable induced shock and distress. I was also shocked to hear the participants had been spoken to that way. Making sense of such negative experiences for the participants involved assigning accountability to the doctor or specialist responsible for the negative experience. There was also frustration expressed at GPs, and specialists, who seemed to not have enough knowledge to make a correct diagnosis in the first place, prescribe an appropriate treatment, or who dismissed participants with an incorrect diagnosis.

Participants experienced both positive and negative experiences in healthcare settings as they attempted to get diagnosed and treated. Misdiagnoses came from both GPs and specialists, in varying combinations. For example, a participant may have been misdiagnosed by their GP but gained a correct diagnosis from a specialist. In some cases, neither GP nor specialist were able to correctly diagnose. Therefore, experiences and descriptions of Aotearoa New Zealand healthcare settings follow a contradictory dialogue, where positive and negative experiences together describe more accurately the experiences of the women in this study, rather than a monologic statement that claims healthcare settings are either exclusively positive or negative spaces (Colyar, 2012).

Doctor as expert but not enough knowledge

Five participants described their GP’s or the specialists they were referred to as ‘experts’ – an implication that healthcare professionals have extensive training and experience with illness. The expertise of medical professionals suggests participants believed they were receiving helpful treatment, or that their diagnosis was correct. As well as trust, there is a heavy reliance on healthcare professionals to be knowledgeable and skilled in illness diagnosis and treatment (Ceplak & Hlebec, 2012). This played an important role in the misdiagnosis experience as it meant the women in this study accepted a diagnosis from their expert doctors, despite it later being incorrect:

I figure she knows what she's doing. She didn't seem worried about it, so I was like ok. I'm not a doctor, I don't know enough about this – Zoe (Hypokalaemia)

The problem is, you assume as a human being who doesn't know as much as they do, that they know what's best because they're the professionals. So, you go along with what they say, and you listen to them because they're the professionals. And that's what I've done. I've kept listening, I've kept going along with them, I've kept doing what they want to do – Amiria (Trigeminal neuralgia)

Because when you're given a diagnosis like that you assume the specialist has looked at everything, and gone through all their protocols – Amy (Pernicious anaemia/Motor neuron disease – disputed)

When participants were specifically asked why they thought they had been misdiagnosed, six responded that it was because their doctor did not have enough knowledge about their illness. The medical professional not having enough knowledge was also a theme that emerged in the literature, specifically around women's bodies, as they were excluded from research (AbouZahr, 2014). Not having enough knowledge was also a way in which four of the women made sense of their experience with misdiagnosis – it explained why misdiagnosis had occurred for them:

They put me in hospital for a good four or five years and just dosed me up on steroids cos they had no idea what was going on – Nicole (Ehlers Danlos syndrome)

All I kept getting was: 'it's a medical mystery. We're not sure why it happens'. Great! That's fine. But that's the one thing that's been consistent: GPs don't seem to be educated at all on this condition – Cara (Sudden sensorineural hearing loss/Hashimoto's disease)

And I think part of the misdiagnosis was that I don't know if the original GP knew that it could affect your heart – Zoe (Hypokalaemia)

That lack of knowledge meant that in some cases there was no referral to a specialist and therefore treatments were delayed or non-existent. When asked, most of the women did not know why their doctors did not have enough knowledge about their illness. Three participants stated that it was due to their illness not being common to the medical community and therefore their doctors did not know how to diagnose or treat it:

Trigeminal neuralgia is such a hard one that even my GP, he's heard of it and he's treated, I think he said about six people in the 40 something years he's been a doctor. He said it is so understudied – Amiria (Trigeminal neuralgia)

The one I like to keep a look into is the chronic fatigue, the fibromyalgia side of things, especially with the new research coming out. Because there's so much unknown about it – Hannah (Chronic fatigue syndrome/Fractured coccyx)

It's very rare. Well, it's not as rare as it was ten years ago... I used to go to the doctor five years ago and say I have Ehlers Danlos and they'd say: 'can you tell me about that?' You know, 'what is that?' – Nicole (Ehlers Danlos syndrome)

Two participants understood the impossibility of knowing all medical conditions, in that medicine is a vast field and no one person can be an expert in all symptoms. Cara and Amy felt that this might have explained why there was not enough knowledge about their illness, and why their doctor did not have that knowledge:

It feels like they're - I don't know, they've got to know a little bit about a lot of stuff – Cara (Sudden sensorineural hearing loss/Hashimoto's disease)

Yeah and that's ok as well. They say well I don't know but I'll find out. That's ok. I don't expect them to know everything – Amy (Pernicious anaemia/Motor neuron disease – disputed)

I felt this sympathy for medical professionals was gracious, considering how the women had been treated. The health conditions the women in this study experienced were not specific to women's bodies, as was the design of this project, yet half of the chronic conditions experienced by the participants are more common in women than men and have been subjected to less interest and research (see for example Briones-Vozmediano (2017)). Historically, chronic conditions with inexplicable symptoms that affect more women fell under the category of 'hysteria' and were not taken seriously by the medical community or considered legitimate medical conditions. Examples of these are: fibromyalgia, chronic fatigue syndrome, or multiple sclerosis (Katz et al., 2008; Saunders-Pullman et al., 2011; Ussher, 2013). This was mentioned by one well-informed participant:

It's always women who are put into categories of things like ME, which is basically just means 'we have no idea what's wrong with you so we're going to label you with this meaningless term and stick you in a box and ignore you' – Bryony (Breast cancer)

The participants' narratives represented contradictory positions around perceiving the doctor as expert and someone to trust (and who's advice should be followed) and seeing them as someone who lacks knowledge about medical conditions. Traditionally, doctors are positioned as the 'expert' who holds power, while the patients are the passive consumers of their 'expert' medical care. In this way, they do not challenge decisions, treatments or expertise, and are expected to trust that doctors are acting in their best interests (Ceplak & Hlebec, 2012; Hagan, Rosenzweig, Zorn, Londen, & Donovan, 2017; Joseph-Williams, Elwyn, & Edwards, 2014).

Women also endure patriarchal power dynamics in doctor-patient interactions, and face barriers to treatment from 'experts' who give a recommendation and seemingly refuse to listen to women who challenge those recommendations based on knowing their own bodies (Joseph-Williams et al., 2014; Katz et al., 2008; Lorentzen, 2008). When coming up against doctors who did not listen and therefore failed to treat symptoms adequately, the women in this study found themselves in another

contradictory position, that of needing healthcare but refusing (or wanting to refuse) the treatments their doctors prescribed.

Needing healthcare and refusing treatment

Six of the eight participants talked about a contradictory position within the healthcare system and the people within it, in that they needed it, but also did not want to engage with it. It was necessary to consult a doctor due to their physical symptoms, but because of historically distressing experiences, at times, they avoided engaging with the health system altogether. If they could, participants had chosen to 'ride out' their symptoms, or sought care only when they interpreted their symptoms as serious:

Some I would have gone to a doctor for and some I'd just go: 'Yeah I'll just let it ride through, it's two months'" – Piper (Chemical sensitivity – disputed)

I don't go to the doctor unless there's something serious though. I'll just treat it at home. I don't go until there's something pretty darn bad – Zoe (Hypokalaemia)

Participants also described refusing to attend referral appointments with other healthcare professionals, particularly specialists. In some cases, this because the specialist had previously treated them poorly, and they consequently were concerned about this occurring again. In other instances, the idea of meeting with any specialist was enough to deter contact, because of previous negative interactions with other specialists. As Facione and Facione (2007) and Lorentzen (2008) elucidate, future health encounters are driven by prior experiences in healthcare settings. Piper and Cara describe their strong responses to seeing specialists:

My GP found a rare auto-immune anti-body came up in my bloods. And he said, 'I really want you to go and see a specialist' and I said to him, 'Fuck, I'm not going.' And he said, 'please, we'll go down the auto-immune line rather than the respiratory line'. And I said, 'I really don't want to go' – Piper (Chemical sensitivity – disputed)

I wouldn't go back and see him. I would have to find a different ENT to the alternative that I saw once just because he was so rude and so dismissive about my condition – Cara (Sudden sensorineural hearing loss/Hashimoto's disease)

As discussed in the literature review, refusing treatment and appointments with specialists, avoiding doctors, and ignoring and downplaying symptoms, are common responses to misdiagnosis. This may be related to negative experiences associated with misdiagnosis in healthcare settings, and not wanting to repeat them, however, it could also be due to trusting the diagnosis they were given and relating new or worsening symptoms to that (incorrect) diagnosis. This behaviour could have serious repercussions for women's health and mortality, and I was concerned for the women who refused to get treatment. Early detection of illness can be vital for treatment success, and mortality, and relies heavily on seeking prompt treatment for symptoms (Facione & Facione, 2007).

Needing healthcare meant that half of the women in this study had sought alternative healthcare or treatments alongside, or instead of, conventional medicine. This included seeing alternative practitioners and engaging with alternative medicines or practices. In most instances these provided a reduction in, and explanation of, symptoms that Western biomedicine had not been able to. Alternative treatment for Piper worked, while Cara got treatment that she needed, and Amy was testing alternative diets to help alleviate her symptoms:

One thing I have done which has worked, I have started looking at Eastern methods of health and wellness. Just cos I was feeling like this wasn't for me anymore – Piper (Chemical sensitivity – disputed)

It was only when I went to see an alternative, a holistic doctor that she tested my thyroid antibodies – Cara (Sudden sensorineural hearing loss/Hashimoto's Disease)

At the moment, I'm experimenting with gluten free diet and fasting because I read a lot about that – Amy (Pernicious anaemia/Motor neuron disease – disputed)

Complementary and alternative medicine's (CAMs), treatments that are not typically provided by conventional health professionals, are becoming increasingly popular (Ramadurai, Sharf, & Ramasubramanian, 2016; Valenti, 2011). A study by Ramadurai et al. (2016) found that people used CAMs out of desperation, when biomedicine did not work. In much the same way, it can be inferred that the women in this study experienced feelings of desperation and frustration with conventional biomedicine, which prompted them to seek CAMs.

Ramadurai et al. (2016) also discussed how their participants had been empowered through using CAMs and regained a sense of control regarding their health crisis. For the women in this study, the use of CAMs was an act of empowerment in that they were able to get treatment for symptoms biomedicine was unable to help with, or that practitioners seemed uninterested in. That is, the women in this study took control of their illness experiences, which enabled a way to overcome the contradiction of needing healthcare while wanting to refuse biomedical treatment. The participants took these steps despite the cynicism of their conventional healthcare providers. Their experiences with CAMs may also narrate how they made sense of their experience with conventional medicine.

A key part of sense-making involves relating one experience to previous and future experiences, as well as a sense of self, personal history and hope for the future (Harrington, 2017; Wright et al., 2004). Participants experiences with misdiagnosis certainly informed their sense of self and decision making around the future use of healthcare settings, in that they refused treatment and interactions with particular healthcare professionals as much as possible, when previous interactions had been ineffective and unhelpful. This facilitated a more coherent sense of self and affirmed knowledge about their own bodies, as well as enabling an ability to fight for

themselves. Being their own advocate empowered them as people, and as women, which is discussed in the next section.

Embedding Agency in the Misdiagnosis Experience

Participants spoke frequently about agency in their misdiagnosis narrative. This centred around being an advocate for themselves and conducting research to better understand their symptoms, illnesses and treatments, and, in knowing their own bodies, continuing to fight for treatment and diagnosis.

Self-advocacy

Self-advocacy is defined as a person getting their needs met while facing a challenge (Hagan et al., 2017). Self-advocacy skills in relation to health can include making informed decisions about healthcare treatment, navigating the health system, working as a team with healthcare providers, and communicating effectively with health providers. It also involves utilising resources and being mindful of non-adherence of treatments i.e. choosing to not adhere to a treatment programme after evaluating the benefits and side-effects (Hagan et al., 2017; Ruggiano, Whiteman, & Shtompel, 2014). These skills can be used to face ongoing symptom management and attend to healthcare needs (Hagan et al., 2017). Research recognises that self-advocacy enables better health outcomes and better healthcare provider interactions between patients and healthcare professionals (Ruggiano et al., 2014; Valenti, 2011; Wiltshire, Cronin, Sarto, & Brown, 2006).

Self-advocacy was prominent in every women's narrative in this study. Self-advocacy ranged from researching their conditions, asking doctors for testing to be done, chasing doctors for test results, making appointments themselves with specialists (particularly as symptoms persisted), designing their own treatments, seeking alternative healthcare (as discussed above), and generally fighting for their health.

The only reason I'm better today is because I did it all myself. I found all my own help. I took all my own stuff – Amiria (Trigeminal neuralgia)

I asked him to test me, but he didn't know what it was and I told him what test to do and then he did it very begrudgingly. I said to him I want this test and this is how you do it. He had to get his books down and look up how you test it – Amy (Pernicious anaemia/Motor neuron disease – disputed)

I pushed it in the sense that I chose to go to him (the specialist) and then he pushed it from the medical side. It was just sort of drifting – Bryony (Breast cancer)

In describing their advocacy efforts, the women's narratives represented exhaustion, distress and frustration. On top of dealing with physical symptoms, participants described contesting a system that did not seem to be interested in their symptoms or health, nor in helping them return to well-being. However, Piper and Cara stated they were determined to fight:

So yes, that was a rather horrible experience. And it left me with the thing, 'oh I just have to fight and fight to even feel like I'm sane' – Piper (Chemical sensitivity – disputed)

I just keep fighting the good fight to go 'well what else can I do?' – Cara (Sudden sensorineural hearing loss/Hashimoto's disease)

Five of the women in this study talked about having to do their own research about their illness symptoms and/or treatment. This was thorough, in-depth research that drew on reputable sources, not a reflection of a 'Dr Google' or the 'Web MD' culture, where a quick internet search provides a self-diagnosis (Lyons & Chamberlain, 2013). These women were desperate for answers to symptoms their healthcare providers did not have, ignored or dismissed. One participant had to turn to the internet to get information about the condition she had been (mis)diagnosed with, after a specialist provided her with the name of her (alleged) condition and informed her it was a death sentence and then said nothing more. However, as the quotes below demonstrate,

when participants presented their research findings to GPs or specialists, the response was disbelief, cynicism and dismissal:

If I'm going to do research, I don't like to do Google. I've got access, because of studying, to journal articles, so I'll try to go the journal article route rather than the quack side of things – Hannah (Chronic fatigue syndrome/Fractured coccyx)

I said to her that every symptom I have and everything I've researched and studied, and then she gave me the: 'and what, googled?' – Amiria (Trigeminal neuralgia)

A lot of this stuff I was reading, that I got from uptodate.com which is a medical site, and I would mention that to the specialist but they're not really keen to discuss it with you. I'm told things like 'oh you read too much', 'you shouldn't believe everything you read on the internet', all that kind of stuff – Amy (Pernicious anaemia/Motor neuron disease – disputed)

Because of poor knowledge by health professionals, three of the women in this study with chronic conditions became experts on their illness. They advocated for their own needs and care, at odds again with the doctor, an 'expert'. Nicole and Amiria described how they had been treated by their doctors:

I tell my doctor what drugs I need, and she gives them to me without asking any questions. That's not good! But yeah, that's where I'm at – Nicole (Ehlers Danlos syndrome)

I said to him I need some amitriptyline's, I cannot sleep at night. And he was good. He gave it to me straight away' – Amiria (Trigeminal neuralgia)

These women were successful in their efforts to advocate for their treatment as their received the medication they need, however Nicole also expresses disappointment that she has to do so, rather than her doctor being more active in her care.

One participant, through her own extensive research, self-diagnosed. After sharing her conclusion with her healthcare team (after five years of suffering), it took a further three months for her diagnosis to be taken seriously and accepted by medical professionals, which resulted in further frustration, distress and continued delayed treatment.

Diagnosis was based not upon them giving me one, but me telling them what I had. I told them I think I've got TN and then the nurse was just like, literally, her face was like: 'why do you think that?' In a rude sarcastic way, that's exactly how she answered me. They gave me some stuff to put me to sleep so I would have a remission period, because I was in so much pain, and it didn't work. And that was when she finally said, 'I think we should get someone else'. They then got a guy in and I remember he touched me and asked me questions. He said, 'oh it sounds like trigeminal neuralgia'. And I was like, I've been trying to tell you guys this for three months! – Amiria (Trigeminal neuralgia)

Here, Amiria's experience demonstrates how difficult it is to self-advocate and receive a diagnosis (and therefore fit-for-purpose treatment) in the face of healthcare professionals who are sceptical, and do not take patients seriously. One woman narrated a particularly striking strategy of self-advocacy, by arguing for her voice to be 'heard' in her medical records. Piper described an upsetting incident where she had to fight to get a copy of her medical file. After receiving it, she realised she had been labelled 'difficult', and that she had no recourse to challenge the label or what was in her file. That women are positioned as 'difficult' is a common theme in women's interactions within healthcare settings (Ussher, 2013), which reinforces ideas about women being hysterical or hypochondrial – with attention-seeking their main goal, rather than improved health. Through "tears and (talking with) one of my friend's"

Piper realised she could start to redress such situations where she had no voice by taking a digital recorder to doctor's appointments:

And I said: 'hope you don't mind but my partner couldn't make it, so I'd like to tape this consult.' Because I came to realise, they're the only ones who write. So, there's no record of my voice, of how I found it. Or whether they recorded it correctly. So, the only thing that ever gets any validation is their voice, their record of my voice. Their voice. So, I thought: 'right, we need to make sure we have a really clear record and I've got one for myself. And it will be a taped voice of both of us' – Piper (Chemical sensitivity – disputed)

Allowing women's voices to be heard was one of the goals of this research project and I am impressed and intrigued by Piper's actions. Ruggiano et al. (2014) suggest increasing communication with healthcare providers as an effective skill for self-advocacy, leading to better health outcomes, but this is difficult for women who have historically been silenced and ignored. Piper did note that after taking her digital recorder to her doctor's appointment she "got excellent service." However, while self-advocacy can elicit better health outcomes for those who are able to advocate successfully, it is clear from participants accounts that this was an incredibly difficult, and often unsuccessful, endeavour. Additionally, not everyone has the ability or the resources to self-advocate.

It was important for the women in this study to have agency to challenge the health system. However, participants' drive to self-advocate was fuelled by knowing their own body and knowing that something was wrong with their body that contradicted what their healthcare providers were telling them. The importance of knowing their bodies was discussed by most of the participants and is explored in depth below.

Knowing own body

Six of the women spoke about knowing their own body. They knew that the symptoms they were experiencing were not normal for them, and that they were physical and not mental. They talked about knowing that their healthcare provider's diagnosis was not

quite right, but because they had been socially conditioned to trust a doctor and the expertise of doctors, they complied with what the medical professionals were telling them. This was also salient for compliance with treatments, even when they were found to be ineffective. Amiria, Hannah and Amy all discussed how they knew their bodies and while they tried to contest medical advice, their voices were ignored:

They'd do more dental work and they just kept doing dental things and I kept saying, 'my teeth don't hurt. My teeth are fine. I'd know if it was a tooth problem'
– Amiria (Trigeminal neuralgia)

It's that whole, you're saying it's not something and they're like 'but it is'. And you're just like, but I know it's not. I'm a dancer, I know how my muscles work –
Hannah (Chronic fatigue syndrome/Fractured coccyx)

And you know your own body. You do know your own body. No matter what people say – Amy (Pernicious anaemia/Motor neuron disease – disputed)

Biomedical knowledge has traditionally been defined as information gained through reasoning, impartiality, detachment and objectivity (Barbour, 2004). In this way of thinking, subjective embodied experience is not considered a reliable way of knowing. For my participants, problems arose when their embodied knowledge contrasted with the biomedical conclusions their doctors reached. When my participants sought to share their expert knowledge about their bodies, their doctors were disinterested or sceptical, instead placing more importance on their medical knowledge and training. However, healthcare professionals typically rely on patient reports of symptoms in the diagnostic process as they are not first-hand knowers of the symptoms, and yet, when it comes to women's reports of symptoms, they are often discarded as incorrect or unimportant. That is, as previously mentioned, doctors assume women are unreliable reporters of symptoms, and that influences the decisions they make regarding diagnosis and treatment (Lorentzen, 2008; Munch, 2004; Wolf & Veinot, 2015). This is also reinforced by tests that are not sensitive enough for women's bodies, that act to support doctor's beliefs about illnesses rather than what their patients are telling

them, particularly as medicine has placed more and more reliance on objective testing, and those tests have been developed on male bodies (Bornstein & Emler, 2001; Lorentzen, 2008; Munch, 2004).

Piper describes a scenario where testing was prioritised over her own embodied experience and knowing about her body. Even more frustratingly, once Piper's GP had exhausted testing for asthma himself (and therefore ruled it out as a diagnosis), he referred Piper to a respiratory specialist, who, while ignoring Piper's symptom reporting, advocated for asthma testing. It also links back to my previous discussion on trust and demonstrates how Piper's trust in healthcare professionals lead her to comply with the testing in a bid to get diagnosed, despite it going against her instincts that she was not experiencing asthma attacks. In this instance, Piper understood she did not have asthma, but ignored her embodied experience to comply with the 'expert' doctor:

I was pretty convinced it wasn't asthma but for the first few goes because they were intermittent and over five years, I just sort of went along with it – Piper (Chemical sensitivity – disputed)

The participants' knowledge of their own bodies, particularly that something was wrong, often motivated them to insist on treatments, tests, or to seek further help from other sources, such as other GPs, specialists or CAMs. Knowing their own bodies meant that some participants valued themselves and their embodied experiences, and worked to self-advocate and empower themselves (Slade, Molly, & Keating, 2009). This fits with feminist notions of constructed knowledge that privileges women's lived experiences (Barbour, 2004). Barbour (2004) extends this further to privileging embodied experience, where a person experiences themselves as a creator of knowledge, valuing their own experiential ways of knowing. Importantly, for the context of this study, Barbour (2004) and Lorentzen (2008) describe embodied knowledge as reconciling experiential embodied ways of knowing with other strategies, where resolutions come through intuition, and embodying and living out the possibilities of those resolutions. This fits with the process of sense-making that

evaluates past experiences for future actions, as well as the contradictory notions of dialogic understandings that value both the embodied experience of symptoms with biomedical information, instead of an either/or resolution.

The next theme, the culture of women, further unpacks how being a woman affected the experiences of the participants in healthcare settings.

The Culture of Women in Healthcare

This theme focuses on how women are seen in Western culture and particularly in the culture of medicine. This included seeing women as mentally, and emotionally unwell, rather than physically unwell. It also included women not being taken seriously as symptom reporters and as sick people, and being told symptoms and illness were all in their heads; either made up, or a reflection of mental illness.

Mental health, crazy, and not a frequent healthcare user

Mental health was mentioned in three contexts by four participants. The first context discussed here involved freely disclosing a current or previous experience with anxiety or depression. It has been well documented in women's history with medicine that women are positioned as mentally unwell, rather than physically (Lorentzen, 2008; Maserejian, Link, Lutfey, Marceau, & McKinlay, 2009; Verdonk et al., 2009). In these situations, it is unclear whether doctors were influenced by previous diagnoses of mental health issues, but it certainly mattered to how the women made sense of their misdiagnosis. For example, Zoe and Piper described how they questioned the importance of their psychological history:

Whether that's a factor too, whether she's looking at me saying 'well she's got depression'. And anxiety. So she might not... not fabricating things but making a bigger deal than they were. I don't know whether that's a part of it too, or if she's just a complacent doctor – Zoe (Hypokalaemia)

I said: 'look, I've had a panic attack before, I know what that feels like. This is not it.' I said: 'I've been depressed, I know what depressed feels like, I'm not talking about that' – Piper (Chemical sensitivity – disputed)

The second context where mental health appeared to matter was when medical professionals suggested that symptoms were a result of anxiety or depression, rather than a physical illness. This was incredibly frustrating for those women, and is reflected in the literature as often the first diagnosis a woman receives, despite the description of physical symptoms that do not fit mental health conditions, such as depression (Briones-Vozmediano, 2017; Maserejian et al., 2009; Morgan et al., 2016). Research demonstrates that once a woman receives a mental health (mis)diagnosis, it is often even more difficult to be taken seriously as a patient with physical symptoms (Donskoy, 2015; Ussher, 2013). Similarly, once a diagnosis is reached, doctors do not go on to consider other potential diagnoses and the diagnostic process ceases (Britto, 2018; Graber, Franklin, & Gordon, 2005). Therefore, an incorrect diagnosis of mental illness is incredibly detrimental. Piper's excerpt highlights how anxiety was privileged over health:

Very quickly into the consultation he went down the anxiety path. About, am I anxious? And I was just so taken back. Then it (anxiety) was just, in my experience, a bee line for that was my diagnosis – Piper (Chemical sensitivity – disputed)

The third context involved four participants who quickly justified themselves to me by stating they were not 'crazy', nor frequent users of healthcare (the implication being that they are attention seekers, or hypochondriacs) and that they had legitimate physical symptoms. This again represents the cultural narrative that women are more often positioned as mentally unwell rather than physically unwell, which has underpinned medical culture. It also reflected the historical belief that women are frequent users of healthcare services as they attempt to gain attention or escape the boredom of being a stay-at-home mum (Nicolson, 2004). In this study, it appeared that

the participants narrated the frequency of their healthcare use to manage their credibility in their experiences with doctors and in their misdiagnosis narrative.

I hardly go to the doc - I don't like going to the doctor, I don't make a habit of going to the doctor. In fact, I would only go when I have these (episodes). They don't see me from one, two-year, three-year slot to the next. I'm not a regular caller – Piper (Chemical sensitivity – disputed)

I never was a hypochondriac. I'd always avoid going to the doctor. I wasn't that sort of person – Amy (Pernicious anaemia/Motor neuron disease – disputed)

Here, Amy is clearly aware of the way women are positioned in healthcare as hypochondriac and that this affects how seriously women are taken as patients. When the women in this study were not taken seriously, it was suggested by healthcare professionals that their illness symptoms were not legitimate.

It's all in your head

As has been represented throughout this work, not being taken seriously, as a patient and as a symptom reporter, is a significant barrier to diagnosis and treatment, and is unfortunately a common experience for women in healthcare settings (Alspach, 2012; Lorentzen, 2008; Slade et al., 2009). Six of the participants felt they were not listened to or were not taken seriously (and therefore not believed to be credible symptom reporters) by their doctors or other healthcare professionals, as the following quotes show:

You lay yourself bare to somebody and they turn around and tell you that they don't believe you or you don't need that, or you don't know what you're talking about. It's pretty rough sometimes – Nicole (Ehlers Danlos syndrome)

That whole 'are you going to be listened to if you go forward and talk about it' – Hannah (Chronic fatigue syndrome/Fractured coccyx)

With my GPs it felt like they weren't listening to me... It's just an ongoing battle until someone takes me seriously – Cara (Chemical sensitivity – disputed)

Female issues do tend to get lumped into the 'not really serious, women worry too much, nahny, nahny sort of attitude' – Bryony (Breast cancer)

The phrase 'it's all in your head' was significant in the literature and also emerged in one of the participant's narratives when she discussed interacting with healthcare professionals. This attitude created a sense of wariness for the participant regarding healthcare settings, which broke down the trust this woman had in the medical system, and led to her avoiding it where she could. In the literature, the implications of this meant patients delay seeking healthcare and are reluctant to return to settings where they are not getting treatment and feel like they constantly have to fight to be taken seriously and listened to (Andaleeb & Millet, 2010; Berg Gundersen et al., 2016). Nicole narrated the frustration of being treated as though she were making up her symptoms:

There's nothing to see, there's nothing to fix, so, what are you here for? We can't help you. Go home, it's all in your head. It was pretty severe and serious but at that point I had doctors telling me: 'your mother's making it up and putting it in your head'. Or, 'we can't find out what's wrong with you so there's nothing wrong with you' – Nicole (Ehlers Danlos syndrome)

The literature supports the experiences of the women in this study in how they were treated in healthcare settings, and how gender plays a role. I was interested in asking my participants specifically what they thought about the subject; the outcome of this is discussed in the section below.

Do You Think Being a Woman Played a Role in Your Misdiagnosis?

As the most significant and explicit question asked in the semi-structured interview, I asked it towards the end of the discussion to give the women time to reflect on how it mattered to their experiences. It was from this question that deliberate sense-making

occurred for participants as they took time to think about their answer. Interestingly, only two of the participants answered the question with assured affirmative responses. Bryony was a particularly articulate participant, who was definite about her gender as a woman impacting on her misdiagnosis. Her narrative supported the literature on gender, research and health. She summed this up concisely:

I think it's the attitude to female biology. The fact that there isn't the research on women's health that there is on men's. That it's assumed that we are, or being hysterical and I don't - I think that we're seen as: there's people and then there's women and we're the abnormal, we're the difficult and you can't worry about people like that in the same way as you worry about, you know, real people – Bryony (Breast cancer)

The rest of the women in this study were unable to give such strong replies. However, they did think gender mattered in some way, but at the same time were unsure, or tried to mitigate their experiences. It seemed like just a hunch:

I think potentially. I don't know that should be a factor or not but, if my husband had gone in and presented the same symptoms and blood tests I don't know if it would have changed or not – Zoe (Hypokalaemia)

<Thinks for a while> At first, I did. But then once I went into the support groups, I saw there were so many males in there. Not as much, it's about 80:20. I can't say now I think it was that. At first, I think it was – Amiria (Trigeminal neuralgia)

Possibly. I mean, women are known as neurotic, aren't they? – Nicole (Ehlers Danlos syndrome)

Hard to say. I mean I suppose - I would say yes – Piper (Chemical sensitivity – disputed)

Yeah and I get that your study is about women and whether it would make any difference if I were a man, I have no idea – Amy (Pernicious anaemia/Motor neuron disease)

I don't know. <Thinks> Definitely felt like it with the alternative ENT. <Thinks> I don't know with the GPs. I think it's just cos they don't know anything about it. <Thinks> It's a hard one to say – Cara (Sensorineural hearing loss/Hashimoto's disease)

It makes sense that the women's hesitant and contradictory responses reflect how as a society we are not taught to consider the way in which gender matters or whether it was a factor in their misdiagnosis. Gender is an enculturated performance that is implicit (Bleakley, 2013; Holmes, 2016; West & Zimmerman, 1987). It operates in the background until it is made salient. In asking the question, gender became relevant to the narrative of the participants. Amiria's excerpt is an example of this:

Couple of things we've found in our question in our research is that a lot of the men though were instantly put on neurological medication and we weren't. But I didn't think of that until you just said that before – Amiria (Trigeminal neuralgia)

Gender not only influences how the patient is engaged with, it also matters to how the health professionals respond. The age of doctors also influences exchanges with their patients, particularly older doctors who are more likely to be influenced by historical cultural ideas about (young) women (Hamberg, Risberg, Johansson, & Westman, 2002; Maserejian et al., 2009). This point was highlighted when Nicole described the impact of the doctors age and gender on how they viewed Nicole and their interactions:

Epecially with those older male doctors I was speaking about. And it was only ever those ones that had that talk with my mother or me that it just wasn't real, and I was used to thinking I was in pain so therefore I was. I used to really not like going to the male doctors for that reason. I don't know if that was the gender versus thing but maybe it was just my conception of it. I don't know. It's quite

funny. Don't think about it until you're forced to really. It's the first time I've sort of considered that – Nicole (Ehlers Danlos syndrome)

It's a culture and it's predominantly men and it's still top down. I think what you're saying is the men's club is still alive and well – Amy (Pernicious anaemia/Motor neuron disease)

Bias and culture operate in implicit ways, and it is only through drawing attention to these issues that we may start to work to overcome them (Beaumont, 2016; Chapman, Kaatz, & Carnes, 2013; FitzGerald & Hurst, 2017). The participants initially all stated that gender mattered to their diagnosis, even though at the time they could not articulate why they thought so. Through explicit discussion around gender and healthcare during the rest of the interview, the women were able to articulate an increasing number of misdiagnosis experiences they, and other women they knew, had had, as well as attitudes towards them that they felt were inappropriate, unfair and distressing. In this way, the women were able to make sense of their misdiagnosis experience through the shared experiences of others and in retelling their story (Dowding et al., 2016; Harrington, 2017; Wright et al., 2004).

The experience of misdiagnosis had a significant impact on the lives of the women in this study. They described scenarios where they were treated rudely, were not taken seriously, and were unable to gain fit for purpose for their symptoms. I will now go on to discuss the implications of the participants experiences in the next chapter.

In Closing

This research project began with my experience of being misdiagnosed, to provide the context for which this project was conducted (Akman et al., 2001). In this sense, as a reflexive researcher, I realised that a part of me was interested in finding a narrative like mine, as a component of my sense-making. Instead, I found similar elements. While I was not treated rudely, and my illness and symptoms were taken seriously in my misdiagnosis experience, like my participants, I strongly believe my symptoms were interpreted against male symptoms (in my case appendicitis), despite research showing women often present with different symptoms. A study from 1995 describes my appendicitis experience eerily accurately. Rothrock, Green, Dobson, Colucciello, and Simmons (1995) found 33% of women with appendicitis were initially misdiagnosed. These women exhibited diffuse and bilateral lower abdominal pain and tenderness, which differed from the typical right lower quadrant pain. Like me, they experienced increased incidences of perforation, abscess formation, and increased total length of hospitalisation. Taking into consideration this information, my appendicitis experience may have been incredibly different if my doctors were aware of this. While my misdiagnosis narrative differed from my participants', our shared elements and individual stories collectively reflect social realities of misdiagnosis (Squire et al., 2013).

That I was motivated by the sense-making around my experience inspired my research focus and design. An incredible amount of anecdotal and academic literature highlights horrific lived experiences of women after being misdiagnosed, and when negotiating healthcare spaces. Therefore, I wanted to draw attention to this kind of experience in the hope that it may lead to change and better outcomes for women in healthcare settings.

To do this, I took a feminist standpoint approach, that aimed to privilege women's voices in research. This meant giving voice to women who had been affected by misdiagnosis. Narrative research provided a space for making sense of experiences through storytelling and sharing lived experiences and knowledge. The semi-structured interview was a great facilitator for doing this and giving voice. My own narrative and

sense-making allowed me to empathise and understand my participant's experiences, as well as facilitate sense-making for them. As a way of understanding health-behaviours, bias and narrative, sense-making is a beneficial tool, and much more research in these field needs to be done. A descriptive interpretive approach provided a basis for finding patterns in data that helped form the themes in my analysis.

I spoke with eight women who had been misdiagnosed with a medical condition that affects both women and men. I wanted to talk to women who had illnesses that potentially should be diagnosed equally as frequently in women and men – and then try to make sense as to why they were not. For example, in my own efforts of sense-making around my misdiagnosis I quickly found a standard operating procedure that men presenting to emergency departments with abdominal pain should be investigated for appendicitis, while women should have gynaecological factors explored. Given that women also have an appendix that is equally likely to become infected, I found it troubling that abdominal pain in women would *only* be assumed to be related to female biology, particularly when delayed treatment could be a matter of life and death.

An androcentric Western culture that values and privileges men and patriarchal ways of thinking matter to health. It creates unequal power dynamics between groups of people and is mirrored in Western biomedical healthcare settings. This means that women are not included in medical research, gender is rarely included in medical training programmes, and women are not in positions of power in medical institutions (i.e. a position to be able to influence policy). What is thought to be known about women's bodies is generalised from research with male participants and is often not suitable or a reflection of women's bodies. Women as patients come up against gender and power dynamics when interacting with healthcare professionals. This means women's voices are not considered to be worthy of listening to or taken seriously, and they are not viewed as reliable symptom reporters, even about their own bodies.

In this research, it is also argued that misdiagnosis in women is embedded within androcentric Western culture and reflects two issues. The first is that there is simply a

lack of research about women's bodies, particularly around those parts that are not specific to their biological sex, such as hearts, appendices, and muscles. Most research has historically been conducted with men and generalised to women. This means, healthcare professionals are not aware of how illnesses manifest for women, and tests are not sensitive enough for women's bodies. This surmounts to an alpha bias: women and men are treated the same, when differences exist (Smirthwaite & Swahnberg, 2016). The second issue is the reasons *why* there is a lack of research around women's bodies. This relates back to women being positioned as mothers, and their fertility and potential offspring need to be protected in Western culture.

The literature reveals how women are valued in society as mothers and how medical research has avoided women as participants because of concerns to unborn children and fertility. Therefore, I was surprised the women in this study did not recount more incidences around their roles as mothers, particularly in relation to interacting with their healthcare providers. This may be because there is a genuine shift in medicine away from seeing women as predominantly mothers. It may be that the illnesses and conditions the women experienced, apart from the one participant with breast cancer, could not be linked to motherhood in some way. Or it may be the case that the questions asked in the interview were unable to draw out this aspect of the literature. Given this study was about gender, and not motherhood specifically, it was outside of the research focus. However, further research around the role of motherhood could be enlightening to women's experiences of misdiagnosis and illness.

The women in this study all described distressing scenarios where they were not taken seriously by healthcare professionals, experienced delayed treatment, and poorer health outcomes. They also talked about there not being enough knowledge about their illnesses and conditions. This was surprising, given these conditions were equally likely to affect men and not just women (I expected there is abundant knowledge about illnesses that affect men). However, illnesses that affect more women than men receive less research interest and funding, and this may explain why there was an impression there was not enough knowledge about the illnesses and conditions affecting some of the women in this study. For example, trigeminal neuralgia, chronic

fatigue syndrome, Ehlers Danlos syndrome, Hashimoto's disease, and breast cancer all fall into this category (see the Index for further descriptions of these conditions). It may be that these illnesses are considered 'women's illnesses' and therefore there is less interest in them.

As pointed out by one of the participants, patients do not have a voice in their medical files or in the consultation room. For the most part, patients are considered symptom reporters, and their participation in their own healthcare and treatment focuses on compliance with doctor's recommendations. There has been a shift towards more collaborative efforts between doctors and patients, with shared decision-making being the focus of patient-centred healthcare (Joseph-Williams et al., 2014), but this did not seem to be evident in the narratives the women in this study shared. Their voices were ignored and not recorded in their medical files. More work around patient's voices may provide the shift in power required to truly fulfil patient-centred healthcare systems (Lorentzen, 2008).

Some of the participants questioned whether the attitude and treatment towards women would (or has) change(d) now that there are more women in medicine. However, I argue that women doctors are enculturated into a patriarchal way of thinking through their medical training. This was evident in the way my participants' female healthcare professionals were just as dismissive and rude as male healthcare professionals. More women in medical training facilities does not change the attitudes of those guiding them through clinical programmes. Nor does it rewrite textbooks that exclude women's bodies or include women in research. Women often are not in positions of power in institutional settings and are therefore unable to influence policy from the top down. The presence of women in medicine has certainly not influenced the subtle gender biases and implicit discrimination women experience in healthcare settings. Ultimately, there needs to be an attitude change when it comes to treating and thinking about women in healthcare.

As some of the participants pointed out, a misdiagnosis may occur for men. Men's experiences of misdiagnosis and how they are treated in healthcare settings may also

be of great value and certainly worth exploring. Misdiagnosis is increasingly becoming one of the highest causes of morbidity in health. It is a vast subject for research and there is not enough currently that understands why this happens, for women and men, or how to overcome it. There is also little research into doctor's experiences with misdiagnosing their patients, which could further offer valuable insight into the phenomenon. In privileging the patient's voices in this research, I have silenced the voices of the medical professionals, and, in a way, denied a holistic option around sense-making for the women in this study (Latz, 1994). Certainly, some doctor's, who may not be GP's (i.e. not primary healthcare providers), may not be aware they have misdiagnosed a patient if they have no further interaction with them. There is generally little opportunity for patients to feedback to healthcare professionals about how they have been treated or their experiences in healthcare settings. Some capacity to be able to do this would be incredibly valuable for patients and healthcare professionals alike, particularly if the healthcare system is invested in improvement and prioritising patient well-being.

It is troubling that an institution that is invested in healthcare and patient well-being does not seem to act in a way to ensure health, care, or well-being. Some of the participants talked about a lack of compassion from the healthcare professionals who were allegedly offering care. I find it difficult to make sense of a medical system that seems uninterested in genuinely helping, and excludes, an entire group of people based on their gender. Since the interviews were conducted, the use of pelvic mesh in women has gained momentum in the media, for example see Broughton (2018). This may have served as an interesting point of discussion with the participants as the phenomenon seems to sum up well the issues discussed in this thesis: there was little research done on the safety of these products, they mostly affect women, and the responses from medical professionals in regard to complaints and worsening health have been shockingly dismissive (e.g. it was suggested to an affected woman that her husband wear two condoms to prevent getting cut by mesh that had damaged her vagina (Broughton, 2018)).

The knowledge produced here is a product of the time, space and culture in which it is situated (Smirthwaite & Swahnberg, 2016). This research recruited a predominantly white sample, reflecting the prevalence of white voices in research (Holmes, 2016). While the focus of this research was not on ethnicity, speaking to different ethnic groups in Aotearoa New Zealand, particularly Māori, would provide another perspective with which to look at the intersection of ethnicity, gender and treatment in healthcare settings. Although the participant who identified as Māori did not mention her ethnicity in her misdiagnosis experience, this does not mean it did not play a role in some way, as group identity (gender, ethnicity) and prejudice, is related to poorer health outcomes (Facione & Facione, 2007). Given Aotearoa New Zealand's colonial history, looking at ethnicity and misdiagnosis is also incredibly important.

The very last question asked before interviews ended was if the participants had anything else they wanted to add. Not all participants did, as they felt they had had the opportunity to share or discuss everything sufficiently. Those that did expressed gratitude for this research being conducted and considered it important. They also recognised that this opportunity had given them a platform to have their story heard and acknowledged that many other women might not. These thoughts and feelings were articulated well by Piper:

Anything else I want to add? I think this is really important research. It will be such like a minefield, but I can see it would be really important. And, I think for all the women who would not have taken their tape recorder, who would not have said fuck off, who would have gone home and not felt great and stayed not great. The hospital system shouldn't make us feel worse. So, that's what I'm thinking of. I'm thinking for the women who didn't get to maybe say this is not ok. Yeah, that's my last thought – Piper (Chemical sensitivity – disputed)

I felt Piper's statement was a wonderful note to end our interview on and is a good place to end this thesis. Medical misdiagnosis does matter and we must continue to address this social injustice issue that has a very 'real' lived implication for the women and their families that are affected.

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HAVE YOU EVER EXPERIENCED MISDIAGNOSIS?

WOULD YOU LIKE TO TELL SOMEONE YOUR STORY?

This research project is exploring women's experiences of misdiagnosis with a physical illness that can occur in both men and women. If you are 18 years or older, a woman, and had an inaccurate diagnosis for your illness I would like to talk to you about it. It should only take an hour of your time.

Interested?

Get in touch with Jessica and organise to have a cup of tea and a chat. You will receive a participation thank you in the form of a \$40 food voucher.

Phone: [REDACTED]

Email: [REDACTED]

Facebook: [REDACTED]

Appendix B: Participant Information Sheet



MASSEY UNIVERSITY
SCHOOL OF PSYCHOLOGY
TE KURA HINENGARO TANGATA

School of Psychology
Massey University Wellington
PO Box 756
Wellington 6140
New Zealand

Women's experiences of medical misdiagnosis: what role does gender play?

INFORMATION SHEET

My name is Jessica Thompson and I am conducting a research project as part of my Master's Thesis in the School of Psychology at Massey University. This project is looking at women's experiences with misdiagnosis. I would love to hear from you if you are over the age of 18 and have, or have had, an illness or medical condition that affects both men and women, which was initially either diagnosed as something else (including a psychiatric diagnosis such as stress or depression) or not diagnosed until much later (for example being told that nothing is wrong, only to gain a diagnosis after persistent symptoms and repeated doctor visits initiated by you). I am interested in hearing your story about how misdiagnosis has affected you. You will be given a participation thank you for your time.

What will participation involve?

Participation in this project will require you to fill out a consent form and a demographics form. We will arrange a time to meet and have a chat. This may be via Skype or in person – whichever is more comfortable for you. We will probably speak for about an hour – though this is also flexible. I may have follow up questions I would like to ask you after our interview. You can let me know if it is ok to contact you again with them.

If you participate, what are the benefits and risks?

There are no known risks for you in this study, although I understand that this subject may be difficult for you to talk about. In this instance, I would encourage you to access support. If you feel like you need to speak to a professional counsellor, I can give you contact information. Some of these services may be free. Any paid services will be at your own cost.

Your story will only be used in relation to my thesis. The interview will be audio recorded and stored by me. I will transcribe the audio recording myself, and at that stage change any names or references to real places will be made to protect your identity. Your data will be kept by Massey University for up to five years on completion of my thesis, and then destroyed. After my thesis is complete, you are welcome to view a summary of the project's findings.

I have no affiliation with any health board, hospital or clinic. I do not receive any payment for conducting this research. I am a student researcher affiliated only with Massey University.

If you participate, what are your rights?

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study at any time during the interview and up to three months after the interview has finished;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded;
- ask for the recorder to be turned off at any time during the interview.

Thank you for taking the time to read this information sheet. Please feel free to pass this on to anyone you may know who has had a similar experience and may be interested in participating. If you have any questions about the project, feel free to contact me or my supervisor, Dr Denise Blake. Our contact details are below:

Jessica Thompson

Phone: [REDACTED]

Email: [REDACTED]

Facebook: [REDACTED]

Dr Denise Blake

(Supervisor)

Phone: 04 979 3412

Email: d.blake@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application SOA 18/32. If you have any concerns about the conduct of this research, please contact Dr Lesley Batten, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 356 9099 x 85094, email humanethicsoutha@massey.ac.nz

Appendix C: Interview Guide

Semi-Structured Interview Schedule/Guide

Semi-structured interviews involve questions that are carefully constructed to elicit the participants' ideas and opinions on a topic of interest, as opposed to leading the interviewee toward preconceived ideas and experiences. The researcher will create a non-threatening, relaxed and comfortable environment where conversation can flow. In this way, the interview process will not be linear and questions will emerge during the conversation. Therefore, the questions presented below will be used as a guide for the interview.

Interview Schedule/Guide:

- Establish rapport
- Outline the purpose of the interview
- Briefly explain why the research is needed
- Restate the interview duration and guidelines about ending at ending time.

The information sheet and consent form will be used to facilitate the beginning of the interview.

Guiding questions:

The body of the semi-structured interview schedule lists the topics to be covered, potential questions and the probes.

As you know, my research is about women's experiences of misdiagnosis with illnesses that affect both men and women. I'm interested in finding out about how women are treated in our doctor's surgeries and hospitals and what their experience is of getting to a diagnosis.

- Maintain rapport and thank the participant for their time.
- Ask whether it would be alright to contact them in the future if there are any more questions.
- Ask whether the participant would like to review the transcript after it has been transcribed.
- Ask the participant if they want to see a summary of report of findings.
- Thank the participant again and remind them that confidentiality will be maintained throughout the research process and in the write up of the data.

Demographics

Age

Ethnicity

Illness

Time to correct diagnosis

Main Question	Topics for further exploration/probes	Clarifying Questions
Can you tell me about what happened with yourself?	What was the final diagnosis? What are some of the symptoms? How long ago was this/when was this?	
When did you start experiencing symptoms?	What were they?	
Did you have any ideas about what was going on for you?		
When did you decide to go to a doctor?	Did you go alone? Who did you see? What as their response? Was there any treatment plan? How did you feel about that?	GP or ED? Male/female? Why/not?
Did your symptoms worsen/improve?	Over what time period was this?	
When did you go back to the doctor?	Was it the same person? Was it an easy decision to go back? What was your drs reaction? What was your experience then? How did you feel about it?	GP or ED
How many times did you have to go back?	How were your symptoms over that time? How were you feeling emotionally? What about family?	Supportive/emotional?
Why do you think your doctor dismissed your initial contact?		
How were you treated when interacting with your dr?	Do you feel like you were taken seriously?	By dr/medical staff/family?
Do you think being a woman played any role in your misdiagnosis?		
Do you think this kind of thing is common?	Have you heard other women talking about this kind of thing?	Or seen anything in the media about it?
Is there anything else you would like to add?		

Appendix D: Consent Form



MASSEY UNIVERSITY
SCHOOL OF PSYCHOLOGY
TE KURA HINENGARO TANGATA

School of Psychology
Massey University Wellington
PO Box 756
Wellington 6140
New Zealand

***Women's experiences of medical misdiagnosis:
what role does gender play?***

PARTICIPANT CONSENT FORM - INDIVIDUAL

Researcher: Jessica Thompson

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being sound recorded.

I wish/do not wish to have my recordings returned to me.

I wish/do not wish to have my transcript returned to me for review.

I agreed/do not agree to further contact from the researcher regarding any further specific questions related to this study.

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

Signature:

.....

Date:

.....

Full Name - printed

.....

Index

List of Medical Conditions

Chemical Sensitivity: can include a wide range of symptoms, which some people link to their environment.

Chronic Fatigue Syndrome: is a debilitating disorder characterized by extreme fatigue or tiredness that doesn't go away with rest and cannot be explained by an underlying medical condition.

Ehlers Danlos Syndrome: is a group of disorders that affect connective tissues supporting the skin, bones, blood vessels, and many other organs and tissues. Defects in connective tissues cause the signs and symptoms of these conditions, which range from mildly loose joints, and skin, to life-threatening complications.

Hashimoto's Disease: is a condition in which the immune system attacks the thyroid. Inflammation from Hashimoto's disease, also known as chronic lymphocytic thyroiditis, often leads to an underactive thyroid gland (hypothyroidism).

Hypokalaemia: is potassium deficiency. Can cause heart arrhythmia.

Motor Neuron Disease: is the progressive and fatal degeneration of specialised nerve cells in the brain and spinal cord.

Pernicious Anaemia: is a condition in which the body cannot make enough healthy red blood cells because it does not have enough vitamin B12. The term refers to vitamin B12 deficiency due to a lack of intrinsic factor.

Sudden Sensorineural Hearing Loss: occurs when hearing is lost very quickly, typically only in one ear. It can happen instantly or over a span of several days. A loss of 30 decibels in three connected frequencies is considered SSSL.

Trigeminal Neuralgia: is a chronic pain condition that affects the trigeminal nerve, which carries sensation from the face to the brain.