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Pesticide Poisoning in Aotearoa New Zealand

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As a nation for over 70 years New Zealand has used unprecedented amounts of pesticides within our workplaces, homes, lands, communities and our National Parks. The health and environmental hazards from exposure to pesticides is now well accepted within Science, but as an illness pesticide poisoning is not well acknowledged within society. Historically pesticide poisoning has been strongly contested by Science, Government, Medicine, Business & Industry and as a result people who have experienced illness from pesticide poisoning frequently encountered denial or de-legitimisation of their illness stories. Despite the long history of pesticide use in this country no study has considered what it is like to experience pesticide poisoning in workplaces in New Zealand, and this study attempts to redress this lack of research effort. A narrative methodology and theories was employed because it explores an illness experience in depth, allows for marginalised stories such as pesticide poisoning to be explored, and is a popular method for exploring health experiences within the Social Sciences. There were sixteen participants interviewed who had experienced pesticide poisoning in their workplaces in New Zealand. This thesis presents three perspectives of narrative theory of the pesticide poisoning experience. The first perspective is of the overarching narrative of pesticide poisoning in New Zealand which shows how the narratives of this study are distinctly automythology quest narratives. The second perspective is how the narratives are structured to give form and meaning, and within this study the narratives are structured within the domains of the Whare Tapa Wha conceptual model of health and the study demonstrates how this can form a foundation for an embodied perspective of health and identity. The third perspective considers the social forces that surround and influence pesticide poisoning illness stories. The participants reconstruct their sense of identity in response to the illness experience and actively advocate for change within their environment. The narratives of this study are surrounded by the powerful authority over knowledge by powerful institutions who sought to deny their experiences of pesticide poisoning.

Keywords: Pesticides, Poisoning, Contested illness, Narrative, Automythology, Whare Tapa Wha, Embodied, Authority, Aotearoa New Zealand

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Chapter 1: Introduction

Technology developed at an incredible rate during the 21st century as a consequence of the scientific advancements made during World War II. As a new era dawned New Zealand saw the introduction of unprecedented amounts of toxic chemicals into the environment. Amongst these chemicals were pesticides a powerful group of poisons that were developed to kill pests that were destroying crops and invading homes and lands. These pesticides were introduced with little knowledge or regard for their dangers to health and the environment, and as a consequence of this, over the years they have systematically poisoned people, animals, wildlife and fauna, water supplies, rivers and sea, and the soil (Marrs & Ballantyne, 2004). Concerns about the negative impact from pesticides grew from the 1940's onwards, but any illnesses by pesticides were hotly contested by government, business and industry, medicine and the sciences who consistently denied the experiences of people who had been poisoned. It took decades for these institutions to recognise the dangers building in the environment from pesticides and by then the landscape had changed forever. Within the sciences and medicine changes that occurred from the 1980's onwards saw the re-conceptualisation of illness narratives as knowledge that could help science understand illness and within this framework, narratives of contested illness could finally be heard. Within the social sciences, the narrative theory and methodology has become popular in exploring the embodied nature of illness, which makes it an ideal method to explore the complexities of a contested environmental illness such as pesticide poisoning.

Pesticides

Pesticides are poisons that are used in our society to eradicate pests (Friis, 2012; Marrs & Ballantyne, 2004)). The term pesticide's covers a wide range of substances (Aktar et al, 2009) and they are categorised by what they are targeted to kill. Insecticides kill insects, fungicides kill funguses, herbicides kill weeds and rodenticides kill rats and mice. Historically many different cultures around the world have used poisons to protect their crops and have used sulphur based compounds, mercury, arsenic, zinc, copper, tobacco and pyrethrum as pesticides (Friis, 2012; George & Shukla, 2011; Marrs & Ballantyne, 2004).

With the dawning of the Chemical Age new, powerful, synthetic poisons were developed for pesticide use (Boudia & Jas, 2013; George & Shukla, 2011). Chemicals developed for weapons in World War II led to the development of pesticides that you find in society today (George & Shukla, 2011). In Germany, scientists working in Hitler's Chemical Weapons Programme developed the first synthetic pesticide for use as a nerve agent in chemical warfare (Karalliedde, 1999, Nash, 2004; Patel, 2010).

With the end of WWII in 1945, chemical companies and agricultural experts began promoting synthetic chemicals as pesticides for insect control (Daniel, 2007) and farmers and industry were eager to use these new products (Nash, 2004). There was rapid growth in

the 1940's as scientists began to synthesise many different formulations of pesticides (George & Shukla, 2011; Penny & Bell, 2005). Since then there has been a huge increase in synthetic pesticide production and use (Horrihan, 2006) with a large number of substances now under the pesticide classification (Marrs & Ballantyne, 2004) and with globally 3 million metric tons of pesticides used annually (Friis, 2012).

Though New Zealand is a small country it manufactures and imports many hazardous chemicals including pesticides (Cromar et al, 2004). Chemicals are extensively used in New Zealand within business and industry and, within the agriculture and horticulture sector (Cromar et al, 2004). The most intensive pesticide use occurs within the horticulture sector which uses 41% of the annual expenditure on pesticides in New Zealand (Manktelow et al, 2004). This country's passion for pesticides is evidenced in the 15% increase in total pesticide use from 1994-2003 (Manktelow et al, 2004).

The awareness that pesticides were toxic for those who worked with them was something that emerged in time despite the fact that these poisons were originally used for warfare (Nash, 2004). Fatal poisonings were reported from the late 1940's onwards but no attention was given to the health impact of pesticides till the late 1960's and no government regulation began until the 1970's (Friis, 2012; Nash, 2004). The development of scientific knowledge and expertise on toxins and their effects, emerged alongside toxin regulation (Boudia & Jas, 2014).

Rachel Carson's book the *Silent Spring* (1962) first highlighted the danger of pesticide use in USA and raising concern about their environmental and health impacts from pesticides and what was acceptable risk (Gunter, 2005) and is considered to be one of the all times books that changed the USA. In New Zealand it was *The Poisoning of New Zealand* a book by Muriel Watts (1994) that contributed to raising awareness of the heavy dependence of pesticide use within New Zealand; the growing concern within the public of New Zealand about impact of this indiscriminate use of pesticides; and the failure of government to respond to these concerns.

It wasn't until 1979 and the passing of the *Pesticides Act* that the NZ government began to acknowledge the growing body of evidence that pesticides were dangerous to the peoples and environment's health, and recognised the need to regulate and control the sale and use of pesticides, nearly 40 years after the introduction of synthetic pesticides into this country (Watts, 1994). Even then in 1994, The Public Health Commission further recommended a reduction in the risks to public health and safety from exposure to hazardous substances (Public Health Commission, 1994) and consequently the Environmental Risk Management Authority (ERMA) was established that finally allowed a consistent process to assess the risk of chemicals in this country (Cromar et al, 2004)

Research on the toxic effects of pesticides on humans has been slow in coming. In fact most chemicals in our environment have never been fully evaluated (Brown, 2007; Cromar et al,

2004). For example when a pesticide manufacturing plant in Bhopal, India released a cloud of methyl isocyanate gas within its community in 1984 causing thousands of deaths and 60,000 serious casualties (Illing, 1993) there was only one published study on the toxicity of this poison available and that had only been conducted on rats (Kimmerle & Eben, 1964). The reason why the health impacts of pesticides have been challenging to establish is because it is unethical to poison people for research purposes. Instead science has depended upon animal and epidemiological studies. The problem with animal studies is that it can be that the biological differences between humans and animals make the studies less relevant; and the difficulties with epidemiological studies is that you can't separate out lifestyle and biological differences from environmental impact (Bayrami et al, 2012).

Pesticides have varying chemical structures that interact in different ways with the cellular structure of the human body (Marrs & Ballantyne, 2004) and each person also has individual biological differences that can make them more vulnerable to the effects of pesticides (Sanborn et al, 2002). Pesticides impact on every system within the human body including the respiratory, cardiovascular, neurological, reproductive and immune and therefore produce a variety of different health effects within the human body (Marrs & Ballantyne, 2004) from acute to chronic effects (Sanborn et al, 2002). It is considered an acute effect with symptoms occur not long after exposure (Quackenbush et al, 2006). This cause's irritation of skin and eyes, sensitisation of the skin and airways, and peripheral and central neurotoxic effects and myoncosis (Marr & Ballantyne, 2004). Toxicology and epidemiology studies have suggested cardiovascular toxicity, reproductive and developmental toxicity, endocrine oncogenicity and immunotoxicity effects (Marr & Ballantyne, 2004).

The technological advancements from synthetic pesticides are considered beneficial if not essential to society because they reduce the amount of insects, fungi, weeds and vermin that invade crops and land (Friis, 2012; Marrs & Ballantyne, 2004) and kill insects that carry serious diseases such as malaria or dengue fever (WHO, 1999). Pesticides do increase the production and quality of crops and reduce production costs, enabling the producing of low cost food and products (Marrs & Ballantyne, 2004; Soares et al, 2009). Some even argue that pesticides are beneficial to our health because they improve nutrition through the production of low cost foods (Marrs & Ballantyne, 2004), but the extensive benefits claimed from pesticides means a juggling of the risk-benefit equation to the population's health (Aktar et al, 2009).

There is a significant social cost to the health of people and the environment from pesticides (Marrs & Ballantyne, 2004; Soares et al, 2009). Today they are the most frequently encountered neurotoxin in the world (WHO, 2001). Regulatory systems around the world have faced numerous scandals that have shown their inability to protect society from the dangers of the Chemical Age (Boudia & Jas, 2014) and despite decades of experience in managing and regulating chemical substances, environmental contamination by dangerous poisons is still a huge scientific, technological, social and political challenge around the

world (Boudia & Jas, 2014). In New Zealand a study on farmworkers in Southland, NZ found that 24% of men and 11% of women had experienced a chemical related illness in the previous year (Driscoll et al, 2004) and within 2003 to 2004 there were 57 cases of workplace poisoning's reported (Pearce et al, 2005).

Environmental Health & Contested Illnesses

An environmental health problem includes all of the hazards and detrimental health impacts that are found where we live and where we work (Brown, 2007). Environmental health acknowledges and investigates external influences outside of an individual's control that impacts on a person's health (Friis, 2012). This focus on external influences is an important departure from traditional healthcare and science that has tended to focus on individual factors such as genetics and lifestyle in understanding health and illness (Lyon & Chamberlain, 2006). Environmental health explores important physical, chemical and biological factors within ones environment that can adversely impact on your health, of which pesticides is just one of many dangerous environmental hazards that society is currently facing (Friis, 2012).

The awareness that your occupation could expose you to hazards that could adversely affect your health emerged from the 1500's onwards (Friis, 2012) but it wasn't until the 19th century that brought sweeping industrial change, that the scientific understanding and study of environmental health issues emerged, as communities grappled with chemical pollution, technical accidents and the poisoning of workers, residents and communities (Boudia & Jas, 2013).

As the Chemical Age began to unfold, concern began to grow about the safety of pesticide use in the environment (Friis, 2012). Rachel Carson and her book the *Silent Spring* was a foundation for the emerging field of environmental health and today the impact from pesticides on public health is considered a major issue in environmental health (Friis, 2012; Lyons & Chamberlain, 2006)).

Pesticide poisoning is an *environmental injury*, damage and impairment (Guidotti, 2011) is caused by being exposed to a toxic environment. Pesticides can also cause *environmentally induced diseases* (Brown, 2007) such as cancer, as the result of the exposure pesticides. There are many health problems that medicine, science, government and industry have disputed as to whether the illness even exists (Moss & Teghtsoonian, 2008) but it is the detrimental health effects from a toxic environment that are the most hotly contested illnesses in modern society, because they are considered important to industry and a crucial part of a modern day economy (Brown, 2007)).

Contested illnesses are frequently dismissed by health practitioners and researchers as too difficult, psychosomatic, or non-existent (Moss & Teghtsoonian, 2008). For example in 1984 200 firefighters attended the ICI chemical fire in Auckland, New Zealand exposing

themselves to 28 different pesticides (Watts, 1994). A government report discounted their stories delegitimising their experience as just stress and emotional upset from attending the fire (Watts, 1994). People who live with medically unexplained symptoms and pain described living with uncertainty, issues with legitimising their illness and resistance to psychological explanations of their suffering (Nettleton, 2006)

Research into contested illness explores the relational notion of power, that recognises that power over health is located within multiple sets of relationships and seeks to under the specific effects of this powerful relationships on illness (Moss & Teghtsoonian, 2008). One aspect of power in contested illness relates to the authority of biomedical knowledge within society and how that affects government policies and how bodies and illness is framed (Moss & Teghtsoonian, 2008). It is also about the power to define bodily experience so that stories of ill health are denied and the power of social context to affect a person becoming ill and the understanding in society of the illness (Moss & Teghtsoonian, 2008).

Contestation occurs amongst a background of inadequate research and knowledge about the health impacts of toxins (Brown, 2007). Despite the lack of adequate knowledge and research; medical science, governments and corporations consistently take the position that a toxin is safe until proven otherwise. This has led to a revolving door policy where a toxin is introduced that causes widespread harm and devastation to the health of the population that is subsequently banned or regulated only to have another toxin take its place with the same lack of research that goes on to create the same devastation. Lead poisoning, radiation poisoning, tobacco illnesses and Agent Orange are all examples of this (Brown, 2007)

With such widespread resistance to looking at toxins in the environment as a cause of health problems there is little support for research and the development of theories and in the environmental research there is also an over emphasis on how toxins cause cancer and death, and that the other symptoms from being poisoned are largely being ignored (Brown, 2007).

Many people are unaware of their exposures to pesticides and so many cases of poisoning go unreported (WHO, 2001). Doctors receive little education on the impact of toxins in the environment on health and so are unable to recognise symptoms or advise on how to manage or treat symptoms. People who report poisonings after exposure to toxins are faced with a lack of knowledge and support for their suffering from the medical profession.

Narrative Research and Illness

A story about illness is very personal it gives voice to the body that has changed through illness, providing important and often overlooked knowledge (Frank, 1995, Ziebland et al, 2013). The importance of listening and learning from patients experiences was originally at the foundation of medicine (Ziebland et al, 2013) but the rapid growth in science-based

medicine and technological advancements led to stories of the ill being ignored or overlooked (Frank, 1995; Moss & Teghtsoonian, 2008). Instead the bio-medical narrative with its focus on the biological mechanisms within the body that could be seen and measured, dominated within health (Lyons & Chamberlain, 2006). Personal stories of illness were frequently judged against the biomedical narrative determining their legitimacy and usefulness (Frank, 1995). Hurwitz et al (2004) suggests that it is not that a person's illness narrative is being ignored but rather that the narrative is transformed and given new meaning by the biomedical narrative, but for people with contested illnesses this new meaning was often to deny or minimise the very experience of being ill. Research has suggested that clinicians are uncomfortable listening to contested illness stories because they are viewed with scepticism because of the subjectivity and potential unreliability of the story (Shapiro, 2011)

Traditionally science has favoured the objective, and the narrative of the distant observer of illness symptoms was preferred over the illness experience lived inside a human body (Hurwitz et al, 2004). With the post-modern turn in the sciences the limitations of the biomedical narrative came to be recognised (Lyons & Chamberlain, 2006). Feminist writings that emerged within the dramatic social change of 60's were critical of the domination of medical professionals within healthcare (Ziebland et al, 2013) and they argued that an experience of an illness is more than the medical symptoms of the illness, it occurs within a social and cultural context, with a loss in life direction and personal identity that a biomedical narrative does not capture (Frank, 1995). From the 80's on there was a rapid growth in patient advocacy groups that demanded for attention to be paid to patients experiences (Ziebland et al, 2013). The World Health Organisation responded and extended the concept of health to include the social, and from this the biopsychosocial concept of health was developed (Lyons & Chamberlain, 2006). With the post-modern turn in the sciences and a greater acceptance for post-modern research methods (Fraser, 2004) people's own personal stories of illness shifted to place of primary importance in understanding illness (Frank, 1995) and this shift in focus to understand patient's experiences attempts redress the historical lack of research effort into illness stories.

Narrative inquiry is a way of thinking and studying the meaning of experience (McGraw et al). It seeks knowledge through the creation and construction of stories in real life experiences and endeavours to see the world through the eyes of others (Riley & Hawe, 2004) giving a deeper understanding of an illness experience (Bingley, 2008). The narrative approach allows for ambiguity and complexity and can privilege exceptional, unvoiced and marginalised stories (Etherington, 2009; Reissman, 1993), which makes it ideal to explore an environmentally contested illness such as pesticide poisoning.

Narrative inquiry is a multilevel, interdisciplinary field that is philosophically influenced by a number of views of reality, that each impact on how the idea of narrative is conceptualised (Andrews et al 2008; Reissman, 2008). This study is specifically influenced by the ideas of

Postmodernism, Social Constructionism, Constructivism, Feminism and Hermeneutics, with each contributing to the understanding of contested illnesses. For example Postmodernism challenges the objective criteria used to understand behaviour, emphasising the existence of multiple realities (Etherington, 2009; Lyons & Chamberlain, 2006). Social Constructionism challenges how truth is understood and practiced within traditional science (Gergen, 1999), demonstrating how the objective criteria for determining “truths” was heavily influenced by history, social context, culture, language and experience (Gergen, 1985). In Constructivism, the meaning of reality is not readily available, instead meaning is imposed on reality (Murray, 19), and are a product of how a person sees and interprets the world they live in, and their experiences through their own personal belief system (Etherington, 2009). How people construct meaning gives insight into how they shape their sense of self and identity (Etherington, 2009). Hermeneutics highlights the limitations of empirical and rationalist types of explanation and how they create detached theoretical reflection on very real experiences such as illness, arguing that this objectification is inappropriate to truly understand the holistic nature of health (Martin & Sugarman, 2001; Packer, 1985). Feminism works to dismantle all forms of oppression, not just for women (Murray, 2004). It challenges the power relations and bias’s within science (Etherington, 2009) and recognises the legitimate sources of knowledge from lived experience’s (Campbell & Wasco, 2000) and values ways of knowing that have previously been devalued in science (Etherington, 2009; Murray, 2004) emphasising the need for knowing the self (Seibold, 2000).

Narratives are thought to capture the embodied nature of illness, showing what it feels like to experience illness from within a sick body. People who have been ill consistently described a biographical disruption within their narratives from their experience (Reissman, 1993.) Identity is linked to our experiences (McGraw et al) and it is suggested that people construct identities in the telling of illness stories (Reissman, 200).

Narrative analysis is not governed by a prescriptive formula (Fraser, 2004) and there are a variety of approaches that are used for analysis (Holstein & Gubrium, 2012). The researcher role is to interpret the stories to analyse the underlying narrative that the participant’s may not be able to voice (Riley & Hawe, 2004) and to resist the temptation to dissect the narrative(McGraw et al) instead perceiving it as a whole.

The narrative method involves a process through which you constantly return to the details in the participants stories to guide the direction of the analysis (Holstein & Gubrium, 2012). There are three types of narrative analyses that will be used in this study, a Thematic, Structural and Dialogical/Performance approach (Frank, 1995; Reissman,2008) that together make a more comprehensive analysis (Atkinson, 2009) by exploring multiple perspectives of the illness narratives of this study. Within the Thematic analysis the key question is *what* is said about the experience of being poisoned, within the Structural analysis the key question is *how* are the poisoning narratives organised or put together to achieve a narrators strategic aims, and within the Performance/Dialogical perspective the key question to

consider is *why* do people choose to tell this story and important reflexivity questions were also considered (Holstein & Gubrium, 2012; Reissman, 2008).

The narrative illness accounts of A. Frank (1995) are also an effective analytic tool through which to examine narrative accounts (Nettleton et al, 2004). There are three distinctive types of illness stories called *restitution*, *chaos* and *quest*, and they can all be present within the same narrative (Frank, 1995). In the *restitution narrative* the disruption from illness is temporary, after a period of being ill people return to good health, and find continuity again in their lives. This narrative represents a belief in the medical profession as they “fix” the health issues a person is facing. In the *chaos narrative* of illness the health issues are not easily resolved and there is a loss of faith in medicine as people realise their illness cannot be fixed. People are absorbed in the pain and the suffering of their illness that overwhelms them. The narrative structure is typically fragmented and a true *chaos narrative* is caught in the day to day struggles and doesn’t conform to a coherent narrative which has a beginning, middle and end. In the *quest narrative* the person still experiences chaos but this is pushed into the background as they learn to adapt to and manage their illness. The person who is ill make changes in their personal life and may begin to advocate for others (Frank, 1995).

Aims of Research

The subject of poisoning from chemicals is so vast and so under researched that it was difficult to know where to start when it comes to developing a research question. With such intense debate around the “cause and effect” of chemical poisoning over the past 70 years it is easy to get caught up in the trap of thinking that these kind of quantitative studies are the only path to knowledge about pesticide poisoning. It is true that much more quantitative research is required to more fully understand the mechanisms behind chemical poisoning but qualitative research in this area has largely been ignored.

In constructing the research question it was also challenging to describe pesticide poisoning in a way that was both meaningful to the research community as well as too potential research participants. The words chemical poisoning produced a too wide scope, when put into a research engine, while just focusing on one poison produced a too narrow scope. The word “pesticides” appeared middle ground between the two, it is well known and often cited amongst research circles, but for the public and media the term “pesticides” is less well known and often used interchangeably with insecticides.

The criterion for this study was carefully considered before deciding to focus on recruiting participants in New Zealand who had experience pesticide poisoning in their occupation. This criterion was chosen because direct exposure to pesticides poisoning is currently easier to establish when you work with it within your occupation, as opposed to people who have been indirectly exposed through spray drift, and therefore you are more likely to find people that have been diagnosed with pesticide poisoning. Focusing on occupational

exposure to pesticides in New Zealand allows the study to also consider work practices within business and industry.

After reviewing a number of qualitative approaches narrative inquiry seemed the best fit for the research question because it was already an established method for 30 years in the area of health research (Frank, 1995) it was advocated as a suitable approach to understanding contested illnesses (Brown, 2007) and it was a good fit for the researcher personally who had experience with the narrative method as a therapeutic technique in their counselling practice and a experienced research interviewer.

Narrative interviews were also the best method for this study because it is believed that they go beyond surface appearances and give greater depth into experience (Ziebland et al, 2013), they are more sensitive to the meaning and context surrounding illness stories (Oakley, 1981) and ethically an interview is considered to be more appropriate when researching sensitive issues. Multiple interviews were preferred to build trust, rapport, and include the participants in the development of research interpretations (Ziebland et al, 2013).

The research question was kept as open as possible to allow the participant's interpretation of the question ((Reissman), (Frank, 1995)) and to give the participant the opportunity to take control of the direction and content of the interview (Ziebland et al, 2013), which allowed the researcher to understand what is important to the participants from their perspective and within their language (Ziebland et al, 2013). To facilitate a sense of embodiment, interview questions were used to connect to the participant's senses, feelings, thoughts, attitudes and ideas and attempted to locate the narrative within real life experience, though the overall role of the researcher within the interviews was to be more of a listener than a questioner and being patient enough to wait for meaning to emerge from the participant's narratives (Reissman, 2008).

Within narrative research ethically it is important disclose the researchers purpose in conducting this research and the background they bring to this study. This will be discussed in Chapter 2.

The aim of this study then, is to conduct a qualitative research design using Narrative methods and theories, to understand what it is personally like to experience pesticide poisoning in your occupation within New Zealand/Aotearoa.

Chapter 2: A narrative of pesticide poisoning

To understand any story in depth you need to know the context within which it is told (Etherington, 2012; Reissman 2008). To know that the researcher, the storyteller of this study, had been poisoned by pesticides within their occupation in New Zealand, is an important part in understanding the context of this research, and in acknowledging the knowledge that is brought to this study (Reissman, 2008) from the researcher's personal experience with pesticide poisoning over the past 21 years.

The following story is the researcher's personal narrative of pesticide poisoning in Aotearoa New Zealand placing in context the research conducted for this study.

I think that one of the factors that deceived me to the dangers of the pesticides in my environment was the beauty of the New Zealand rural landscape. My previous knowledge of pesticides before my exposure was limited. I had seen news stories on the Vietnam War Veterans whom had been exposed to Agent Orange and I had read and watched popular media depictions of chemicals like the movie the *Toxic Avenger*. The experiences of the Vietnam Veterans in a war in another country and the movies that portrayed toxic dumps and factories with oozing drums and vats of fluorescent green substances seemed far removed from any environment I thought I would find myself in. The rural community in New Zealand where I was poisoned was nothing like these previous conceptions. Instead it had beautiful sandy beaches draped with pouhutakawas, perfect for swimming and fishing and was surrounded by rolling hills of bush filled with manuka, totara and kaiakatea. It was a summer vacation hotspot and drew tourists all year round. To me and many others who sought the sanctuary of this place it really was paradise and it wasn't a place that I would have expected to find danger in.

I had come from the city and had been in the area for several months when Work & Income approached me and said there was work down the road that had come up, that I was obliged to take or lose my unemployment benefit. This was at a time when Work & Income subsidised people's wages so that employers would take them on. My employer was a cattle farmer turned flower grower. He grew these flowers called calla lilies. They are long-stemmed with trumpet like flowers that come in many vivid colours from burgundy red, fluorescent yellow, burnt orange, apricot and multiple shades of pink as well as the original white flower. There is a superstition that you never bring white calla lilies to the sick as they are meant to signify death but overseas in Japan and USA they got top dollar getting as much as \$5 per stem.

My employer's property was a couple of kilometres back from Hihi beach on the edge of the estuary into Mangonui Harbour where the locals collected oysters. His property was sprawling flat acres of grass meadows covered with a hodge podge of buildings, greenhouses, with cattle roaming around. My tasks were simple I was to plant the bulbs of the calla at the beginning of the season and then pick them when they were in flower and

pack them for overseas, and then at the end of season dig the bulbs up again and separate them for the following season. It was a mind numbing job but as my muscles hardened and my strength grew I learned to appreciate the value of hard physical labour and I have never been as fit and strong as I was then. There is also a powerful connection to the land and the environment that grows between people who work the land as I did. A week wouldn't go by when I wouldn't marvel at the beauty of nature and how my job allowed me to witness this.

It was 3 months after I had started work, that my husband (then boyfriend) also started working for my employer again subsidised by Work & Income. There were 3 employees then plus my employer. We were from the city and in many ways less sheltered but we were completely naive when it came to country life and its strong dependence on poisons which our work colleagues were not. Both of them including my employer had been poisoned before in previous seasons. My employer's solution was to get an employee to do the risky jobs and the other employee was just as relieved when we did the risky jobs too. I wonder to this day why nobody warned us when they had some awareness that exposure to these poisons could make you sick. I think that there was just an acceptance among county folk that these poisons were necessary to productivity and being exposed was just an occupational hazard.

Over a period of 2 years I was exposed to multiple poisons in every aspect of the job. Before the calla bulbs were planted they were dipped in a growth hormone to increase the amount of flowers. The bulbs were meant to be dry before we planted them but often they were dripping wet. My hands would swell up and become very itchy but I was told that this was just because the calla bulbs are an irritant which they are. We were not provided with gloves or encouraged to wash our hands before we ate. I hate to think how much growth hormones were taken into my body over this time but by no means was this the worse poison I was exposed to. The most risky poison I was exposed to was various organophosphates meant to kill bugs such as aphids and thrip and various fungicides to stop the flowers getting freckled by a fungus. These poisons were used when the callas were in flower in an attempt to get more of the product to market, and then organophosphates were used to dip the heads of the flowers in once they had been picked, so that no pests would arrive overseas and risk getting a hefty fumigation charge. Now if you know anything about pesticides then you would know that part of pesticide regulation has been determining a withholding period, a time when it is recognised that it is unsafe to touch the flowers without getting poisoned. This is particularly apparent with organophosphates because this poison is absorbed directly through your skin and is one of the few substances that can penetrate the blood brain barrier that protects our brains from harm. In my workplace the withholding period was not adhered to and again we had no protective equipment or had any knowledge that we needed any. The most warning I remember was after a morning of my husband dipping flower after flower into a bucket of organophosphates with its fluid running down his hands the other employee suggested to him that he might want to wash his hands before he had a cigarette.

The symptoms from being poisoned crept up on me and by the time I was aware that I was getting sick, I was very sick indeed. When I got home from work and on my days off I could barely get out of bed or off the couch. I put this down to the physical challenges of my job but the fatigue just got worse and worse till I could do nothing without great effort. I was aware of the headaches not long after the flower season had started. An organophosphate headache is very distinctive. It is like you are surrounded by a bright white light that you cringe to get away from but even if I buried myself under my cover of my bed in a dark room I still couldn't escape the light. With the light came the pain that would make me whimper like a child and the constant nausea which combined together would cripple you. The physical pain in my body also crept up on me so that by the time I was aware that this wasn't normal, the pain was my constant companion and the fatigue, headaches and nausea had also become normal.

Along with the physical suffering came the psychological suffering. I found it hard to think or even comprehend sometimes what people were saying. I would get confused and forget where I was and what I was doing. It felt like my brain wasn't working as well or that parts of my brain weren't connecting anymore. Along with this cognitive decline came an intensification in my moods and the development of sudden mood swings. My anxiety started to soar and I feared everything. I couldn't go anywhere without being consumed by a terrible fear that something would go wrong. I couldn't answer the phone for fear of who was on the other end and what they would want. At the worst of the illness I became so overwhelmed while driving that I drove through a red light during rush hour traffic barely avoiding a major car accident. I got out of the car and refused to drive for 6 months and then had the slow task of learning to drive again without fear. This terrible fear forced me to retreat from this world into social isolation. It simply made me too sick to go out into the world.

Though the anxiety was debilitating it was the episodes of rage that truly frightened me. If you looked at me you probably wouldn't have considered me a threat but with the power of the poisons flowing through me I felt that I could tear a person physically apart with my own hands. I started experiencing homicidal nightmares, thoughts and impulses. The nightmares were so real that I was often relieved when I woke that I hadn't hurt anyone. The conflict between me and my partner intensified and we would both act irrationally towards each other. The worse was one day when we were having an argument in the car that had quickly intensified for no reason. I suddenly found myself with the accelerator down heading for a cliff ready to kill us both. The cries of alarm from my husband pulled me back at the last minute but I learnt not to trust myself after that day. I simply could not trust my emotions and I was dangerous to the people around me. Later my husband and I learnt to identify these moments as a chemical rage and if you suggested that to the other when they were in this state it could snap you back out of your rampage or at least give you the strength to walk away; though of course world war 3 would erupt if we both went into a chemical rage

at once. Not only did these episodes bring out the worst in yourself it was also exhausting and would take days to recover in an already sick and struggling body.

Along with the extreme anxiety and irrational rage came an intense sadness that connected me to the sorrows of the world. You couldn't watch the news with some story about suffering in Africa without being reduced to tears. It was enough carrying your own sorrows but now you carried the sorrow of the world. It was very overwhelming and left you feeling weak and pathetic as if you couldn't cope in this world.

As all these symptoms crept up on me there was a dawning realisation that something might seriously be wrong with me. It was through my dreams that my first insights came. One night I dreamt that I was in the flower pack house with my employer and the other employees. In the middle of the pack house was a white bull that was so bright that I could barely look at it. The bull bucked and thrashed around as we all struggled to get out of its way but I could barely move and fell to my knees as the bull came closer and closer my overwhelming fear before I woke was that I was going to die. Despite these subconscious feelings that something was wrong it was actually a choice I made that led to awareness.

I had come to love the Far North and enjoyed the connection to the land. Growing flowers for a living started to become a viable option and I had ACC trust fund that came available when I was 20 years old that could be my venture capital. If I hadn't decided to enter the flower industry then I probably wouldn't have known that I had been poisoned or at least known so soon. We bought some calla bulbs and bought a bottle of growth hormone and on the back of it said protective gear should be used at all times. I remember the look of disbelief as we read the label, but we throw this stuff around like water I said. Just as the symptoms crept up on you so did awareness of what was happening. I started paying attention to my employer's chemical practices and started asking for protective gear but still not truly understanding the danger I was in. The relationship with my employer had been deteriorating for some time. Having four people all poisoned in one workplace is probably not good for staff morale what with the intense emotions of anxiety and anger bubbling under the surface with every employee. Things came to ahead when I started asking for protective gear and questioning his chemical practices. My employer responded by firing me. I responded by reporting his practices to OSH and went to a Doctor who signed ACC forms that he believed I had been poisoned. I never knew then what risk this Doctor took in doing this.

And so began my 2 year battle with OSH and ACC to prove that I had been poisoned. My employer cleared his workplace of chemicals dumping many of the half empty containers in a pit that he buried out the back of his property. This pit was right next to a stream that flowed down into the estuary. My employer denied our allegations of his chemical practices and said we were making it up because he had fired us and OSH believed him. I had many conversations with the manager of Whangarei OSH and their nurse who would treat me with disbelief and anger telling me my symptoms were either not chemical poisoning or that

I was lying and making it up. Words cannot express the sense of hopelessness and despair I felt during those years. My belief was that this is wrong, I'm sick and someone else has done this to me surely someone must take responsibility for this, but I had no idea that what I was fighting for was technically impossible, that nobody had proved that they had been poisoned in their workplace before, OSH comfortable in this knowledge felt happy to show contempt to me and my suffering. ACC was a bit better, they never said I was lying to my face but they kept deferring to OSH to resolve whether I had been poisoned in my workplace and OSH kept deferring to ACC to resolve whether I was experiencing chemical poisoning symptoms.

Caught between this impasse between government agencies it would have been easy to give up, except for the fact that I was very sick and driven by fear and anger this illness would not let me give up. I had always experienced intense dreams as a child but once I had been poisoned every night I would be plagued by dream after dream. I would wake up each morning exhausted but also anxious that I should do something, that this is wrong. I would ring people to relieve my distress in ACC and OSH asking them each time what are you doing about this. I found along the way that I was good debater and that despite their best efforts OSH couldn't get me to shut up and ACC started to consider whether there was any truth to my story. A decision was made to send me to an OSH and ACC scientist who specialised in occupational health. I was relieved by this and felt that finally someone is listening but not long before I went to the assessment I spoke to a union representative who asked whom I was seeing and then expressed his disgust and said he never accepts chemical poisoning. I was very depressed about this that OSH and ACC were sending me to someone whom they expected to make a decision against me. This hopelessness followed me to the assessment that I flew to Auckland to do. Just before the assessment an elderly man came out into the foyer where I waited for my appointment whom I assumed to be the Doctor I had a massive panic attack and all I could think is no one's going to believe me. By the time I got to my assessment I was a total wreck so much so that when the Doctor told me I was suffering from pesticide poisoning I nearly fell of my chair in shock. I imagine ACC and OSH had a similar reaction.

The fact that I was able to prove that I was poisoned was truly a miracle for its time but I wasn't aware of this then. I didn't know that chemical poisoning was difficult to prove because you have to establish cause and effect. Because my employer had cleaned up his workplace and lied about his chemical practices I had no evidence that the workplace was toxic, it was just my word against him and clearly OSH were believing him. But not long before I went to the assessment I had a stroke of good luck. Because we had got into growing our own flowers I had taken photographs of the workplace and in particular the pack house where all the chemicals were stored. I had taken these photos but left the film undeveloped. When I finally developed the film I realised what I had. You could see coffee cups sitting next to boxes of poisons and buckets of organophosphates overflowing onto the floor. I could prove I wasn't lying and thereby established the cause of my illness. I was able

to prove effect because over the years of my employment I had gone to Doctors complaining of pain, headaches and nausea and within my assessment it was clear to the Doctor that I was experiencing high levels of anxiety. At the time these were the only recognised symptoms for organophosphate poisoning. Despite the fact that no Doctor or OSH had ever ordered for my blood to be tested my symptoms were accepted because they were consistent with the emerging knowledge of the time and that I had reported them before the conflict with my employer.

The Doctor deemed that the workplace was toxic and therefore anyone working there would have been poisoned. I was diagnosed as having an occupational disease as the result of multiple acute organophosphate poisonings. ACC accepted my claim and OSH had to reverse their previous stance but by then it was too late. I was advised that legal proceedings against an employer had to be initiated within 6 months of receiving the complaint and because it had taken 2 years to make a decision my employer would not be prosecuted because of this technicality. So essentially I had won but I had also lost. No accountability was ever taken for me being poisoned. If I was in the USA I could have sued my employer and the government but in NZ we have no such rights and I had to accept an unfair outcome in a very unfair system.

What I did win was that ACC and therefore the government had to take some responsibility for my poor health. I received 80% of the wages I had earned while working which was just off minimum wage which wasn't much but later I learned that my employer had to pay through his ACC levy every dollar they spent on me and that gave me some measure of satisfaction. The best part of ACC was they were willing to fund health practitioners and so I was able to see physiotherapists, counsellors and acupuncturists who helped manage the chronic pain and the other symptoms I was experiencing.

It was during this time that I turned to studies to help me cope with my illness. I had left school and home at 16 years old with School Certificate but for personal reasons and not academic. When I was at school each year we would do SAT tests and each time afterwards the teachers would come to me and tell me you are not trying your capable of so much more. After years of sickness and feeling like my brain was frazzled I wondered if I was capable of anything anymore, but I felt this deep instinct that I had to make my brain work to fight of this illness and that I also needed more knowledge to find my way forward. I started studying psychology just one paper a semester and within this I found a way to exercise my mind, a way to distract me from my pain and a pathway forward.

When I first became aware that I had been poisoned I had contacted the poisons centre who had sent me printouts on all the poisons I had been exposed to but for me with only layperson knowledge I could barely comprehend them. Now armed with this new found knowledge from my studies I started to find some clarity.

Organophosphates (OP) I discovered were originally developed in WWII for use as nerve agents in chemical warfare. A terrorist attack in a subway station in Japan where Sarin gas was released is an example of an OP nerve agent (Karalliedde, 1999). Having experienced how organophosphates can debilitate you both physically and psychologically I could see how OP's can be an effective weapon. If they didn't kill you they rendered you inoperable.

I was exposed to various types of OP's. Without adequate protective equipment OP's are easily absorbed into the body through inhalation, ingestion and dermal contact (Mearns et al, 1994; Snyder, 2006; WHO, 2001). Though OP pesticides are made up of a combination of compounds they are all considered to act by a common mechanism (Milesen et al, 1998). The OP's caused toxicity through binding with an enzyme found within the blood called acetylcholinesterase (ACHe). AChE is essential for the normal control of nerve impulses within the central and peripheral nervous system. Its function is to break down acetylcholine (ACh) a neurotransmitter that bonds with post synaptic fibres within nerve cells. The OP's deactivate AChE inhibiting it from performing its normal function of breaking down ACh. This results in the accumulation of ACh within the cholinergic synapses of the nervous system, over stimulating muscarinic and nicotinic receptors and prolonging the action of ACh. This changes the function of the autonomic nervous system, the somatic motor neurons and the brain (Dreisbach, 1987; Karalliedde, 1999; Mearns et al, 1994; Milesen, 1998; Ray et al, 2001; Sadock, 2007; Savage, 1994; Tarter et al, 1988).

The type of OP pesticide used the level of dosage and the mechanism of exposure all impact on the onset and duration of poisoning symptoms (Tarter, 1988). Typically the inhibition of AChE produces an acute cholinergic syndrome minutes to hours following poisoning (Salvi et al, 2003). Mild symptoms last a few hours while moderate to severe symptoms last 1-6 days (Tarter, 1988). OP acute exposure produce sensory and behavioural disturbances of restlessness, emotional lability, ataxia, lethargy, mental confusion, loss of memory, generalised weakness, convulsions, coma and in severe cases depression of the respiratory centres causing death (Salvi et al, 2003; Tarter, 1988). The acute phase usually dissipates within days or weeks (Salvi et al, 2003, Tarter, 1988) while the intermediate syndrome may develop 24-96 hours after the acute syndrome. Symptoms include respiratory paresis, weakness, depressed tendon reflexes and transient extra pyramidal symptoms. OP delayed neuropathy may develop weeks after a severe exposure (Salvi et al, 2003). SPECT scans of persons with acute organophosphate poisoning demonstrated defects within the vicinity of the parietal lobes (Yimazler, 1997).The tolerance to OP's and cholinergic stimulation occurs following repeated exposure's that mask's pathology (Mearns, 1994, Ray et al, 2001; WHO, 2001) and after significant exposure DNA alkylations are produced (Ray et al, 2001; Smulders et al, 2004)

The more I studied the more questions I had. Why when I did the least dangerous job in the workplace did I get so much sicker faster than my work colleagues. I discovered that my mother had been poisoned with pink's disease when she was a baby and that her father had

been poisoned in the coal mines. It made sense to me that this had in some way affecting my vulnerability.

The problem with all the questions I had is there are so little scientists out their trying to answer them. When I was first accepted for chemical poisoning only a few symptoms were accepted by the medical profession and it was expected that these symptoms would just resolve in time. Now nearly 20 years later every single symptom I had has been connected to pesticide poisoning.

I spent 5 years on ACC after having my claim accepted and though the financial support wasn't much the access to treatment was essential. However ACC armed with their lack of knowledge of the long term effects of poisons made moves to remove even the limited support I was already receiving. The government started an initiative to remove long term ACC beneficiaries and chemical poisoning was an easy target. They never said I didn't have symptoms they just said the symptoms I had were not compensable anymore. However they did acknowledge that because both my husband and I had been poisoned that they were uncertain as to what impact this would have on any children we might have.

I was now 29 years old, out on my own living with a debilitating illness with no access to treatment and expected to fend for myself. Sending me out to work is akin to sending anyone with a disability out to work such as the hearing or visually impaired, there are things you can do but it is limited, you have to work around your disability and it requires the support of employers and the people around you. However unlike the hearing or visually impaired your disability is not obvious and the community has no knowledge or awareness of what you are suffering and therefore they have little empathy and there is no support.

It was very difficult after years of social isolation with chronic anxiety and pain to force myself out to work but I tried I really tried. In the end any type of fulltime work was unsustainable I would just get to exhausted, overwhelmed and stressed. It was also hard to trust any employer. It was easy to see employers as mercenary and your health as expendable to them. However after years of trying I had finally gained a few qualifications and at a colleagues suggestion I went into self-employment as a counsellor. I found working part-time but for better money was the only way forward. I was responsible for my well-being and if I was too tired or stressed I would take time off. I was also thrown into the world of healing and I started to comprehend that I had some knowledge to contribute to this area.

In my early years of study my focus wasn't just on understanding what I had been through, but how to find a way forward through the pain and suffering. There were a number of ideas that had an impact on me but the most important and enduring was the introduction to Whare Tapa Wha a Maori conceptualisation of health (Durie, 1994). On my psychology courses it was introduced as a quaint concept from an indigenous culture that has relevance to Maori but no real practicality to the outside world, but to me it gave me the first real

pathway through my illness. Whare means house and wha means four, so to be well we have to keep the four interconnecting sides of house strong (Durie, 1994). These four sides include tinana (physical health), hinengaroa (psychological health), whanau (family health) and wairua (spiritual/identity health) (Durie, 1994). Wairua is usually translated as to mean spiritual but conceptually the word captures so much more. It is about cultural and spiritual needs, and a person's values and beliefs systems (Durie, 2001) it is about the traditional, religious and personal, journey spiritual beliefs that supports a person's identity (Pitama et al, 2007). Maori also argue that within the *tinana* aspect is a body identity and within the *whanau* aspect is a family identity (Durie, 2001) and so hypothetically each aspect contains a key part of identity that together forms the whole of the identity impacted by health.

Wairua is about where you come from, what language you speak and what you spiritually believe in, but it is more than that. It is about whom you are and what your identity is and identity is a crucial aspect when considering health. I was young, fit and healthy women who was now crippled by pain and suffering, I did not know who I was anymore, how I defined myself or even how I fitted into this world anymore.

With the lens of Whare Tapa Wha to now focus my health issues through I began to find a pathway forward. When I looked at tinana or my physical health the most obvious challenge was the pain but this model encourages you to identify your strengths too and I noted that acupuncture helped manage the pain as did massage, osteopathy and chiropractor. When I looked at hinengaroa it was easy to see how the intense mood swings were my greatest challenge so I began to develop strategies to manage moods the first step being self-awareness of what's happening. This established some level of control. When I looked at whanau the challenges to my relationships brought on by pain and mood swings led me into social isolation. Increasing social support and reducing isolation became a priority. Finally in looking at wairua I began to look at the silver lining in my poisoning experience. I could see how hard it had been to both fight this illness and fight the system for recognition and support for my illness. I could see how strong, resourceful and determined I had to be and that my experience had the potential to help others. I began to build a strong identity based on my poisoning experience.

It was in the early days of my studies that I started to recognise that it was important to me to one day conduct meaningful research for people who have experienced poisoning. But 16 years later as I came closer to having this opportunity I admit I got cold feet. This subject was so personal and important I feared I wouldn't do it justice. It was also so difficult to know where to start considering the significant gaps in knowledge and lack of research. It was easy to get caught in the trap of thinking that research that seeks to establish cause and effect of pesticide poisoning is the only meaningful knowledge currently required, considering that diagnosis has historically been hotly contested in our society. However for me to walk that path would be to deny the knowledge that I had already gained about pesticide poisoning. I already knew poisoning did exist and that there were people in society

who had been living with it since the 1940's. I began to ask myself as a person whom had experienced pesticide poisoning what knowledge would be the most meaningful and helpful to me. It was from this I formed the basis of my research question.

To maintain a sense of *critical subjectivity* though out the research process the researcher's personal experience of pesticide poisoning was not suppressed but also didn't dominate the research process, instead it was consciously drawn upon as part of the inquiry process (Szarycz, 2010).

Chapter 3: Methodology

The goal of this study is to explore what it is like to experience pesticide poisoning in your occupation within New Zealand/Aotearoa as stated in Chapter 1. The methodology used to collect and analyse data is presented in this chapter covering 1) participants and 2) procedures.

A qualitative design was used in this study.

Participants

The population sample consisted of 16 participants, 3 females and 13 males. Their age ranged from 42 to over 70 years old. Half of the participants were of New Zealand Maori descent and the other half were of New Zealand/European descent. The participants were located throughout the North Island of New Zealand in Northland, Auckland, Hamilton Whakatane, Taranaki and Wellington. In this study 14 participants had received either a specific diagnosis or acknowledgement from the government that they had been poisoned, 2 of the participants had no formal diagnosis.

Purposeful sampling that used criterion and snowballing methods (Lunenburg et al, 2008) were used to select participants. The criterion for participants was that they had experienced pesticide poisoning, in their occupation, and within New Zealand/Aotearoa.

Several strategies were utilised to find participants for the study. Areas were identified that were high in horticulture and agriculture and advertisements were placed in the free local newspapers asking for participants; the internet was used to search and contact people whom had been in the media for pesticides and asking them to pass on the request for participants to their networks; and the researchers asked their own network of people.

Procedures

A research diary was kept throughout this study from the research proposal stage through to data collection and analysis stages. Within the diary the researcher developed concepts and goals, processed discussions with the research supervisor and explored the researchers own embodied experience from the research conducted. The researcher also attended both clinical as well as research supervision throughout the research process to manage any adverse reactions from the research experience. To be transparent to the participants of the study and to be ethical, the researcher disclosed of their experience of pesticide poisoning before the interviews.

In the preparation stages, initial contact with 7 of the participants were made directly by the researcher on the phone or in person and the aims and criteria of the study were discussed. While initial contact with the other 9 participants of this study was made indirectly through a representative for a pesticide support group who acted on their behalf. Each participant

was sent or given an Information Sheet with the research question on and an Informed Consent form for the study. Informed consent was carefully managed and discussed at various stages throughout the research process to ensure that participants were willing and prepared to engage in an interview. Each participant was given time to consider the forms there was another discussion on the phone or in person about the study addressing any concerns and gaining verbal consent to interview. A convenient time was arranged to visit each participant in their home and for the support group on their usual meeting day.

All of the interviews were filmed on a Panasonic camera capturing an audio and visual representation of the participant's experience. In the one to one interviews the camera was faced directly at the participants with the researcher behind the camera so that the researcher could see whether the camera was effectively recording. The rationale behind the placing of the camera was to avoid any failures with technology that may affect the recording.

During the interview stage the researcher started with an open-ended question at the beginning of each interview and from this the participants produced their narrative. The question for this study was: *Tell me about your experience of pesticide poisoning starting from the beginning?*

During the interview process the researcher prioritised utilising open-ended questions that attended to the embodied aspect of the participant's experience. The researcher also used other open-ended questions that attended to different aspects of the narratives including the cultural context; the beginning, middle and an end of each story; the significance of other people to the story; historical continuity; any metaphors, symbols or images in the story; and choices and actions. These questions were memorised rather than read from script to encourage the connection between the participant and the researcher and to ensure the continuity of the interview.

Researching a sensitive topic such as pesticide poisoning required a greater awareness of ethical issues (?) because of the potential negative effect on participants from the research both directly or indirectly (?), from discussing a subject matter that is private, stressful or sacred (?) and that could cause distress to the participants and the researcher

A number of participants did become tearful while they were telling their stories. The participants had been advised before the interviews that they could stop the interview at any time, no questions asked; and they were also asked during interview when the researcher could perceive they were becoming distressed. For two of participant's the camera was turned off for few minutes before they asked if they could continue. Though the original intention was to leave each participant with a list of counsellors for their area this soon became impractical and unethical because a number of participants already had a counsellor, a number of participants felt their support group's was like counselling, and a number of participants would have felt like I was telling them they needed help,

disrespecting their own experience. The researcher did check in with each participant at the end of the interview to determine their reaction. Some of the participants expressed feeling tired by the end of the interview but all of participants felt the experience had been positive and for some healing.

In the end this study conducted unstructured narrative interviews with 16 participants. The majority of interviews were conducted over a 6 day road trip driven across the North Island. The trip was taken twice by the researcher with 2 weeks separating each trip. There was 12 participants and one group interview in the first round of interviews. The original intention of the study was to interview all participants twice. However this soon became impractical for some participants of this study because of their serious health issues. A number of the participants in the study had to be driven in from rest homes and so were unable to be interviewed more than once; and for another participant the researcher arrived to find that they had been taken hospital. In the second round then, the researcher had anticipated only interviewing people from within the original 12 participants. However 4 more participants from the support group turned up and volunteered to be interviewed the second time round and it seemed a too good an opportunity to pass up as well as unethical to turn them down. In the end 2 participants were interviewed once and 12 participants were interviewed twice, 1 participant was interviewed 3 times and 1 participant was interviewed 4 times. Of the participants who were re-interviewed, 5 participants were re-interviewed within 2 weeks, 1 participant within two months and 7 participants were interviewed both in a group and individually on the same day. All of the interviews were completed over a 2 month period from the end of January, 2013 to the end of March, 2013. Overall there were 24 interviews conducted that produced 22 individual and 2 group narratives. Unfortunately due to technical difficulties 2 of the narratives were lost, one of the group interviews and one individual. By the end of the data collection stage there were 23 interviews ready to be transcribed. The length of the interviews ranged from 17 minutes for the shortest interview and to 1 hour and 15 minutes for the longest interview. There was a total of 15 hours and 40 minutes recorded.

After each interview had been completed the researcher analysed the narratives attending to their thematic, structural and performance/ dialogical aspects as wells as reflexivity questions and took written notes. Then after the first round of interviews had been completed each interview was then reviewed by the researcher and in depth notes were taken to track the progress of the content of the interview. Once all the interviews had been reviewed, the two sets of notes taken were then compared together and reviewed against the overall research and analysis questions and from this the summary notes on emerging themes from the first 12 interviews were then developed. In the second round of interviews the summary notes were discussed with 6 of the participants who validated and expanded on the emerging themes, allowing them to shape the analysis of the study.

Each transcript was then personally transcribed by the researcher. The transcript was gone through twice. Writing the transcript fresh first and then going over the transcripts for any gaps. In the transcribing the researcher attended to what the participant said any long pauses or nonverbal body behaviours that expressed strong emotion; as well as all interactions between the participant and the researcher. Within the transcribing the researcher attended to inadvertent disclosures that the participant might not have intended. For ethical reasons these aspects of the narrative were kept within the analysis stage but not presented in the final thesis.

The transcripts were then reviewed three times focusing on first the thematic, performance/dialogical, and finally the structural aspects of the narratives. For each analysis notes were written on the transcript in a different pen colour. Aspects of the transcript that grouped together under specific analysis questions from the thematic, performance/dialogical and structural framework were then written up and then reviewed against the main research question to see what themes had emerged as the most meaningful to the participants and the strongest themes within the 3 analysis's were identified and further developed. All theoretical claims were evidenced by participant's accounts and any alternative accounts were included in the interpretations of the data to persuade readers as to the "trustworthiness" of the interpretations presented in this study. However the researcher acknowledges that this is just one perspective and that other inquirers may find alternative interpretations from the data collected for this study.

The three narrative themes that emerged from the thematic, structural and performance/dialogical analysis were then reviewed against current literature and then structured so that the sequence of the stories remained intact The final analysis of the 3 themes are presented in the following 3 chapters with each chapter structured to flow as a narrative.

Chapter 4: The over-arching narrative of pesticide poisoning in NZ/Aotearoa

The narratives of pesticide poisoning in this study are similar to other illness narratives (Frank, 1995; Reismman, 2008) in that they described a biographical disruption in the participant's life story. Illness interrupts the participants lives, changing their plans, their goals, and for some their hopes and dreams.

C: not very long after I retired she started feeling sore getting it in the joints up here, oh well the end of story was lung cancer, and ahh that type of cancer once you detect it, it's too late anyway you know, so in 2000 she died so I lost you know the golden years that we were supposed to have

Elements of all three narrative type's *restitution*, *chaos* and *quest* were found weaved into the narratives of this study, and as Frank (1995) reported there is often all three types present at once. For two of the participants in this study the disruption from pesticide poisoning was only temporary. After a period of living with the illness, they recovered and found continuity again in their lives, which is similar to the *Restitution* type of narrative (Frank, 1995).

K: so for me it was a bit of a shock for a while having been poisoned because bit of a mood swing I felt a bit flat at the time I was having trouble getting my fingers to move properly I was really struggling getting them to move they weren't sort of working like they should ,toes weren't working and various other parts weren't working very well either so ah it was quite a relief to find after a while that I actually did heal and this actually did get out of my system did go away but cholinesterase test be a good idea to have on a reasonably frequent basis if your using organophosphates, I basically handle Borat's these days

Overall though, in contrast to other studies on narratives of contested illnesses (Whitehead, 2006), *restitution* was not a typical characteristic of narratives of pesticide poisoning. Instead people who experienced pesticide poisoning typically describe an experience of *chaos* and *quest* within their narratives, reflecting both the chronic nature of this illness and characteristic's that are specific to pesticide poisoning. Whitehead (2006) suggests that there is a linear trajectory to the narrative illness types and this study supports this, but the stories tend to typically begin from *chaos* and then lead into *quest*, and then shift back and forth between the two.

The majority of the participants in this study experienced a permanent rupture to their life from pesticide poisoning and they experienced *multiple layers of chaos* from the perpetual disruption to their life from illness.

L: mmm you know just the question about how do we feel about that experience, I mean I've already said there was anger before, now down the track, I guess it's more, you know so how do we, you know how do we remedy this thing, this catastrophe

A description of some level of chaos was present in all the narratives, but only 2 narratives would be consider purely a *chaotic narrative* and therefore not narrative at all, because of their level of fragmentation and lack of coherency (Frank, 1995). People who live with difficult to diagnose illnesses tend to experience a greater level of uncertainty and stigma,

with the lack of support from Doctors maintaining a cycle of chaos (Whitehead, 2006). Living with uncertainty is a key part of a pesticide poisoning experience. Two of the participants in the study who had never had any “official” medical recognition of their pesticide poisoning experience, tended to show a greater level of chaos and fragmentation to their story.

A: and they said oh its, one of the doctors said at the medical hearing that it's just my belief that we get sick from sprays, because I said if I never know when I'm going to get sick it depends where I go or who's spraying you know, if I land on sprays, if a farmer sprays, I'd have to drive on the road to get to a job, or to get anywhere, I if I drove past a spray truck, you know ,that's pretty, that's I mean that's the worse, I might not, I might hardly be able to sleep and or I might get this huge all these flu symptoms and cough that will last for 2 months or something but it doesn't seem to matter what symptoms I get,you know it's just my, because I believe it's from pesticides you know, it's not valid

The experience of illness from pesticide poisoning evolved into a personal quest for many narrators as they used their personal experience with illness to facilitate change for themselves, others and their environment. Of the 16 narrators in this study 10 of them had the *quest* theme dominating in their narrative and this included the one participant whose narrative was the closest to the *restitution* type. This could be representative of the type of participant who volunteered for this study. Most did so because they wanted to raise awareness of pesticide poisoning, but only some would be considered activists. It could also be reflective of how the experience of pesticide poisoning changes people and makes them want to advocate for change in their environment. Overall the *quest narratives* tended to be well structured and lengthy and were also highly social and political, as they seek to contest the social structures and practices (Fraser, 2004) that led to their poisoning

E: um, and um slowly but surely it started to, to develop inside of me, the illness that you it was up until a few years ago when I finally accepted the fact that there was something here, was telling me that there's a job that needed to be done, if that's a better way of saying it, see um and like I say the people that were helping me then, but I finally succumb to their demands if you like, ahh, they said to me, you don't, you had the most roughest, hardest induction in to this, to this, into this issue, is said what are you talking about, what did you mean, they say well, course you had no ears and because like that, because you don't want to listen to anybody, you almost stuffed it twice ahh, and the pain factor that you were going in, that you were going through, you were getting your butt booted, shake your bloody ideas up, you've got a damn job to do you know, like that ,but I guess from that point on I, I, I slowly but surely learnt um, ahh this is not about you

The narratives of this study tended to progress through similar stages that were distinctive to the pesticide poisoning illness. The following overarching illness narrative follows the participant's through different stages of their life journey as they experience pesticide poisoning. A defining feature of this experience is that though the participants don't often know when their symptoms of illness began, the narratives always have a clear beginning, when their *exposure* to pesticides occurs. The stage that follows this is when the participants start to develop awareness of illness symptoms and go through a time of *realisation* that their exposure to pesticides has occurred. It is at this stage that the chaos from the illness experience begins to be truly felt in the narratives. The next stage then takes you through the participants *struggle* with both the negative impacts on their health and the lack of acknowledgement by society. It is here that the greatest level of *chaos* from the illness experience is felt. The participant's then describe an experience of *integration* of the poisoning experience as they come to terms with, adapt, or recover from their illness

and it is where the quest aspect of illness experience begins to be felt. For some of narrators there was a final stage where they went through a sense of *empowerment* where they built a strong identity from the pesticide poisoning experience and created change in their environment. This stage is the most representative of the quest narrative. The narratives were typically sequenced with a description of the exposure at the beginning, then a description of the realisation and struggle with illness symptoms which commonly overlapped, and then for some a level of integration, adaptation and empowerment from the illness experience.

The following narratives describe the exposure to pesticides in workplaces within New Zealand/Aotearoa over the time period from 1950's to the 1990's. As stated in Chapter 1, the first pesticide board to regulate pesticides didn't form until 1979 and a consistent process to manage pesticides didn't happen till 1996, so that all of the narratives of pesticide poisoning describe exposures to pesticides at a time when there was little or no regulation of pesticide use in New Zealand/Aotearoa; and since awareness of the health impacts of pesticides developed alongside the regulation of pesticides, all of these narratives occurred during a time when there was no awareness in society of the dangers of pesticides to health and the environment, and no social representation of what pesticide poisoning as an illness actually was.

V: so I came to the boardmill, I went into to see the ah the person whose in the office there, you looking for a job, I said yeah, start now oh no no, could I start on Monday I said okay you can start on Monday so I started at the boardmill in 1954, I took early retirement in 1987"

D: I worked there (pause) from 1973 to 1978, things got worse since then all sorts of different things

P: Well it goes back many, many years, um with my husband working at the mill. 1975, I think it started there, somewhere there anyway, um not knowing what was happening anyway at that time, anyway but he worked at the mill, um then a few years later I began as a cleaner there as well

K: right well what happened with my particular situation was that I was spraying a lot of houses for fleas and this was in the um early 90's

A narrative of pesticide poisoning typically started with the workplaces and practices that led to their exposure and the specific pesticides they were exposed to. Many of the participants were exposed to numerous pesticides at the same time whose combination of effects have never been investigated, but individually the main pesticides that participants were exposed to were Organophosphates, 245T, Paraquat and PCP. The Organophosphates and Paraquat are now regulated with strict requirements for full protective equipment; and the 245T and PCP are now banned by the New Zealand government because of their negative impact on health and because they don't break down in the environment as Rachel Carson's (1961) book the *Silent Spring* first documented. The participants exposure to pesticides occurred in various occupations within the sawmill industry, the horticulture and the agriculture sector, within chemical factories, and working as a pest exterminator in New Zealand. The majority of exposures occurred within rural environments, with the exception

of the pest exterminator whom worked in the city. Exposure to pesticides is higher in rural communities and research suggests more, well accepted.

B: at the mill, well I there was 2 of us we used to be pals for 20 years we made pallets at the carpenter shop, and then they, when they get these overseas orders, special orders, we go build special pallets and the all the timber is soaked in big vats, they 'ld dip it in with forklifts, and then they would bring it over to us, you nearly have to had to we have these automatic guns they go right down to the wood and then stuff splashes back into your face"

D:"but we used to fill, fill the um 20 litre drums, and we used to fill the, um, all about that big plastic container (makes gesture with hands), sometimes you would get splashed in the face, sometimes the, would the machine wouldn't cut off, you would get on your hands and that"

The lack of protective equipment being available in their workplaces was typical for the majority of participants which is reflective of the lack of regulation and awareness on pesticides. The lack of protective equipment used with pesticides such as carbamates and organophosphates have been shown to contribute to the high number of poisonings overseas (Roldan-Tapia et al, 2005).

M: I was about 18 and a half I suppose, and then breathing in this bloody thing, I we didn't, we didn't have a mask, well I can't remember having one, I can remember the bloody stinking stuff

*T: and that was, that was I grew up I went to work I went to a saw mill in *****and started to work, I mixed the PCP with my hands, no gloves, no mask but you could smell the fumes in the air and it was strong and all our boss said, so ah, to do was ,when your finished, tip it in there ,which is a dip where the timber goes down into before it goes into ,out onto the chain and you know the guy outside lifted it off the chain and onto the stack, so ah I've actually mixed it, um*

Though some narrators were developing their own awareness and went on to develop their own protective equipment for their work.

B: you know we didn't take much notice for a while until one of the saw mill workers said you better be careful with that, dipped in a vat over, ah, over at the sawmill and its poisonous, oh god, so I would get a handkerchief wrap it around my mouth, we had to build hundreds of them for the special order for overseas and they said, we've got, we've got to do that because the wood contaminated coming over, but it was sent overseas, cause when I said do you have to, that stuff into those vats the timber over us build the pallets and they said , it's ,it's whatever , we'll do it for, they said its gotta be properly, I , I can't think of the word, for the timber to go overseas so we built them for years, we did get affected by it and we were the only 2 alive all the rest have died, carpenters"

Lack of awareness of the dangers of pesticides was a common theme throughout the narratives

A: but um you know I had no, it didn't cross my mind that I was health, I didn't know at all how poisonous those sprays were, you know I knew I didn't like the smell

C: and the other thing was never pushed by management was the fact that the toxicity of the stuff you were bloody handling

Narrators who worked in management within these workplaces also had inadequate knowledge and lacked the awareness to protect the people they worked with from exposure.

R: so you shared similar experiences with the other guys in this group with the poisons

M: well it was my job to supervise them and I was never told I never looked at it from a poisonous, that it was poisonous I didn't know it was pure ignorance

R: how do you feel about that you didn't know?

M: bloody lousy

Though it was clear that some in the industry did have knowledge of the dangers of pesticides and this wasn't knowledge that they were prepared to share.

L: yeah, and just to add to that Merv, I mean the safety gear that we were given, was for the nature of the job not the nature of the chemicals, so ah I've spoke about the people that were bringing the chemicals into the sawmill yard would be wearing a full on astro suit with respiratory mask and looking like spaceman, and here's the people on the ground you know doing, doing the hard, hard yards, they had a pair of gloves that, you know you took, they might get a hole in them and you took it to your boss I want a pair of gloves, and we just got the one out of it, and that gap, two pairs was the solution of it, and what you do at night, you would hang them up on the heater, and that's the worst thing you could of done, you know it just, it turned it into a toxic element to come go on your skin,

Though some questioned the use of pesticides, most in their ignorance did not. It is suggested that most incidents of individual poisoning are due to uninformed use, misuse and abuse of pesticides (Grieshop & Winter, 1989).

R: How do you feel about that they never told you

B: Oh I feel terrible really, you know we were never ever told about it, and I put a complaint in one day when, and I said why do we have all this stuff so wet with the gunk coming over, you know, they took no notice of it they just, they just said it's gotta go overseas, said it's gotta be, I said yeah but don't forget all the cardboards gonna go on top off those pellets I said, and that will soak through, by the time it gets to the country where it's going too, you know I think of all those sort of things, and they, they knew it was carrying on ,but it you know, now you're thinking of it, it's you know how the hell am I still alive when all these other chaps have died

Pesticide poisoning became a whole life story for a number of participants.

*L: ah from the beginning I guess I would have been about um 3 to 4 years old when I first moved from **** where I was born moved to W----- um and my first introduction to chemical poisoning is um learning to swim as a 4 year old back then in the 60's when you learnt how to swim usually your brother pushed you in the back and you ended up in the water and a this is K---- canal we are talking about here we lived just about 50 metres from their saw mill site from the mill site and um about oh 50 meters from K--- canal where I learnt to swim as you do when you learn to swim you gulp a lot of water in so that probably would have been my first ah initial exposure so um also as, as children we would continuously playing on that waterway and we would go down to the sawmill site and take drums 40 gallon drums and make rafts with them and sail them down this river its really ironic now in 2008 were having to dig out the sediment from exposed canal that ****canal chemically exposed canal trying to clean it up using biotechnology*

Many of the participants had been exposed to pesticides throughout their lifetime, within their communities and within multiple occupations. The chaos from pesticide poisoning seems to be intensified by being repeatedly poisoned.

T: so I grew up with it there and then ah what did I do ah I went into forestry, for the same company, and and then I started using chemicals, you know roadside spraying and just ah different other spaying working in in forestry which which became quite um quite a big task cause we sprayed right through the summer.,ah different, different types of sprays the first one we used was 245T which you know about, and ah then Toron and then the roundup came in and a few others that ah paraquat you spray over the forest to dry it out so you can burn the forest, forest off for replanting so your all exposed to all that, not only in the chemicals but you know it ah smoke inhalation and then everything else, dust and yeah it was all

coming from what you sprayed so it was all coming back at you, in a different form you know through the smoke and the dust, and it would go up into the air when you started lighting, lighting your forest fires

The participant who showed the greatest similarities to the *restitution* type narrative had experienced one exposure to pesticides. The rest of the participants had been exposed to pesticides for years and some for decades showed greater levels of *chaos* and despair. Within trauma therapy it is well accepted that multiple incidents of trauma (Courtoise, 2008) cause deeper wounds within a person's psyche and causes a deeper fragmentation of a person's identity. Pesticides poisoning is an *environmental injury* and the narratives of this study support this by shows parallels with other traumatic environmental injuries.

Multiple occupational injuries were reported by a number of participants within the same workplaces, showing the huge cost that they had paid with their health and what happens when there is no regulation or awareness around pesticides and in health and safety in general within New Zealand workplaces.

F: I've got a problem with my ears

R: With hearing?

F: (laughs) yeah

R: Your doing really well

F: Yeah that was caused at the mill too

R: Really?

F: It was industrial related, you know it's not giving us you know earmuffs, no safety equipment, and you know working in the saw mill you know right beside the saws, very noisy

R: So you got poisoned

F: yeah

R: You lost your hearing

F: yeah

R: And you nearly died from a head injury

F: yeah, yeah

A slow period of realisation where they first started to recognise illness symptoms, and then connecting them to their exposure to pesticides, was typical for all but one of the participants. The chaotic change in narratives when people realise there symptoms are not attributable to simple causes has been reported in other narratives of contested illness's (Whitehead, 2006).

S: "okay and so anyway we started getting sick and, the nature of the, our particular poisoning it was um it really happened kind of slowly, kind of you didn't actually notice it, like one would expect that you would you know, um, symptoms started slowly, and example is um you know you would feel um nauseous pretty much every morning, up until smoko or lunch time when you had a cup of tea and had some stuff to eat and that just happened slowly over a period of time, and um before

you knew it it was kind of normal you were used to having a sore stomach and just feeling a bit nauseous, and so it was quite hard for us to pick up, to actually notice it for quite a long time, until the symptoms started getting quite strong, um, from there we um, we finally started to realise that we were getting sick and some things were going wrong, and that um, just the way we were thinking and things were starting to get a little bit fearful or funny and we became aware of that"

Much of the *chaos* I believe that comes at the beginning of a pesticide poisoning narrative is the realisation that your illness has been caused from you being "poisoned", it is hard for outsiders to comprehend the horror of knowing this, that an external agent has invaded your body and is harming your health. Some participants retrospectively acknowledge this time of realisation of exposure, as a time of "enlightenment" indicating the importance of being aware of what is happening in their body, even if this brings *chaos* from uncertainty.

N: "um they monitored us pretty closely with blood tests, every, every month we were in for blood tests and to take a baseline um when you baseline was 20% you were poisoned, when you dropped to 20% and below mine got to 50% and below before I got notified, the first I knew was the boss rolling up on a motorbike, like sort of stop stop, um yeah and just at that time I didn't realise I was poisoned, I didn't, didn't know the symptoms of poisoning but once they started to run through you know the symptoms and how it affects you, I was ticking so many boxes, it was you know ahh, yeah ah, it affected me in ways I didn't expect it to, um my speech, um rashes just, just things that were coming out, um, my sense of smell had gone, um, um yeah ahh being able to communicate too like I say cause it slowed my nerve impulses down so much"

There have been a number of studies documenting the challenges people find in recognising changes in their body as signs of illness symptoms (Lyons & Chamberlain, 2006) and this is for illnesses that are well accepted in society. For example in a study of illness narratives of people living with lung cancer, people reported not recalling significant distress before they were diagnosed with lung cancer (Levealahti et al, 2007). The challenges in symptom recognition therefore are tenfold for illnesses where there is no recognition or awareness in society and this increases the challenges faced by people who have experienced pesticide poisoning. People who have been poisoned have greater uncertainty and chaos in their life because they don't know what is happening to their body. In contrast the participant who had the most training in pesticides prior to exposure was the only narrator, who were able to recognise their illness symptoms. But nearly all the other participants had little or no knowledge of pesticide poisoning symptoms and so for the majority of participants the realisation that they had been poisoned occurred months, years and for many decades after they had been exposed to pesticides.

L: there was 26 of us and there was the 4 that um had their urine tested um when they were working there, in all 4, all 4, a ll 4 were put on to sort of like light duties type of thing, : they were taken away from where they were being exposed, which was ah, the blood tests you know, you know once it came out, that we were treated as the baddest of this um most dangerous hazardous chemical in your system, it's in there you know, it categorically say's that we've been poisoned, that's evidence it's not going to do any good to our people that are up in the cemeteries

By the time participants recognised their illness symptoms in their body and made the connection to their pesticide exposure in their workplace, they had long since left the job.

P: must have been about 2,3 years not working at the mill, veins were starting to pop, pain, probably stress as well and um and the ah yeah 2000 he got really sick, he didn't really know how sick he was at that time, the nurse from the hospital called over to see him he was working on the vehicle but when he got the news how bad it was he really went down knowing what he had, and, he could relate all of that to when he was working at the mill,

A problem with seeking any help from medical professionals after you have experienced poisoning is that if an environmental exposure history is not taken, then your exposure to pesticides will be overlooked, because it can have similarities to other illnesses (Sanborn et al 2002) and because it can cause environmentally induced diseases that distract the medicine from the origins of an illness.

T: you know it's after you finish work where everything in the later years after you which is right it was about 20 years after you finished and all you know all the different sickness just came at you from all different places all different angles, but you're getting the same sickness as that guys was getting or that one you know when your all in the doctors all there for the same reason, for the same sicknesses, yeah so

R: How do you feel about that going to the doctor and seeing the other people?

T: well it made, made you wonder whether the doctor knew what he was talking about when it comes to you know your particular problem

Research has shown that medical professionals routinely overlook assessing environmental exposure (Sanborn et al, 2002) and this is based on this century standards. In one study 80% of children diagnosed with pesticide poisoning were initially missed in their first assessment and only 3 of 25 confirmed cases of pesticide poisoning did the person who had been poisoned actually volunteer their story of exposure (Sanborn et al, 2002). Therefore participants in this study who had been poisoned by pesticides had to know they had been exposed and taken this story to their Doctor to have any chance of having their symptoms of pesticide poisoning recognised

The challenges in getting a diagnosis create chaos for the participants as most grapple with the uncertainty of what is actually wrong with them. Other studies have referred to the "chaotic" structure of the illness narratives of people with medically unexplained illness (Nettleton et al, 2005). In the narratives from this study there are layers to this experience of chaos that are distinctive and specific to pesticide poisoning, that comes from living with uncertainty about your future after you have been exposed to pesticides. At this realisation stage of the narrative you can see the first layer of chaos from pesticides poisoning is the *uncertainty of diagnosis*. An important difference in the narratives of this study is that the diagnosis experience that is often found and actually usually clearly defines the illness experience in other studies on narratives is replaced by the realisation experience that poisoning has occurred. This seems to reflect the challenges in both the participant recognising illness symptoms and in having these symptoms recognised by medicine and having a diagnosis of pesticide poisoning made. Only three of the participants of this study actually received a pesticide poisoning diagnosis within 2 years of being exposed. Others waited decades before this was acknowledged and some never had it acknowledged. Others have noted that in the narratives of people who live with contested illnesses, where there is a lack of diagnosis, there is a level of fragmentation to their narrative (Nettleton, 2006). Perhaps this fragmentation comes from the multiple layers of chaos and despair that people experience with living with a contested illness and in particular from *uncertainty of diagnosis*. Most illness narratives that aren't contested tend to eventually have a definite

time of diagnosis that their narrative is structured around, but people with contested or undiagnosed illnesses don't have these dates to form their narrative around, and instead their experiences are formed around increasing levels of realisation as they both grapple with their own understanding of illness, as well as finding others who can help them to understand their illness.

B: over at the sawmill, when it came out to people we' Id finished, at the mill, and all these people getting affected with it, you know it's really frightening, what we, what we were going to get

Z: and more or less decades after now you know being there for 35 years, it wasn't until just now that I think, think back to the time, we were, we were working there, it was terrible

Realisation of illness symptoms and there connection to their exposure to pesticides ultimately led a many participants to make the next connection that they had inadvertently exposed their families to pesticides and that their family member's illness symptoms were connected to pesticides. In a study in Ecuador, family members of farmers who used pesticides, were exposed in their home because of a multitude of exposure pathways (Sherwood et al, 2005)

T: Cause like you say you know all all the spraying and different other things we were using ended up on your clothes , your taking it home and your taking it to the other places that you go to you might go to a marae to a tangi something you know and its on your way home so you call in there there your giving it to other people in a way you know you sort of didn't know untill you stop now to I can't actually think and the amount of time you know, sort of you know that's the thing you know when you get a pain you know if you went onto a mill site now think back for the amount of time that you, you ah, sort of you know what you had you sort of coming off you to other people infected other people with it including your family

Now days it is advised that all clothing that has been used during exposure to pesticides should be washed separately from other laundry in a household to avoid inadvertent exposures (Sanborn et al, 2002) but most of the participants were unaware of these dangers so that many families experienced direct exposure to pesticides from the residues brought home by the narrators. It is the potential harm from having exposed your own family to pesticides that creates another layer of chaos distinctive to narratives of pesticide poisoning which is the *uncertainty of the harm you have caused to your family*.

C: um but for the generations coming know, within my own family, the complaints have come up you know, my, one of my daughters, she's had this heart complaint from when she was very young, had it from various times and you know tumours in her heart, to and I take her to the Doctor, one of the old time Doctor's you know, just about had her diagnosed but he wanted to send her away to Greenlane with the full diagnosis but he couldn't nail it, but she finished up in green, greenlane, you know it appeared and they took out this bloody tumour, now, although it was right in the stage that I was exposed and I'm doing what Sam was talking about, they used to shut us down during the slow time, summertime in the place there, in the section that I worked in, was the slower time, that's when you know we used to do a lot of it, but in the season we used to make what you call Botox board, and it's all craft, it's all chemical pulp, we had it on the ground there, of course cause we were slack, so we used to go over there and the only time at the saw mill, we used to go in there and scrap around where Sam was scrapping there under the green chain there, we used to take firewood home from there, you would have the offcuts, and we would stick it in our fire and the fumes would come out, we didn't know, I didn't know about all this bloody shit that was going on here , you know

As their awareness continued to grow so did the realisation that not only had the participant's and their family been exposed to pesticides and was suffering from health

effects, but that their entire community and environment had been exposed to pesticides as well. Within this emerges another layer of chaos distinctive to pesticide poisoning the *uncertainty of the harm caused to your environment*.

L: What Sam, Sam is talking about, is um a good point here, um at the moment um it's only the sawmill workers, you actually had to be working in the sawmill, to be getting the eh, the free annual health check, but all that, and what were saying is but hang on a minute, um cause there was the civil gang that used to go and clean up, there was plumbers, there was electricians

C: all the services eh

L: yeah there was all these people doing it as well, um you know there is um office ladies, who used to um, dust in the offices, ahh the pennywagon sorry, and they would be dusting in the offices, they would be going into smoking rooms, be cleaning the smoking rooms, be cleaning the urinals, the toilets, so these, these people have been exposed as well

C: and even the fire brigade too as well

G: yeah the fire brigade too

L: yeah, yeah the fire brigade would go to practice on the sawmill site,

G: yeah

The realisation of illness symptoms from their exposure to pesticides leads into and often overlaps with a description of a period of struggle where the participant's awareness of their illness symptoms grow and the impact of their physical body is more keenly felt. Similar to other studies illness symptoms and body sensations were portrayed by the narrators as familiar and a normalised part of their life (Levealahti et al, 2007). At this stage in the narrative the participant's sense of identity is challenged and unravels in response to their illness experience. The chaotic aspect of the pesticide poisoning experience hits the participants full on, as they struggle with changes in their physical body in their psychological mind and the breakdown in their relationships.

Frequently the participants described struggling with the physical symptoms of pain and fatigue. Chronic pain impacts on a person's connection to their body, how they relate to the world, and impacts on their sense of identity (Bullington, 2009).

V: my leg started to... me, then I start, it gives me like a ulcer, that's what happened to me and then it healed up, they go work on it at the hospital, sometimes they do it over here, oh you know they put something on there, but they, they said to me, oh you better go to, the hospital, the doctors, at the hospital so anyway the doctor had a look at it, different doctors you see, so they sent me to a hospital, it was all different then, you know yeah and then they say it's good, so they said hello, it's okay, so I was back to work again yeah

R: okay so throughout work there you kept getting these pains in this leg

V: yeah and it's been like that ever since then my leg you know

Fatigue or general malaise is considered to be one of the earliest signs of neurotoxicity from pesticide poisoning (Sanborn et al, 2007) and it is also something that is easily attributable

to other causes and therefore easy to overlook. Fatigue is also one of the main symptoms of chronic fatigue syndrome, another contested illness, and it has been suggested that pesticides is connected to the development of these illness.

R: you said about being knackered can you tell me more about that

M: Oh it did, it made me Oh I believe in general I become very tired, I just all the time I wanted to go to sleep, and I sometimes put it down too pills like the painkillers I might have had and that, and then they would give me another pill to stop me getting constipated, and you know I would say this is crazy I says knock that one that painkiller on the head, I'm going to put up with the pain for a while and it didn't make a lot of difference it except I did have more pain

Many other physical symptoms felt in the body from pesticide poisoning were described by the narrators of this study indicating the diverse effects pesticides can have as they interact with the biology of different individuals.

R: mmm what happens when it catches up?

M: yeah well you realise just how it catches up um for me personally like I say I lost my sense of smell I was tongue tied, um rashes, a lot of skin rashes, itchy blisters, itchiness that would come up like a blister, one of the worst thing that was the night sweats, I had night sweats for a couple of years, just, you now wet through as soon as you tried to sleep but um they, they eventually um eased off, but that, but that would have been, one of the symptoms I had the longest, the night sweats, the night sweats, and the fatigue, you know and just no stamina you know I was young I was 18 I should have been you know jumping out of my skin, yeah

Acute and chronic neurological changes inside their body were frequently reported by participants.

K: the issues I was basically having was my fingers weren't working very well and various other parts of my body weren't working very well either it was as if I had trouble connecting to them and that was what was happening so I decided that under the circumstances I better get get this looked at because I was having a few problems with that and I went along to my Doctor he was at Newlands at the time and I was referred to a um specialist who was out at Plimmerton a Plimmerton Doctor did some tests

As the brain struggles to function and communicate effectively your sense of control breaks down within your body. Neuropsychological deficits have been reported in acute and chronic exposures for some pesticides (Roldan-Tapia et al, 2006), for example some of the OP pesticides showed deficits in visual scanning and processing after chronic OP exposures (Starks et al, 2011) and there are long term cognitive effects from chronic exposure to pesticides (Baldi et al, 2011).

S: numbness um most of my body is partially numb, desensitised, I have feeling everywhere but not a very high one, so um you have to be careful (Laughs), you can hurt yourself sometimes and not realise just how bad that is, and you have to be careful getting into a hot bath because it's so hot it can burn you, sensations aren't quite there, often I wake up at night with dead limbs, I can't move, sort of like a pins and needles feeling but it's kind of developed further and further, so you got not the same pins and needles sensation but you actually can't move, your arm or your leg, it happens at night, I have to sort of drop it down a level of the bed and blood runs into it and it comes back

Mild cognitive dysfunction is also one of the earliest neurotoxic effects from pesticide poisoning and exposure to pesticides has been associated with the development of neurodegenerative diseases such as Parkinson Disease and Alzheimer (Baldi, et al, 2011;

Sanborn et al, 2007). In one study, people who had chronic low dose exposures to pesticides saw a 70% higher incidence of Parkinson Disease (Ascherio, et al, 2006)

V: starting from the very beginning ,is ah, um the first time I've been here um is ah I think it's just over ah about a couple of years ago, a while back, my thinking is I little bit past my energy, yeah why, why, ah, see there I, I feel as if I'm forgetting something, um and ah, um what I mean by forget things is, say my wife she, she says oh would you could you do this, but the moment after she says that to me I, I have a tendency to forget, things like this, are and there are times that when things are running smoothly enough in here, so to me it seems as if it comes, comes through here and at times quite well

There was a chaotic nature and fragmentation in the narratives of people with memory problems. Farmers exposed to pesticides previously, performed worse than controls in tests on sustained attention and information processing speed (Stephens et al, 1995). This loss of control over your mind is not easily understood by outsiders and is probably one of the most chaotic aspects of this illness in general and it is not easily researched from the outside in. It is well recognised that facing serious illness challenges a person's sense of identity (Frank, 1995; Reissman, 2008) but pesticide poisoning attacks identity on a whole other level, as the illness literally breaks down your cognitive processes from which you form a sense of identity.

N: um yeah, don't know, it's yeah, you know it's a sort of dazed and confused, sort of, sort of feeling in a way, dazed and confused, yeah when I read at the beginning I was, I was really just the way it slowed down your mental processes in the early days it was yeah, so dazed and confused and this short fuse, um going somewhere to do something getting there and thinking shit what have I come to do, that sort of thing um doing a simple job you've done 50 times before all of sudden you gotta go now shit how do I do that you know, things like that um, people's names, someone you've known for ages and you, you, it's a block of mental recall, um like even on the nursery, I was always pretty good with plants names and things like that, I could look at something and rattle it off just like that but the after you got poisoned, now what was that again, it sort of. yeah like I say a dimming of a light you gotta take a step back and, really think a lot, a lot harder than what you'd normally have to do when things happen

The narrators identities then further deconstructs and the chaos intensifies as the participants lose control of their emotions. The majority of narratives described intense psychological symptoms from pesticide poisoning. Participants experienced sudden mood changes where they experienced fear, sadness and rage in their body.

S: it makes all your emotions really extreme from people that I've heard talking about chemical emotions and stuff I, you see it in their eyes, they all go through the same thing but people don't like discussing it because it brings up all these mental health issues, there's a real stigma and that, people don't like admitting it, but, but it effectively it screws with your brain, it makes you very unstable for a while,

Research indicates that mental health issues can cause and influence physical illness, and physical illness has been shown to influence and cause mental health issues but in each case the origin is considered to be either physical or psychological (Bendelow, 2009) Pesticide poisoning is different because you can't separate the physical and psychological affect within the body. Pesticides directly affect biological mechanisms within the body that influence emotions. For example we now know that organophosphates interfere with neuron transmission in the limbic system in the brain which is involved in the regulation of emotions (Sadock& Sadock, 2007). People with OP poisoning have reported "out of the

blue” suicidal and homicidal thoughts that can lead to impulsive, random acts of violence towards suicide or homicide resulting in death (Davies et al, 2000).

Z: too um but what I notice with, with him was um his mood swings, were terrible, um and initially I thought it was something to do with me but it wasn't, um and I was so concerned, I actually noted them down in a book and I used to call them the Black Hole of Calcutta moods because they were black, and um in questioning him he actually didn't know what was happening to him really, he said I don't really know why I'm this so um yeah that, that was difficult”

Pesticide poisoning is associated with an increase in mental health symptoms which sees profound mood changes, mood swings and the inability to control and regulate your emotions (Sanborn et al, 2007). The loss of control of bodily functions is considered a key aspect in illness (Frank, 1995), the loss of control of your moods is another aspect to this illness experience as your body displays new or intensified behaviours as a result of being poisoned.

N: um I still, um a lack of tolerance I suppose, getting not having this, you know like a short fuse, you should be you know little things can piss you off really more than what they should

Studies have found associations between pesticide exposure and minor psychiatric morbidity, depression and suicides amongst Canadian farmers (Sanborn et al, 2007). Research suggests that the neuropsychiatric changes in the body from pesticide poisoning are some of the most enduring symptoms. New Zealand has a high suicide rate (Fergusson, 2003). The suicide rate is high amongst farmers in New Zealand (Gallagher et al, 2008) and this is consistent for many rural communities around the world. Some of these suicides have been associated with pesticide poisoning (Patel et al, 2012).

R: What's it feel like to have these moments

L: ah dark, angry, dark, stressed out, you know like, I would feel like a tight, tight um all in my muscles, yeah rigid as, like a , how would I say it , probably a you know like a boil, ready to pop

Poisoning from organophosphates in particular had been associated with an increase in psychiatric disorders, especially anxiety and depression (Salvi et al, 2003; Kamal et al, 2005). The more severe the poisoning the higher degree of mood changes can occur (Jamal et al, 2003) and some suggest that the depressive disorder from OP's is its own distinctive form of depression (Davies et al, 2000).

People who experience illness are often stigmatised by society (Frank, 1995) and those who experience mental health issues are even more stigmatised. Traditional hegemonic masculinity teaches men that they should not express their emotions openly even ask for help when they are distressed (Lee & Owens, 2002) and pesticide poisoning intensifies emotions challenging hegemonic masculinity identity. The experience of many of the psychological symptoms that are created by the body in pesticide poisoning can deconstruct a person's sense of identity, and might be why many men who are poisoned don't seek help, and why the pesticide poisoning experience has gone unrecognised for so long.

R: What did it look like these moods?

R: What's it like having a group of people explosive, like that? What would happen?

C: What would happen?

L: Back in those days you just, I'm mean you had, cause you always, always had a nutter that just went off eh

C: yeah

L: You know, they just went off, so we sort of walked away, from the, walked away from all the others, you know you would grab them and say hey settle down you know and of course tomorrow that same guy would be working beside you, and, and we had those flare ups

L: yeah

Pesticides have also been shown to be associated with an increase in social isolation (Sartorius, 1983) A number of the participants from this study described withdrawing or isolating themselves from their family, community and society because of the illness symptoms from pesticide poisoning. In a study of Iranian war veterans living with chronic disease as a result of chemical warfare, social isolation was a key outcome from being poisoned (Hassankhani et al, 2010).

S: I have quite a quiet life, um I don't socialise a lot with people, which is just a coping mechanism, of, of dealing with chemical poisoning, so it's difficult and stressful in social situations, I just can't be round people so um, I find my own support from a, I'm sort of forced to live life on the fringes of society, you know I suspect that most people who have been chemically poisoned put themselves in that same situation.

Perhaps the isolation is linked the *monadic* embodiment of illness (Frank, 1995), where the person chooses to face the illness alone and feels that are protecting other people by withdrawing inside themselves.

R: How does that impact on being with people

N: yeah being able to communicate you know at work too can be an issue, people can take you as being um reserved or arrogant or something like that because your not communicating with them, it's not the fact that your not, it's that you find it hard to you know, to try and string sentences together in a logical meaningful way, yeah I don't know being able to express yourself, sort of yeah

Considering the intensity of the psychological and physical symptoms of pesticide poisoning this could well be a factor, but it could also be because being poisoned by pesticides affect's the ability for people to connect to and be part of this world and that is why they withdraw as well.

C: I think it was more stressful when Mum was alive, um not because of her, but because she was there and a, and a man could you know, later on I realise hey all this stuff that was going on in a guy, it could turn around on her, you know, but you know I'm glad to say, I never ever did, there were some quite moments, you know she didn't like those quite moments, that's when she knew there was something and she would prod, just to free, free, cause ahh what we had quite a few of us I'm sure, locked it up didn't want it, pass it on, kept it in

The struggle with the knowledge that they're exposure to pesticides had impacted on their family's health was difficult for a number of participants Not only did they feel the loss of control from their own individual health experience, the chaos was increased by loss of control of their family's health. The narrators describe their struggle with miscarriages...

Z: like first of all , I didn't realise this initially but um, when I , my first pregnancy, um I lost one of the twins but I didn't realise that, and then um the second pregnancy I had, my son was born but actually, it nearly died on me twice, so apparently all of that is relative

... or birth defects in their children and grandchildren.

C: the last 2 years, these, these things started happening to my kids, you know one of my daughters, my daughter she is the fittest people I know, person I know and she didn't smoke, energetic, cause it's a heart, heart condition you know, I've got 2 of my moko they've get palpitations now and then, where's this, where's it all coming from, so you look into my family history, we never had a history of heart problems or anything, so how, or how, why you know

Research supports that there is increased risk of birth defects in the children of people who have been exposed to pesticides (Sanborn et al, 2007).

F: it wasn't until just now that I think, think back to the time, we were, we were working there, it was terrible ahh, as the boys said, you mentioned anger, well that's how I feel now because it's, I've passed it on to my wife and my kids, children, one of my kids had a deformed leg, you had ah, um, yeah, 2 toes missing and I yeah I blame that the toxic poisoning"

Specific defects that can occur to the body include limb reductions, urogenital anomalies, central nervous system defects, orofacial clefts, heart defects and eye anomalies. In one study the risk of spontaneous abortions were 6 times higher in farming households (Sanborn et al, 2007). The risk can be twofold, if the parent has been exposed to pesticides prior to conception and if the foetus is exposed to pesticides after conception (Sanborn et al, 2007).

A: "um yeah I feel like my children have suffered a lot and um they still are and um whether I don't know how much it's to do with what was in my body, or just that whether the chemical sensitivity just gets passed on"

The struggle with whether their exposure to pesticides had caused genetic damage was also very challenging for participants. Within our genetics lies a part of our identity connected to our body, with pesticide poisoning the participants lose control of their genetic identity creating another layer of chaos the *uncertainty of genetic identity*.

C: you know if I go tomorrow it doesn't matter you know, but I would like to see, a thing to take is to set something up for my kids mokus you know, so they don't have to go through this crap you know, it's such an insidious bloody thing , it just sneaks up on you

In recent years there has been the development of simple tests that can identify the environmental effects of toxins on a person DNA, these tests have shown that pesticides cause intracellular genetic damage which is called genotoxicity (Yadav & Sehwat, 2011). The sense that blue-print of what makes the human body is now corrupted is a chaotic and overwhelming feeling. There are a number of studies that show positive associations between pesticides exposure and chromosome aberrations, and these aberrations are a predictor of increased cancer rates (Sanborn et al, 2007). Within the corruption of the DNA in the body you see the construction of family narratives as genetic disease guide expectations of anticipated losses for future family members (Werner-Lin & Gardner, 2009).

M: I think, it's just another, another thing that were holding on to, that you know, I, I, I um I live in hope, you know that there's something positive that we can try and do, ahh not much bloody good to us, I'm much too damn stuffed, *** said about all, all the buried

Just as pesticides have different effects based on individual biological differences, there are differences between males and female's based on their biology (Quackenbush et al, 2006) which causes specific effects unique for women, but few studies have ever focused on female health and pesticides (Flocks et al, 2011). For example some pesticides can disrupt endocrine function and mimic hormones such as estrogen (Sharara et al, 1998) either blocking off or triggering estrogen activity within the body and this may be a factor in hormone related cancers such as breast and ovarian (Garcia, 2003) A study of female farmworkers consistently believed pesticides could adversely affect pregnancy but did not receive any information on those risks (Flock et al, 2011). Pesticides are also known to be stored within the fat cells within body. Women carry significantly more adipose tissue than men and therefore the potential for women to get ill from pesticides being released into their body again, if they lose weight, is far higher for women because of these biological differences (Quackenbush et al, 2006). Women experience pesticide poisoning in their body differently than men, and therefore it can interact differently with each genders identity.

A: it just seemed really abnormal the way that I previously been quite slim, and then suddenly you know boom I was overweight with these hugh breasts, I felt so uncomfortable in my body you know I felt, and I was falling I kept I was trying to study psychology at University as well as work and I was falling asleep all the time and I don't know if that was a continued symptom of the spray poisoning or um I was just over doing it, but I it was just all too much, for me because um as far as I saw I I was I must have been eating too much that's why, I must have been overweight, because I was always trying to fast and go on diets you know I'd go on a 3 week fast and do everything I could, to um but nothing really worked you know, um I had no idea about, hormonal pesticides or anything back then (laughs)

In contrast research suggests male health is influenced by a conventional masculinity that is often threatened by both the experience (Seale & Charteris-Black, 2008), males are less likely to recognise illness symptoms and to seek medical help. They are also more likely to take greater risks with their health and on average die earlier than their female counterparts (Lyons & Chamberlain, 2006). Some suggest even that the health system is geared towards females and that a male friendly model would improve health outcomes for men (Gough, 200[^]). Interviewing most of the men of this study you very much felt that there industry was a "man world". Since the industries where exposure to pesticides occurred were mainly male dominated at the time, then the male gendered stereotypes that encourage men to "be a man" and discouraged them for reaching out for help with their health, likely affected how long it took to discover pesticide poisoning as an illness. The male gendered stereotypes of health is probably the reason why it took a woman to be the first person to be accepted for pesticide poisoning in their workplace in this country, despite the fact that there had clearly been thousands of men in this country who had previously been poisoned by pesticides in their occupation. Woman and feminism has also been very vocal in advocating for female dominated health issues and as a consequence they have gained recognition and attention to their causes (Gough, 2006). Maybe one of the reasons that there has been such little momentum and interest in pesticide poisoning is because it is a male dominated illness which has way less advocacy.

In this study very serious and life changing illnesses that Brown (2007) call's *environmentally induced diseases* were reported by participants. Exposure to pesticides in your occupation is associated with in middle age circulatory diseases, stroke's, any cancers and lung and cholinesterase-inhibiting pesticides is associated with reduced lung function, Chronic Obstructive Pulmonary Disease and a rise in respiratory symptoms (Chakraborty et al, 2009). This leads to the next layer of chaos identified in the narratives from this study which is the *uncertainty from having of getting an environmentally induced disease*.

B: and anyway I never thought about all this poisoning stuff, and then I woke up one morning, on a Sunday morning and, felt good, went out and, had a shower and a shave, came back and, well I went in my bedroom and I always made my bed first, being on my own, and then I came out to make my breakfast, it was straight after my breakfast I went for a walk right down, they had the meds, yeah I um made a big plate of toast and tomatoes which I had growing outside, I cut them all up and put them in the oven, heated it up and then the damn tea towel slipped of the bench, and I bent down to pick it up, hello I can't pick it up, oh I can't ohh, shocking I nearly passed out and I looked at my hand ahh god what have I got here, I'd only heard about one other chap who had had a stroke I never took much notice of it, I thought I would never ever get it and I certainly had it, I went out and yelled out to my friend, I said, what's that, oh god, this stroke, since I've had the stroke I can't remember different things it just goes and I in a couple of minutes

A number of the narrators in this study had family and friends that had died from *environmentally induced diseases* that they attributed to pesticide exposure. Exposure to pesticides in your occupation is associated in middle age, with an early mortality from all causes (Charles et a, 2010)

P: um I said to my son, I said let dad go, let him go peacefully, he said but he is still breathing and I said he is not, he's got that down there and that's what's keeping him alive, I said Dad didn't want to suffer to the bitter end but we've let him suffer, I said since he has been here, he left Whakatane he had that, trying to suck everything out, he couldn't breathe, what he used to do he kept squeezing my hand, and I knew he wanted us to let him go, so anyway, I said to them let him go, turn it off...um it was hard for them and hard for me but I felt it better that he went peacefully (crying)"

The link between pesticide exposure and cancer clusters was first noticed long ago by people who had been exposed to pesticides in their environment. It is now well accepted in science that being exposed to environmental pollutants such as pesticides does increase your chances of developing cancer (George & Shukla, 2011).

C: oh well he wrote a letter bloody scab ah, as the result that came back there is nothing wrong with your hearing, but you've got a great bloody tumour on your pituitary gland, yeah it was about the size of my thumb that one (laughing)

The link between cancer and pesticide's has received a significant amount of attention from environmental health research (Brown, 2007). Thus far epidemiological studies have shown that non-Hodgkin's lymphoma, leukaemia; brain, prostate and kidney cancers have the strongest links to pesticide exposure, but cancer of other organs are implicated as well (Bassil et al, 2007; George & Shukla, 2001).

Z: yeah and he passed away just over 2 years ago with cancer of the kidneys and apparently um the specialist in Tauranga said um that's apparently um where a lot of people get it cancer with ingesting all those, um toxins and he did have another patient there he was treating who had agent orange and my husband was in a worse state than him, um yeah so my husband basically was diagnosed with having cancer and then um only given 2 months to live"

Explaining the link between pesticides and cancer conceptually, you need to visualise a chain and imagine that it takes 5 different links in that chain to cause cancer. Then pesticide poisoning causes one of those links (Basill et al, 2007) in that chain, that takes you that much more closer to developing a potentially fatal disease. If you take into account that you may already have a genetic influence that increases your likelihood of getting cancer such as breast cancer, then being poisoned by pesticides could be the factor that tips the scales towards the development of the disease. Research linking pesticides to cancer (Basill et al, 2007) suggests that the high incidence of cancer found in our society today may be a product of the Chemical Age. A Frank (1995) developed his types of narratives from his own and other's illness experience from cancer, and it is well documented the chaos that comes from both experiencing cancer and the fear of it returning.

As the participants struggle with the physical and psychological symptoms from pesticide poisoning, and their identity changes from the person that their family used to know, this ultimately leads to a negative impact on their relationships.

C: but in those early stages yeah my wife bore the brunt of, what so much just the silence, yeah not so much the anger, frustration perhaps but ahh, the anger, but there was never, never the violence you know some I can, I could control that, but I heard you know a lot stories from other guys, where they just went bomb (gestures with hands)

Within society there is an expectation (Parsons, 1951) and some say pressure on a person to get well again after a period of ill health and the restitution narrative is encouraged (Frank, 1995). For many of the narrators of this study their family didn't understand the nature of their family member's illness or how to respond to it and relationships ultimately began to disintegrate from the pressures of pesticide poisoning, increasing the chaotic nature of the illness.

L: before that time of not knowing why I was suffering from chronic pain um, ah well I had mood swings, you know dark mood swings, things that would come out of nowhere, I would be angry at everything and anything, and ah our relationship with my wife broke down, not once but twice, in our marriage we've been married 37 years now, with about 5 years of

P: during the year 2007, sorry I've got to go back to that, I don't think he realised how sick he was, I didn't know how sick he was either, cause he had these----mood swings, start swearing, sweaty, arguing all the time, se we found out it was iron, we thought it was. I have to look after myself and we had 2 mokos that we brought up they were involved in everything, they were----koro, so you only can take so much, and we had to separate because of our mokos. He was at that stage he was getting all growly, and yet his koro, loved him (crying) so we separated, went our different ways. We were still friends, still husband and wife, and he got so sick

As the struggle with the symptoms of pesticide poisoning continued some of the narrators turned to drinking to cope. Considering that pesticides increase anxiety and that alcohol has an anxiety reducing effect could be why some narrator's reached for the only "medications" they had available, but pesticides can increase the intoxicating effects of alcohol (Davies et al, 2000) and toxic psychosis has been misdiagnosed as alcohol intoxication (Savage, 1994).

R: sounds like your saying that the drinking was a way of coping

C: it was

R: yeah

C: it was, well, we didn't realise it, we just, just part of that, part of that scene eh, but then after, or when the toxins caught up with us

L: yeah

C: we started to have a damn good look at the rest, you just had to look at what was going on, um geez look at that, was this the reason why

A sudden inability to tolerate alcohol is an indicator of toxins in the person's environment (Horrigan, 2006). Severe hangovers and quasi-allergic effects are associated with pesticide poisoning (Davies et al, 2000). Some people got drunk and worked through their aggression, while others took through their aggression into their favourite sport.

L: mmm, it was exactly what happened, in my case, yeah, um I took it, you know I wasn't very much of a drinker back in those days, but um so I would just take my frustrations out on the rugby field, yeah, you know they used to call me a dirty player, I think it was more heart eh Tim

R: you must have had a lethal rugby team

G: well they sure did

Group: (laughs)

The struggle to get the support or understanding from their family, medical profession and government was a common theme amongst participants.

S: but um it makes it very difficult for the exposed person to um, and to ah, to live or function because there's no support out there what so ever at all, there is no understanding, you know if you get cancer or something everybody rallies around you, everybody know what's the risks are, there's all sorts of information that you can go out there and educate yourself over, with chemical poisoning, your basically alienated, your basically pushed out to the fringes of society and um and family and friends don't know how to deal with it, the medical profession doesn't like believing it, um and so it, it does, it makes you um quite isolated (nods)

The social representation of pesticide poisoning at this time was largely that it didn't exist or wasn't that bad, which denied or minimised the experience of illness. The participants struggled to legitimately take a sick role in society (Parsons, 1951) and the inability to do this created greater chaos and further impacted on their identity. The lack of social support only compounded the difficulties and suffering that the participants were facing.

R: How do you feel about that, that it's hard to prove

A: um I feel quite frustrated, um it's because I went to you know, I went to a lawyer um shortly after I found out that the council were, too, when I found out the council sprays were making me sick I went to a lawyer and and yet I knew that and that was when I started going from one person to the other to find out who can prove it so I could have something in writing, and there wasn't anyone, you know just like the Doctors at the medical hearing EAV isn't um a recognised diagnosis and or, I should have asked them what is, you know how do you diagnose someone who has pesticide poisoning, um, I still don't know, if there is anything, um, and so it seems like, its set up, um you know its still the same frustration, and having people, you know when you speak about it, it's this, you never know if someone's going to think you're a bit nuts or something, um, or just not really have much of a clue what your talking about, you know I prefer not to speak about it

This is typical of the “emotional battering” that has been described in other illness narratives (Frank, 1995), but which I think is further exacerbated in pesticide poisoning experiences because the illness is almost completely rejected by society and this makes people desperate and pushes them further into isolation. The lack of information and knowledge about pesticide poisoning in society increased the uncertainty after being poisoned by pesticides

C: yeah a lot of if's pops up, yeah what if's, yeah you start questioning yourself, you start questioning the company, you start questioning everything that happens yeah, and ah now and then you come up with an answer but when your dealing with something like this, as insidious as this, that creeps up on you, where did it start, where's it gonna finish you know, well it finished up in your bodies, might be past on genetically, will it be past on and all our kids inherit it, some factor within their genetics that stuffed up, you know, will it come back we won't know till 30 to 40 years down the track

The struggled with the knowledge that their employers knew that the pesticides were causing them harm was a theme for many of the participants.

*P: ***, um I think it was 1987, when he um got redundant and at that time that's probably, probably um the company they were working for, forgotten the name *****they already knew what was happening to get our guys redundant cause you know it was good money good money at that time when he did get paid redundant all his sickness's happened with him*

That there, employers refused to be accountable and take responsibility for their exposure to pesticides was also an ongoing theme in the narratives of this study.

E: but low and behold we thought we were on to something good there but what happened was, what was needed was all our work records and health records from the mill, over here, so they came over here to look for it, and somehow, they conveniently, they conveniently disappeared, so we, we became exempted from the, from the research eh

As the physical, psychological and relational changes from the illness began to have greater impact, the identity that the participants had built previously was systematically deconstructed by the illness experience, intensifying the chaotic nature of the illness experience within their body. This experience of having to renegotiated your identity as part of an illness experience is well documented in other illness narratives (Murray, 2004)

L: “my whole whole life has been living with chemicals um I spent 10 years in the sawmill industry, um fiercely competitive rugby player, wanted to be an All Black, um I spent 12 years , was in 10 years , about 10 years in the mill and then moved across to the other side the pulp pulp paper side where I worked with the raw materials gang were we unloaded um chemicals, every chemical comes through the mill and we would unload it off containers, and out of railway wagons, um then after that, I took took the redundancy and moved down too Otaiki down south, um Wellington way and then um, I worked in the in the abattoir for about 10 years and um I was still playing rugby at that time and I ended up um Captain of the Horowhenua 3rd Division team, and ah one of the most proudest moments in my life we won, ah the 3rd division and right to go to 2nd division, um I just happened to um captain that team with Carlos Spencer and Christian Cullen a proud moment in my life and round about 1998, I was diagnosed with this ah bone disease

Many participants had developed a strong sense of identity based on their connectedness to their job and workplace. The awareness of their exposure to pesticides and the impact on their health challenged how the participant's perceived themselves, as something they had previously valued and taken pride in became contaminated.

M: I've always been a hard worker, you know I worked my way from the labourer through too the civil department with all the labourers, nah, floor carpenters ah what we call handy men you know they would be able to pick up anything and do anything on the building site, and then all the cleaners in the mill and it's a big job you know, okay I love my work

For a number of narrators they were the second generation to be exposed to pesticides. Within the individual narratives of pesticide poisoning you can see the further development of a family narrative of illness, based on the exposure to pesticides.

N: but it yeah, um you know I've got elderly parents that have been farming with things like that and they've dealt with different chemicals and all that, and some of the things I see coming through now in them as well

A number of narrators described struggling to find a safe environment after they were poisoned so that they weren't exposed to pesticides again. Exposure to pesticides can increase the risk of getting Post-Traumatic Stress Disorder (Brown, 2002) and psychological symptoms can develop around the fear of being poisoned again (Mearns et al, 1994; Sadock & Sadock, 2007). The combination of PTSD and the psychological symptoms from pesticide poisoning may put a person at high risk of suicide and aggressive behaviour (Davies et al, 2000; Karalliedde, 1999).

A: "but but I didn't know how long term that, I thought we would find somewhere safe to live or I thought the council would stop spraying, you know we could live somewhere away from orchards and aerial spraying, you know if I knew how hard it was I, I don't know honestly what I would have done anyway, it's like that there was never any good options"

Following a period of struggle all narrators came to a period of *integration* where they show some level of adaption to their illness experience. As people adapt and adjust, their experience of their illness changes (Frank, 1995). This is the period when the *restitution* narrative is most evident for 2 of the participants from the study as they experienced a slow sense of recovery from illness.

N: the length of time it took to get it slowly out of my system as well, which for my bloods to return to normal it took over 6 months, that was just it get it back to its baseline, and then probably 12 months after that before I didn't notice anything so, so much, but yeah um, what I'm scared of is now is what's coming further down the track you know you read all the research and things like that on it, it's sort of something that's sort of constantly in the back of your mind, you know what's this going to cause, you know what's it gonna sort of morph in to but I've already had one brush with cancer already

The participants with *restitution* aspect in their narratives also continued to work with pesticides and their pesticide poisoning experience was perceived as a temporary rupture, that became integrated into their identity as part of learning their trade before they found continuity with their lives again.

R: What would have made a difference?

N: Not doing it to start with (laughs), there's the answer, I don't know I suppose I was so young too, I was just in, in a trade, I took it all as part of the experience, part of learning, part of getting my ticket, yeah

As stated at the beginning of this chapter the *quest* story tended to dominate amongst participants and it is at this stage that it starts to emerge. Here the *quest* story is enacted by the participant's as they make significant vocational and personal changes, in direct response to the chaos from the pesticide poisoning experience.

C: you know the other thing is too you know ahh you have to laugh at some of this stuff that goes on here or else your gonna knock your head against the wall that's not gonna do you much bloody good is it, I say laugh at it, bugger it just get on with it and that's what I say, that's what I say to my Doctors as well

The term “integration” is often used to describe change in trauma focused therapy (Hijazi, 2012). It recognises a stage towards recovery where a person is able to acknowledge and process, and then finally accept the chaotic experience that they’re body has been through. The person is able to reduce the disconnected and disembodied state that the trauma has induced and develop a stronger sense of identity within their post trauma body. In studies of people living with HIV/AIDS, the illness threatens their sense of identity and people often experience transformations in values, spirituality and life priorities in response to these threats (Ezzy, 2000) and this is true for the narratives of this study. Within many trauma narratives you can see what Frank (1995) calls the *automythology quest* where the severe trauma has devastated a person’s identity and has challenged them to reconstruct an entire new sense of identity, to put the chaos of their traumatic experience in the background. For example people reconceptualise themselves as survivors not as victims and this effects the way they perceive themselves and others, reorganising there identity (Courtoise, 2008) The *automythology* quest is also typical of serious illness and was dominant in the narratives of this study making the process of *integration* in trauma narratives relevant to the narratives of this study. Frank (1995) suggests that people tell illness stories to work through their own identity and to guide others who follow them. Others suggest that this re-organisation of identity is essential for whether one stays in constant *chaos* or whether they move into a sense of *quest* (Murray, 2004). The term *integration* has similarities to what other researchers have referred to as *biographical work* to develop a new sense of identity (Murray, 2004). Conceptually *integration* takes you deeper into the embodied experience and draws you into the particular aspects of the experience that the participants needed to change in order to put the chaos in the distance and build a new sense of identity. In this study all of the participants showed a degree of integration and reconstruction of identity from their illness experience, and this increased their ability to manage, cope and get support for their illness symptoms and move forward from their illness experience, despite the ongoing chaos from living with a serious illness.

S: the negatives ah, well you know my health has been ruined, you know, it, it makes like tough, you know it puts some extra stress in day to day life, that you've gotta live with, that other people don't, and it's definitely difficult but as they say you know what doesn't kill you makes you stronger and so

The narrators that continued to experience long term illness symptoms described their experience as a permanent rupture that changed their life. As part of their reorganisation of identity that integrated the poisoning experience, all of these participants began to develop strategies to cope with the different aspects of their illness experience, and as the participants learnt to cope better with their illness symptoms they reconstructed a new sense of identity based on their poisoning experience.

C: there are days yeah, there are days when um, I find I've gotta push myself, I do and um, the um, well see a lot of us are on bloody dope and drugs and chemicals and , and I get pissed off with taking all that bloody junk, and ah, but that time

when I personally feel's flat, you know absolutely flat, and you talk about how you felt the, the absolute tiredness and ah, I have got to that extreme, but just, I just don't feel like doing anything, just want to sit down eh, just blob out, I don't feel like reading you know, half the bloody time I don't watch, watch TV, you know, you just, just want to sit, you know a couple of hours or something, and, and then the flesh starts to come back, yeah there are times there so you know, and I'm pretty sure I'm not the only one eh, that's like that and I think that's the ebb and flow that goes with you know the, the human body, you know we gotta go with it in waves eh

The various strategies that the participants developed enabled them to manage both the psychological and physical aspects of the illness.

R: What kind of tools did you learn?

L: um not to catastrophise, um, well I was just crazy, I mean simple things like my daughter might be travelling down from Hamilton and back here and I would be thinking she might of crashed, worrying about those sort of things, or worrying about a clean house, um I mean those sort of things you know, not even worth worrying about and there here was I, just getting uptight about dishes in the sink, um those sort of things, impacting on the whole family unit, yeah you know, so quite a crazy time, but I was fortunate once I got to identify the problem and got the tools to be able to deal with it"

Exercise has been linked to the management of chronic pain (Nijs et al, 2012) through the release of opiates into the body, it can also balance neurochemicals involved in mood, burn off the adrenalin produced from anxiety in the body and exercise muscles that have been wasted by serious trauma or illness and was a strategy employed by a number of the participants to manage the symptoms in their body from pesticide poisoning.

B: and I like to trying to keep fit and I do a lot of walking and all that sort of stuff

S: He does a lot of walking, I see him go past my place

R: Does that help

B: I've had a, I've had a stroke, so ah I was meant to be in a wheelchair, but I used to be, the Doctor at the hospital, he said I've ordered you an electric wheelchair, I said I don't want any wheelchair, I want to walk, oh well, well see about that, and after 10 weeks, I was, he was quite surprised, I walk now (unlegible)

R: everyday

B: I do it every day, about two or three times

R: wow

B: I've gotta have my walks

L: yeah

R: that's helps and you see him

L: yeah I see him, going back that many times

B: Otherwise I would be, I would end up in a wheelchair and not be able to walk. I'm still paralysed in my left leg and left arm, it's all paralysed, now I've got arthritis in my wrists, and that, that, that doesn't do much good, just have to use my walking stick

The strategies that the participants developed to cope better with their illness symptoms reduced the negative impact that they had been having on their relationships, reducing the level of chaos in their life.

R: mmm how, how did you move past your relationships being on the rocks from when you were quite sick, how did you um, how did you and your wife cope

F: well it was tough, and you know just had to walk away from it, I just walk away when an argument starts, yeah

At the same time family members started to develop a more accurate and supportive social representation of pesticide poisoning as being a “real” illness, that was having a real impact on their family member, and were able to start giving their support also reducing the experience of chaos in some of the participants lives. Research supports that even if you have a terminal illness you live longer and have less pain if you have good social support (Lyons & Chamberlain, 2006). Being able to get the understanding and support from their family was an important part of learning to cope with chronic illness as documented in many other illness narratives, and it restored a sense of family identity and connectedness to others.

R: How did you cope with 2 people who have been poisoned in a relationship together in the same household?

P: Well it was hard, actually because like I said, not knowing how he was suffering and I was suffering as well, um, I learnt years later, that we both had a problem and we didn't deal with it, um, how we dealt with it I suppose we dealt with it by arguing and swearing to one another, um but I did go to counselling in the end because he wouldn't come, I knew I needed to go somewhere, um, and I think through that it helped because it was just getting to bad, two sick people in a house just didn't work and your trying to look after the family, cope with them, cook, wash, look after the man, what about if you can't look after yourself, you know in the end that's how I thought, if I can't look after me how can I look after every body else in the house, so today I really care for myself, cause I've got a moko, moko's and they really get me going I want to see them go to school, our first moko starts, um 2 weeks time.

For many of the participants who experienced pesticide poisoning, they needed to find more support from both health professionals and other people who could understand their experience, this support reduced the level of chaos they were experiencing. A number of women in this study had sought professional help from counsellors but most of the men from this study found support groups to help move forward from the chaos of their experience and make personal change in their environment.

V: but ah, um the length of time that I've spent here has been enormous for me, it becomes ah, what I say it's, I was just about to show a few tears because ah, like the a, like the reason that we are here, it kind of helps, well I can see that it happens not, it happens with me, so I'm losing, losing a bit of memory, that's all

It was clear that the men in the support group were able to take greater emotional risks with one another and show their vulnerability because of each other's support. They were able to be empathic witness to the *chaos* in each other's suffering, which Frank(1995) challenges is hard for anyone to do.

M: the anger, it has to have a point where it comes out yeah, and talking to, talking to these guys, round the table as we do, that, that quiets it down

Traditional helping therapies have been focused towards women (Lee & Owens,2002) perhaps a group where there are other men who have gone through the illness experience is more helpful, healing and nonthreatening to men who experience serious illness. Within the support group you could also easily hear the meta- narrative of pesticide poisoning that

had evolved within the group over the many decades that the group had been formed. Here the illness is taken into the political and social realm forming a collective identity (Whitehead, 2006). In this study what a meta-narrative feels like, is when the people you interview repeat nearly word for word the same perception of their experience. For example, distinctive to this group was the concern with the medications that they were being prescribed by their Doctors and how they were interacting with the pesticides they knew they still had in their body. Many of the group expressed the same identical concerns or they felt they needed to explained why they did take their medications, making it part of their narrative as well.

T: They keep telling us it's this that and other thing , and you be you and he is the doctor so you got to go by what what he has recommended and you and let you know its not going to fix it, cause it didn't, so ahh, so ahh we've been ah taking pills just for the sake of taking pills and all that, cause a lot of us we used that like they said guinea pig before in there, well you know we're we try one pill that didn't work so they gave you another one, that didn't work and give you another one, that didn't work they gave you another one, until you, you start to wonder what are they doing to you, so you know you stop taking them and the next, my next visit to the doctors I say I'm not taking any of those and he said why not, and I said it's not making me any better, so what, so what's the use of taking them

The meta-narrative from the support group was similar to other narratives in this study and that is why I argue that *restitution* is not a strong type in narratives of pesticide poisoning, because this requires a sense of belief in the medical system that was lacking in the narratives and the meta-narrative of this study.

The meta-narrative effect comes from both the group members sharing the same experiences and from regular discussions within the group about the effects of the experience. This is probably expected for a support and advocacy group that had been running for 30 years and where members have known each other for a long period of time prior to that in their workplace. The meta-narrative for the support group was distinctively a *automythology quest* narrative. For environmental and occupational diseases to be believed and accepted it often requires a social movement by communities who have been impacted by toxins (Brown, 2007) and you can see the social and political aspects within the meta-narrative of this study.

For other participants who were more isolated learning to cope was about having good knowledge and awareness of the impact of the pesticides on themselves and the development of a new coherent sense of identity as well, again similar to the *automythology quest narrative*. In a study on cancer patients, identity work is used to describe the process of evaluations of the meaning of their illness, within the actual context of ongoing, organised social relationships, including the medical system (Mathieson, 1995), and identity work was typical of the integration and empowerment stage.

S: well, part of, part of dealing with the chemical poisoning the psychological side of it, without going, it's coming up a real strong sense of self identity, a strong understanding of who and what you are and what makes you tick so that you can isolate out, what, what are chemical factor's, if you say to yourself I'm not really as upset as what my body feels, you rationalise those things out, work it out, and um I've found that a good way of dealing with it

This indicates the importance of self-awareness in reconstructing a sense of identity especially when you have less ability to share your story with others. The need to develop a new sense of identity after experiencing illness is documented in other illness narratives of women experiencing breast cancer (Murray 2004) and it is the reconstruction of identity that I argue reduces the level of *chaos* that is experienced from pesticide poisoning.

Alternative treatments were popular amongst narrators indicating the importance of holistic care in dealing with chronic health issues (Barnes et al, 2008) and perhaps reflecting that these professions at least offered some form of treatment which the medical profession did not.

L: you can't smoke cigarettes, you know you can't, you know maybe in the future we may be able to get alternative treatments with ahh um acupuncture, rongoarongoa, you know mirimiri all those sorts of alternative treatments, to be able to ahh help our grandchildren, our great grandchildren but it, it's about, it's about ah, an option, ah alternative to western medicine

Drawing from your cultural identity helped many cope as they looked for hope despite the ongoing chaos from illness all around them. Cultural identity and spiritual supports (Baldacchino, 2001) can become a strong anchor when coping with serious illness. Many of the Maori narrators in particular described finding hope and purpose in focusing on supporting the next generation with pesticide poisoning.

*L: the focus has always been for, me and probably *** and SWAP, is a it's about the next generation and so we, if we awhi the family in there grieving process um, we care for them at that time, the whole family unit, I mean, and that what its about, it's about whanau, iwi, you know it's about that, it's about ah, um, we talked about it before, its about legacy that we leave, um and it's got to be a caring legacy to be able to identify um children, great, great grandchildren and there could be, you know, affected by our chemical exposure"*

Empowerment is a stage in a pesticide poisoning narrative where participants use their experience to change the environment they lived in.

E: and I think for me and that point there I took it upon myself, to be the one to stay close to all these people as they were doing their work, you see even we went around testing all the sites I walked, I walked around with all the consultants, we, we brought in to do this, and I met a hell of a lot of them from there ahh, just, just at ahh, at the technology that, that, that was used today, to, to identify, to help identify all these sites, so with the 28 sites that we registered here there cutting through the chase, I could tell you where all these sites are, I can tell you the levels of um contaminations in all of them, and um, and so on and so forth ahh, I can even tell you what, what contaminations are that are in there now ahh,

At this stage of the experience the *quest* story is enacted as the participants advocate for other people who have experienced poisoning, for the environment that has been poisoned and for more effective standards and regulations with pesticide use in New Zealand.

*A: um but the more I, I you know I've been in several groups toxin action groups, um I'm in a group at the moment, cause they were trying to aerial spray *****wetlands, and you know when they aerial sprayed ***** , so I've been in touch with as many people as possible over the years so that I don't feel so isolated, and that I'm it's really important for me to talk to people that understand, and that suffered I've talked to lots of suffering people and um so you know so many people that don't like it, don't like what's happening you know, we've had 3 different petitions for ***** , ***** and now *****city there's another petition to stop the council spraying, um it seems to be more and more accepted, you know slowly, slowly, slowly I can actually say well this is what's happening in*

Others have noted how people who have been poisoned by the environment often go on to be researchers themselves and this were true of a number of the narrators in this study, including myself (Brown, 2007). For those who experienced this sense of *empowerment* it was evident that this was connected to the strong sense of identity that they had evolved from their illness experience where they found direction through the *chaos* of the ongoing illness experience. Conceptually, *integration* is connected to the re-establishing of identity and *empowerment* and is one step further where identity becomes based on and draws significantly upon the pesticide poisoning experience. This conceptually as a whole resonates to the *quest narrative* the most.

R: can I ask you what does it mean to you now having got the Queen Service Medal for your work with pesticides?

E: I can understand now why they said to me this is not about you, what, what this, what, what that recognition has done for SWAP, it's actually put them into um, um, I won't say the political arena, I suppose it's taken this whole issues to a international scale now if you like, and, and the more I look at it, that ah, the more I see that, I can understand it now ahh

Though as indicated previously even the participants who experienced a sense of *restitution* when on to experience a sense of *quest* and this may be a specific aspect relevant to the pesticide poisoning experience and maybe environmental illnesses in general. This awareness led many of the narrators of this study to initiate changes that made the environment safer for all New Zealanders.

K: I also wasn't happy with the fact that people were being poisoned on the planes every time a plane used to land in NZ people from MAF used to go in with a can spray to spray the planes and some people were getting headaches including me I came back and I got one hell of a headache getting this inhaling this spray and I said to the guy what is this stuff it was just a type of um what I thought was a pyrethroid it was a bit more than a pyrethroid it had the wrong sort of propellant it had all sorts of issues with it that were causing people headaches and respiratory issues and um I did a bit of study into it and they were telling me it was a world health organisation requirement to have these sprays on planes and I checked on this and it was all nonsense I went to the science protocol way back in 1994 were we agreed to stop doing this practice but we were continuing to do it in fact NZ was coming a dumping ground ahh the plane fumigation people were flying in here and they were getting sprayed so I got a lot of publicity you know I eventually got the whole practice stopped

The narrators built a strong identity based on a sense of *quest* from their pesticide poisoning experience, not because anyone told them too, or because society imposed these beliefs upon them.

*E: but anyway, with all those, with all that, um as I'm sitting here now it's been part and parcel of the education like on this, on this, on this journey, um again just to cut through the chase, this has probably been the most incredible journey that, that, that um, um that's ever happened to me, something positive ahh, its' not about *** you know, it's about a whole lot of people*

The narrator's of this study re-constructed there sense of identity because it was essential to surviving the actual biological symptoms experienced within their body caused from pesticide poisoning. Survivors of pesticide poisoning are often fierce fighters because the illness demands this of them. To stay deep in the emotional chaos from pesticide poisoning is extremely risky to your health which only serves to deepen your suffering and keep you separate from society. Of course, part of living with the chronic effects of pesticide poisoning is to be constantly re-visiting the *chaotic* aspect of this illness, but finding ways to

push back the waves of chaos and find some meaning in your day to day suffering, is the true embodied intent of the *quest narrative*.

Chapter 5: Illness Narratives and Whare Tapa Wha

In the narratives of this study it came through strongly how identity effect's a person's experience of illness, which is consistent with other studies that suggest that when people experience a biographical disruption from illness they reconstruct their sense of identity through the telling of illness stories (Reissman, 1993).

Z: um my husband was actually quite artistic, and wanted to do um, do other things in his life, but I always felt there was something holding him back, to reach his full potential and one day in the meeting here I discussed that, that I felt that and everyone kind of nodded their heads, they hadn't reached their full potential in life because there's a lot of pain they had to deal with, a lot of frustration, a lot of mood swings all of those sort of things were put in their way, and so they weren't able to reach their full potential in their lives

It is important in narrative enquiry to attend to the forms and functions of narratives (Atkinson, 2009) and how a story is constructed (Trahar, 2009). When you look at the narratives as a whole you can see that they are formed around a physical description of their exposure to pesticides; the struggle with the physical and psychological symptoms of their illness; the impact of the illness symptoms on their relationships with family and friends, as well as the necessity to relate to medical professionals and government departments about their illness; and how all these challenges affected their sense of personal and cultural identity and their need for spiritual support.

Z: um having the support here as well, mmm, yeah, yeah, so mmm and I know um when I first came here I was probably quite angry, and I just wanted to get everything out there I stood up and spoke to everyone about my husband's story you know, and I had one of the gentlemen there had tears in his eyes nodding his head he understood everything I was saying, you know I said this is my husband's story and my story as well

I have argued in Chapter 2 that identity could conceptually be considered as the *wairua* aspect in the Whare Tapa Wha model. How the narratives of this study are put together and made whole fits nicely into the construct of the Whare Tapa Wha (WTW) conceptual model of health. For example each narrative did have a *tinana* or a physical aspect, a *hinengaroa* or a psychological aspect, a *whanau* or a relationship aspect and a *wairua* or an identity/spiritual aspect and that the interconnections between all these domains captured the entirety of the illness narratives of this study.

You could argue that the WTW model is more meaningful to this study because it represents a Maori perspective on health and because half of the participants were Maori, but all of the participants consistently described both the challenges they experienced from their illness, and any integration and adaption that increased their ability to manage and cope with their illness, within the WTW four domains of health.

This suggests that the relevance of the WTW model of health goes beyond just Maori perspectives on health and there are a number of reasons to support this. First of all, the WTW model emphasises the importance of cultural identity to the health experience (Durie,

1994) and this cultural identity is distinctly Maori, but these views are consistent with current views within critical health psychology that argues that culture is highly relevant to health (Lyons & Chamberlain, 2006), and so inclusion of cultural identity is appropriate for all people.

E: because again and I think I knew it then but I didn't, didn't know as I, as I, as how much I knew it now, ah I know it now and to me there isn't an issue bigger than this, in the world really, cause there's nothing, when we talk about the health of the environment or the health of Papatuanuku, Ranginui and Papatuanuku, straight away humans are affected, and again it goes back to, to what you hear Maoridom say all over the place that, I am the land, the land is me, I am the river, the river is me, I am the mountain, the mountain is me, those, those sorts of things ehh and I could see, I felt really, rather than see, that, goodness, that's what this thing is all about eh, I mean to say there's no use us, just concentrating on the health issues, to us as humans, and leaving the land as it is, so in order for us, to get well, from a health perspective, we also had to heal Papatuanuku and to me it's about healing, healing her first

The uniqueness of the WTW model of health was it gave a comprehensive description of health that actually came from the people who were experiencing it. Maori were facing poor health outcomes (Rochford, 2004) there was significant disparity between Maori and non-Maori (Robson, 2008) and the current health system in New Zealand were not meeting Maori needs for health (Durie, 2001). The development of the WTW concept by the Maori people challenged the dominant biomedical narrative of the time that focused on the disembodied body and not on the whole of a person's health, challenging essentially the medical colonisation of health (Frank, 1995). The model is often described as a traditional Maori approach but it is actually a perception of health based on contemporary Maori thinking of the time (Durie, 1994). The WTW model is a holistic unified model of health, and it has been successful in helping Maori, where other health models have not. (Rochford, 2004)

Illness narratives are thought to capture the embodied nature of illness (Frank, 1995) and I argue that this is why WTW is relevant to all of the narratives of this study, because it essentially captures the structure of the embodied experience of pesticide poisoning. When you look at my own personal narrative of pesticide poisoning in Chapter 2 it also fits into the WTW concept. This model resonated with me because it captured the embodied sense of what I was experiencing and that was why it was meaningful to me. Developing the WTW model to a theory of embodiment takes the concept beyond being just a meaningful to Maori but to being a concept that is meaningful to all health experiences as a whole

There are a number of reasons to support that the WTW model forms the basis for an embodiment theory. The model includes sensations, emotions, thoughts, physiology and biology which are considered to be embodied knowledge (Moss & Teghtsoonian, 2008). It doesn't reduce the body to a thing that is just described (Frank, 1995). Instead it captures the ideas of 'gestalt' perceiving health as a conceptual whole and it is holistic because it takes into account the physical, psychological and social dimensions of health (Bullington, 2009). It captures Merleau-Ponty's ideas of embodiment showing how mind, body and the world are intertwined together (Bullington, 2009) and it connects to Frank's (1995) ideas of embodiment of showing how loss of control, body-relatedness, other-relatedness and changes in desire all fit within the 4 domains of WTW. It has the elements of an

interactive theory of emotion, that connects to the mind, body and society, and shows how the embodied self is meshed with social life (Bendelow, 2009). The WTW model could be perceived as a development the biopsychosocial concept (Suls & Rothman, 2004). For example it is a multisystem approach to health, that specifies links between the different subsystems of the biological, social and psychological and how they connect to a self-identity that conceptually contains the macro variables of culture, socioeconomic status, and ethnicity, showing how they interconnect into a whole, where each have an equal pull on the state of a person's health.

*L: the focus has always been for, me and probably *** and SWAP, is a it's about the next generation and so we, if we awhi the family in there grieving process um, we care for them at that time, the whole family unit, I mean, and that what its about, it's about whanau, iwi, you know it's about that, it's about ah, um, we talked about it before, its about legacy that we leave, um and it's got to be a caring legacy to be able to identify um children, great, great grandchildren and there could be, you know, affected by our chemical exposure"*

It is the metaphor of a house that creates this concept of a whole, taking the abstract idea of health and connecting it with the most basic meaning of embodiment (MacLachlan, 2004). The WTW model then goes further breaking down the structure of health into four interconnecting and interdependent part's that together capture the embodied experience of health. WTW model recognises that there are threads that pull the aspect of a health experience into a meaningful whole.

When you look at other cultures embodied accounts of health, the WTW model conceptually allows inclusion of all of these experiences of health. For example the Chinese accentuate that health is a need for balance and connection to nature; the American Indians perceive health as a balance between the mind, body and spirit, the Circassians in Israel see health as connected to physical wholeness and social participation; and Aboriginies see health as about social connectedness (Lyons & Chamberlain, 2008). The WTW model can actually account for cultural differences in the experience of health. Within our wairua or spirit/identity it is our cultural inheritance and spiritual identity that defines our beliefs as to what is important to our experience of health.

P: the man above me, is always guiding me, so to ask for help and he is always there to give me that strength and if it wasn't for the Lord, I think I wouldn't be here today and all the sicknesses I've had myself, knowing my body, he's given it to me and I love him so much I can't do without him whatever I want I ask him that, we go and its done, it's just believing in him, that really makes me so happy

I argue that within wairua or identity are the individual and collective epistemological beliefs about the "right" ways to cognitively grasp reality (Zagzebski, 2009) and this is connected to what a person thinks they should feel, see and do. A universal theory of embodiment has to be able to account for both, spiritual or religious beliefs and for people who have no such beliefs. I have argued in Chapter 2 that we all have spiritual beliefs and other research supports this (Baldacchino, 2001) this includes what we believe exists around us while we live, and the belief of what happens to us and others when we die. These views may seem diametrically opposed to one another and within the modernist views based on realist

assumptions, these two opposing views of reality could never be conceptualised as a whole. In contrast, within the post-modern perspective both beliefs can co-exist within multiple views and can co-exist in the same space.

To re-conceptualise the word spirit as a lay knowledge term for self-identity, brings identity back into the body and since in the WTW concept all health starts from your wairua within this model, there also lies an embodied theory of identity formation. Within the metaphor of *whare* or a house, you can actually see the suffering from the impact of illness and trauma on health, and you can see in action the *restitution*, *chaos* and *quest* narrative types and their specific effect's upon identity. For example within the *restitution* type narrative, you can imagine cracks appearing in the house, and causing the structure to weaken and break down, and the impact from the weather starting to creep in. Fortunately help is available and arrives in a timely manner, scaffolding is put up around the house to support the structure, and then the house is fixed, so that the no signs of damage are now visible from the outside. No identity reconstruction is necessary in the *restitution* type narrative because the house and therefore identity never truly collapse. Within the *chaos* type narrative the house is disintegrating and it could collapse at any time, but there is no help available to fix the level of damage that has already occurred to the house. The weather bombards the house and destroys it further. The identity systematically deconstructs.

S: the negatives ah, well you know my health has been ruined, you know, it, it makes like tough, you know it puts some extra stress in day to day life, that you've gotta live with, that other people don't, and it's definitely difficult but as they say you know what doesn't kill you makes you stronger and so

The *quest* type narrative recognises that all is lost and further hope is futile for the disintegrating house from the *chaos* type narrative. A choice is made and what is left of the original chaotic structure of the house is smashed down. In its place a new foundation is laid and a new stronger structure is built, able to withstand the elements of natures that it now faces. The person reconstructs a new form of identity.

A challenge with theories of embodiment is that they are not easily conceptually transferred into practical applications within the health field (MacLachlan, 2004). Taking the biopsychosocial model from a concept of basic science to real applied applications has also been a challenge for Health Psychology (Suls, 2004). In contrast the WTW model has been influencing the New Zealand health system since its conception in the 1980's and has had significant impact since the 1990's (Durie, 1994) showing the real applied applications of the WTW model. It also indicates important applied possibilities for the adaption of the WTW model as an embodied theory of health, as an embodied theory of identity and as an adaption of the biopsychosocial model to include identity.

When you look at applied applications, conceptually all of the 400 psychotherapies that have been developed to treat mental health issues fit within the WTW concept and all of the disciplines of Science that each on some level contribute to the understanding of health, conceptually fit under all the aspects of the WTW model adaption. The adaption of the

WYW model can explain how Psychology influences health and why all psychotherapies are equally successful, is because they each target aspects of the WTW dimensions of health that then in turn influence the other domains of health. The WTW embodiment model also explains why therapy is sometimes not successful. Not many therapies directly target and try to change the wairua/ spiritual identity and within psychology the mental health issues considered the most resistant to change are the personality disorders, and depressive disorders such as dysthymia, or complex PTSD and attachment disorder where depression, trauma and rejection has become weave into aspects of the persons personality.

I have argued that the WTW model captures both the structure and the embodied nature of illness and identity construction within the narratives of this study and therefore this makes it ideal to give structure and create depth to the description of embodied experience of the research process from the researcher's perspective.

When considering the embodied nature of the research process I considered in what ways did I attempt to establish a physical, psychological, relational and spiritual/identity connection with the research participants and in what ways did I experience a physical, psychological, relational and spiritual/identity reaction to the participant's narratives.

V: but. yeah I just can't believe in myself, I can't believe that this is what's happened to me you now sitting with somebody who is a complete stranger , who is not now

R: it brings up a lot of emotions

V: yes

To show the participants who I were when I met with the SWAP group I prepared a mihi or greeting in te reo Maori, this conveyed my respect but also told who I am, and as a Pakeha researcher I learnt that you can never underestimate the power of a good mihi when working with Maori.

C: that's what I believe it's achievable, and you've come on board now, it's such an insidious bloody thing ahh, it just sneaks up on you, like it did with you it just sneaks up there its waiting for you and it (squeezing hands), but apart from that, I you know I can't elaborate too much on, what you gone through and what we've gone through

At the beginning of the research I had disclosed that I had experienced pesticide poisoning, and before the interviews I discussed this with participants because they were interested and needed to know about my experience and for some affected whether they would be interviewed at all. A researchers personal experience can create an engaged, embodied connection to the narratives of the participants (Holstein & Gubrium, 2012) and this connection is considered necessary to enter sufficiently into the dialogue with participants stories (Holstein & Gubrium, 2012). This disclosure of my person experience built trust, rapport and emotional connection between the researcher and the participants and showed vulnerability and a willingness to engage sensitively with their word view. The participants self-presentations are influenced by the perceptions of the researcher and what the researcher thinks of them (Sikes, 2000) and this reciprocity established closeness.

V: I don't know they might have missed it out here, but it did come up on me, yeah my feelings, feelings for the others yeah and of course my thoughts on what's, what's been happening, what I said things like that, and, sookie (laughs), yeah ah and today has been the first time that's happened to me. I just, just whats, ah, it's the first time I've actually ever shed tears here and it's because the feeling of others, in there, as well as myself included and ah my thoughts and feelings for the other 2 guys

There was a number of ways that I established a physical connection with the participants of the study. I was most importantly, emotionally present in my body at all times. I shared lunch with a number of the participants which built rapport and connection and drew me deeper into their experiences. I toured the town where many participants had lived which connected me to the heritage of the community gave me greater awareness and empathy for the experiences I was researching. There were also some participants who hugged me at the end of the interview showing to me how meaningful the interview had meant to them and how strong a connection of trust and respect had been formed.

I connected to the participants through *hinengaroa* or the psychological aspect by emotionally and cognitively communicating to the participants through my body. During the interviews I relied on the Person/Client Centred strategies by Carl Rogers (Geldard & Geldard, 2001) to facilitate a good narrative interview. This approach is thought to influence both the depth of the illness narrative and the level of co-operation from a patient in a consultation with Doctor also. Within the interviews there was a sense of letting go of control and just go with the flow, like being caught up the tidal pull of the sea you wait to see where the tide take's you. There were some expectations by participants that you should take control of interviews but they all adjusted to the unstructured approach.

R: Well Betty how does it, how does it it felt talking to me about it

P: good, it's good and I'm happy, because, you understand anyway, yeah, it's talking to someone that understands, who, who did we have before, we had somebody, I don't think I could speak to her, like I'm speaking to you now

How you relate to a research participant and can ultimately facilitate a strong alliance between researcher and participant affecting the quality of the interview conducted. I was challenged by relating to participants in two ways. During the interviews it was hard for me to understand how you still work with pesticides after you have been poisoned but I was educated about this and their narratives ultimately opened my eyes to industry in this country. With four other participants it was more challenging to relate because they had hearing or memory difficulties.

V: (pause) sorry my hearing aid I don't know if it's the battery or what,

R: that's okay

V: I will leave it off, I may hear now

R: okay

V: you'll have to talk a bit louder

R: Okay then, you just tell me about your experience of being poisoned and start from the beginning so start from the beginning of the story or being poisoned can you do that

In the end in the above interview we completed to my surprise a 40 minute interview, and looking at the video tape afterwards I don't think that he ever heard me correctly. But what he did understand was my body language, from which I conveyed emotion and was able to relate to him

The research process also triggered important spiritual/identity, physical, psychological and relational challenges for the researcher.

Physically the research process was exhausting while at the same time it seemed to intensify my own personal experiences of pain. The embodied experience of the research process challenged the coping strategies I had already developed to manage pain brought me back into my body and as a consequence the research process was literally painful to me.

Emotionally there was one particular moment when, all of sudden, in the middle of our conversation wanted a participant wanted to show me his amputated limbs, in took all of my will power not to pull back from him emotionally and shut him down stay engaged as he laughed and joked with me. Later when I watched the video I was relieved to see that I didn't withdraw visibly and did stay connected, but it bothered me that I felt this reaction. I believe that my body attempted to withdraw from the participant because idea of losing your limbs was too painful to contemplate as others have described (Mullan et al, 2006).

Relational aspects that influenced the research experience were staying with the Maori organisation where I was going to interview participants. Over two days I was dined and entertained by people who took me for walks on the beach and did a tour of the town's cultural heritage which was inspiring. This friendly and supportive environment built my connection and respect for the town and its people while also provided a relaxed environment from which I could do the research I had come to conduct. Another aspect was over the 2 days I met with the SWAP group, I learnt about the meaning of whanau and the power of the collective to bring about social change and I couldn't help notice but notice how the social isolation some of the other participants who were interviewed.

There were two important spiritual identity shifts that came out the research experience for me. When I first met SWAP members I overheard one of the participants of my study say to another before I had interviewed them, she's interested about the people, not about the land. This made me think about my motives and expectations. When I looked at my beliefs around this I found that I had come perhaps to resent on some level how society seems to be more interested on focusing on the environment than on the people who were getting poisoned and I had an expectation that this study would let the people, not the environment be heard. I remember the look of determination that came over the other SWAP members face and in many ways I am fortunate that I had made this bias because. I was driven around the town of the SWAP group taken to the site of the old mill and the

canals and marae where toxic waste full of pesticides had been dumped and he described to me the houses and the families and the children playing in this wasteland and as my horror just grew and grew, I had a revelation and was truly humbled as I was shown how the health of the land is integral to the health of the people. Other participants also connected health to the environment reinforcing this concept for me.

The final learning I had from this study included the physical, the psychological, the relational but most of all it affected my sense of identity. During the research process it became increasingly clear to me that the deep pain that many of participants felt was because their experience with being poisoned had either directly or indirectly harmed their children or prevented them from having children.

R: How do you feel about that?

P: it's not nice, I mean, we, when we got married, even though I had 6 children we tried to have a baby, we had, I've had miscarriages, so that was it, we couldn't have any...yeah, so he legally, we both had to legally adopt my youngest son, he wanted to adopt the whole lot but I said that's to many, 6 of them, so out of the 6, we had to both legally adopt, our last one"

The participants experience deeply affected myself, this is because for a number of years prior to this research project, my husband and I had been trying to have a child. I could get pregnant, but each time I would have a miscarriage and that would devastate my body. The last report I ever received from an ACC Doctor stated that they were unsure how pesticide poisoning would affect any future children, because both my husband and I had experienced pesticide poisoning. During the research process in a private conversation not on camera with one of the participants we discussed whether you should you risk having children if you know that you have been exposed to pesticides. His answer to me was we never had a choice and he honestly did not know what he would have done if I had a choice. After this conversation I was in turmoil, I could no longer disconnect from what the participants of this study were telling me or what my body was telling me. As I drove away from Whakatane down by the waterfront, looking out to the vast ocean, I couldn't help by cry and grieve for what I now recognised I had lost forever. I couldn't hide anymore, I had to accept that because I had been poisoned by pesticides, my body was unlikely to ever carry a healthy child and that I would never know a sense of family in that way. I was in a state that Frank (1995) term's a narrative wreck, in the end, I think that this is the ultimate chaos that comes from pesticide poisoning, is that there is always another layer of suffering just waiting to emerge and disrupt life all over again and you constantly have to rewrite your life as I adapt to the changes that come from living with pesticide poisoning.

Chapter 6: Knowledge and Illness

It is strongly evident in the narratives of this study of how the power dynamics that surrounded over who had the authority of knowledge on the health risks from pesticides impacted on all aspects of the pesticide poisoning experience for the narrator's of this study. It was the lack of knowledge of pesticides, the search for knowledge on pesticides and the legitimisation of their own knowledge on pesticides that was a key theme throughout the illness narratives told by the participants, as they sought to contest knowledge in society that denied both the danger of pesticides and their experience of illness. Research supports that people with medically unexplained symptoms engage in significant information seeking to explain their symptoms (Nettleton, 2006).

R: How do you feel about that now that you didn't get to see a Doctor?

N: yeah oh, yeah now you've brought it up I'd be, I don't know it was sort of, I grew up in a place too, where chemicals were there, you know there was a whole suburb built around the chemical plant and it, I think there was a lot of politics around it as well, a lot of things were happening and people were scared to, to step forward about what was happening

Because most narrators didn't know or understand or take seriously the potential negative health risks in exposing themselves to pesticides they willingly took on jobs where they handled or came into contact with dangerous pesticides, without any or inadequate protective equipment and then for many, unknowingly taking the pesticides home, exposing their entire family, and then were a witness to watching their community be filled with toxic waste. All based on the authority of knowledge in society that represented pesticides as harmless. Frank (1999) noted that the sense of "choice" a person has with their health occurs within social contexts where conventions ultimately seek to constrain the choices that are made. Pesticide poisoning is an example of where the authority of knowledge over the health constrained the participants from making informed choice about their exposure to pesticides that ultimately impacted on their health. This situation eventually forces lay people to become their own researchers themselves in their search to understand and cope with the illness they are facing. Brown (2007) sees these people as being activists in the environmental health movement.

K: I crossed swords with MAF and that and I kept pushing it but we got the whole practice stopped, we embarrassed them so now these days if you're on a plane in NZ unless it's a charter plane it shouldn't be sprayed and I'm certainly very much in favour of putting unwanted pesticide exposure to people especially ones of that toxicity level, in the states they require you to be 3 hours out of a house while its being applied, in NZ they were spraying it while you were in the house so to speak and you couldn't get out of the house, hell you open the door of the plane, where can you go and that's what was happening so we got that stopped as well

The narrators of this study face many challenges in trying to show the dangers of various toxins and get action taken. Brown (2007) believes that this is because they are challenging the status quo of science and the *dominant epidemiological paradigm (DEP)* an entrenched group of beliefs and practices about what causes disease found within science and

government. Within this model what is called layperson knowledge from individuals whom have been exposed to pesticides is devalued and ignored.

If lay knowledge had been recognised as an authority on illness from the 1940's onwards, and the power dynamics between government and industry and within the science's and medicine had not combined to prevent the growth of knowledge on pesticides, then the narratives from this study could have been vastly different. The narratives of this study are an example of how relationships between a narrator of illness and the witness can be compromised by oppressive forces that threaten the ability to bear witness and receive the persons story illness story (Chow, 2003).

Instead government, industry, medicine and the sciences placed their superior authority over knowledge about pesticides, and consistently took the position that pesticides were safe until proven otherwise. For environmental and occupational diseases to be believed and accepted it often requires a social movement by communities who have been impacted by toxins (Brown, 2007). It is only through the widespread reporting of health symptoms by people exposed to toxins that the environmental health impact of these toxins is eventually discovered. This reporting is done against a background of suspicion and contempt by the authorities and medical science (Brown, 2007) The term "mass hysteria" has often been applied to the concerns of people that have been exposed to toxins (Aldous, 1994). Their concerns for their health are dismissed initially as hysterical and non-rational, only later to be proven to be a very rational response to a very serious health threat once adequate knowledge has been acquired.

Because illness narratives are evolving and changing, traditional science struggles with the "reliability" of illness narratives (Frank, 1995). Despite the trivialisation and delegitimise of their knowledge of pesticide poisoning, many of the participants from this study showed a fierce resistance in their narratives. Narratives have been shown to contest dominant social practices (Fraser, 2004) and this was true of the narratives of this study as the narrator's had to challenge powerful institutions and contest their authority of knowledge over pesticides, often against overwhelming odds.

E: you know, I said don't think that were dumb, were not dumb I tell you that now, we made sure were not dumb with people like you, yeah, yeah so quickly that's, that's probably, probably what eh, what that thing is all about really eh, and we had the same with eh doctors, got issues with the ACC at the moment, there in a position to now where they can't argue with us, not even the Doctors

In exercising their powerful authority over the health of the nation, Government, Industry, Medicine and the Science's failed to follow the ethical principle of *precaution* (Jas & Boudin, 2013) in determining the health impacts from pesticides. Some Scientists even stated that they felt the drama was overplayed when researchers were attempting to raise awareness of pesticide poisoning around the world (McEwen, 1993) and others felt that narrative enquiry, that focus on illness stories, needed to be treated with caution by Medicine and they shouldn't be thought to be able to influence medical care (Bury, 2001), indicating the

resistance to listening to illness stories in medicine. In other countries it has been reported how government originally intended to take precautionary measures with the advent of the Chemical Age, but that pressure by industry who tied down governing bodies in litigation, led to the systematic dropping of standards (Jas & Boudin, 2013). New Zealand was likely to experience similar pressures that allowed industry to dictate to government the health standards for pesticides.

S: so we fought and we fought and we fought, and we eventually got Occupational Health and Safety to accept it after going through ACC system, and seeing a specialist, it was finally, finally all accepted, but again there was another big problem with, with, the governmental system was by the time you could actually prove that this had happened any period for prosecution under OSH law had expired, that had to be done in 6 months, so again, um, the message for employers if you poison people and are irresponsible, just sack them you know

These pressures can be seen in today's society. New Zealand unlike many countries in the world do not have a system in place to gather detailed information on the use of pesticides in this country (Holland & Rahman, 1999). The New Zealand government does not know the quantity of pesticides being used in this nation, because it is commercially sensitive information for Industry, so they can't determine their true health or environmental impact. The powerful influence of industry can be heard in the narratives of this study as the participants recognise the risks in contesting illness with industry.

Though the pressure by industry must have been significant, when looking at why both government and the nation embraced pesticides as a whole we have to consider our identity as a nation as a contributing factor. In New Zealand there is long history of farming the land (MacLeod & Moller, 2006) and as a nation many take pride in that, and some consider farming the backbone of the nation. Colonised by Britain (Clark, 1949), New Zealand became a major producer of primary goods first to Europe then to around the world and as a nation we significantly benefit from this. Currently New Zealand has a large agricultural and horticulture industry that depends on a multitude of pesticides to manage crops and lands. Agriculture intensification continues to strongly grow in this country and at the same time so does pesticide inputs go into the land (MacLeod & Moller, 2006).

Many of the narratives referred to what they called the "kiwi attitude" to explain pesticide poisoning in New Zealand. This seems to indicate that a risk taking attitude that is distinctly "Kiwi" or New Zealander contributes to the poisonings that happen in New Zealand.

R: so its sounds like your experience has um led you to be a bit more of an advocate and um that's quite big changing things that happen in planes and that

K: well it does I mean a couple years ago was a lady who had a severe asthma attack coming back on a plane to NZ it was a charter plane and she nearly died and it my comments to MAF I wrote at the time just another bunch of cowboys trying to kill of New Zealander's I was quite blunt about that and as a result of that there was one woman it was one of the more senior people in MAF we had a meeting and we discussed this they were going on about we need to control insects coming into NZ we need to control the pests in NZ, yes we do but theres got to be other ways to do that than poisoning the people

If this was the typical attitude was both in government and industry then risk-taking with pesticides was likely to be high and potentially still is. Studies have shown that government

officials show pro-pesticides attitudes and should not be considered neutral in the debate on the dangers of pesticides because they are part of the status quo power structure surrounding pesticides (Burch & Harry, 2004). Overseas studies have shown a link between attitudes to pesticides and the willingness to develop safer practices (Lichtenberg & Zimmerman, 1999) and the more harmful pesticides were perceived, the more sensitive fruitgrowers would be to their pesticides practices (Isin & Yildirim, 2006). Knowledge based and social orientated approaches are need to minimise the harm from pesticides, which involves political change to increase learning of hazards of pesticides (Sherwood et al, 2005).

The “kiwi attitude” is currently reflected in New Zealand governments “100% Pure” tourism marketing campaign, which ignores 70 years of massive pesticide use. The powerful impact of both the “kiwi attitude” and pressure by Business and Industry on government regulation in New Zealand is evidenced in the recent tragedy at Pike River where 29 miners lost their lives due to inadequate health and safety standards. The subsequent development of the Work Safe Ministry, in response to the inadequacies identified in health and safety regulatory bodies of New Zealand, indicated that as a nation we are still a long way away, before we can really trust the regulatory bodies to protect New Zealanders.

K: the trouble is you need to have someone monitoring that knows what their doing, we've had a labour inspector going out there checking chemical but at the end of the day they really don't understand our procedures we need some people form our industry, monitoring our industry and that's not what's happening at the moment

Pesticides act through a neurotoxic mechanism that is relevant to both targeted and non-targeted species (London et al, 2012). If the *precautionary principle* held power over the ethical foundation of all decisions that involve health and safety in this country, then the New Zealand government would not be currently dumping 1080 all over the native forests of New Zealand, with a pesticide, said to kill possums specifically, when it in fact it kills every living thing in the bush, especially when lay knowledge by hunters and scientific knowledge confirms that this pesticide is in our waterways, killing our fish and any dogs or horses that come into contact with it. A study conducted this year in New Zealand claimed that the levels of 1080 found in our fish in our waterways could not cause poisoning despite the proof that the pesticides were indeed in the fish. Much of the controversy around pesticides is what Government, Science and Medicine determine is an acceptable risk to exposure to pesticides (George & Shukla, 2011). This study that determined that exposure to 1080 was an acceptable risk to the New Zealand public, failed to take into account the accumulative effect of exposure to multiple pesticides within our environment, which research suggests can combine to unsafe levels (Sanborn et al, 2002). The risk's from pesticides is not an answer that can be provided by science, instead the risks around pesticides is a question for society to consider (George & Shukla, 2011). The economic impact of pesticides in non-target species (including humans) has been estimated at approximately \$8 billion annually in developing countries (Aktar et al, 2009) and there are now figures to assess the level of economic impact from 50 years of massive pesticide use with little or no regulation.

R: How do you feel about that attitude

I: um your sort of stuck between a rock and a hard place cause you don't want to make too much noise, but you don't want to see people going down the same track as what you have as well, so, its sort of ah, you've got to find the right channels to you know to get through the hierarchy to get someone that will listen that will do anything, um because at the end of the day it all comes back to the supposed bottom dollar and speed and things like that

Kiwi attitudes and a lack of precaution were all contributing factors, but one of the most important contributing factors as to why the New Zealand government and industry took unnecessary risks with the health of this nation, is because of money and greed and because they had the power to do so. The potential benefits from pesticides through gains to the nation's wealth by an increase in productivity and income through agriculture and horticulture and other industries were considered vitally important to New Zealand; and any potential risks to health and the environment were either not considered, ignored or minimised because of this tunnel vision focus on wealth that corrupted consideration of the wider picture. One of the reasons that there is a lack of acceptance by pesticide poisoning illness stories is because any acceptance would involve accountability and responsibility that would come at a high cost to Business, Industry and Government (Brown, 2007).

R: That's what's important to you now?

Z: It is, it's very important and um because you know the men they trusted the company they worked for and um yeah there was trust, you never kind of questioned it really years ago, you trusted the you know, your employer you didn't really question all those years ago, so, and I always feel that the powers that be knew what it was going to do to the people that worked in that environment but the affects wouldn't show until years down the track

The pesticide poisoning narratives of this study serve as an example of how conflicting values between a country's productivity and income versus its human and environmental health can lead to actions that negatively impact on the health of a nation. All activities concerning pesticides should not be based on commercial considerations because there are inherent difficulties in fully evaluating the risks to human health due to pesticides (Aktar et al, 2009).

C: its all, it's a, it's a the issues down the track, that the so called authorities there fully aware of, there not bloody stupid, they know but all they're doing you know, everything is measured in terms of dollars, you know, and that's, that's the issues so we your, gonna get to sets of values clashing you know

Even on today's standards the narratives of this study indicate that the New Zealand government still is not taking responsibility and effectively monitoring pesticide use in this country more closely. The importance of education and training of workers is a major pathway to ensure the safe use of pesticides (Akatar et al, 2009). Both the narrators who still work with pesticides within industry accentuated how standards in New Zealand were leading to frequent hazardous pesticide exposures and the reduction in the effectiveness of pesticides because they were being inaccurately applied, a concern reiterated by the World Health Organisation (WHO, 1999). The fact that the Grow Safe course is perceived by one of the narrator's of this study that actually continues to work with pesticides as just a measure largely seen to protect industry from litigation rather than protect workers and the public from being poisoned, is very alarming. As one study noted the focus of research and

interventions tends to be on the crops, the bugs and the pesticides, rather than the people who design, chose and manage practices (Sherwood et al, 2005) It is suggested that the absence of immediate negative feedback during exposure will influence whether any measures are taken to reduce exposure (Stephens et al, 1996).

R: okay then you, you mentioned that something had come up at work um since

I: yeah the guys that are doing herbicide spraying full time they brought up at a safety meeting about trying to get their bloods checked, and the answer from the management was you have an annual medical check bring it up then, which some of these guys had just started so that's 12 months down the track, you know, and their not going to have much of a base level or anything to go by ,but yeah just, just all the slack attitudes out their towards it

The government continues to be ineffective in enforcing lapses in health and safety around pesticide use in this country. Within 2003 to 2004 there were 57 cases of workplace poisoning's that were actually reported (Pearce et al, 2005).In 2015 the WorkSafe Ministry no infringement notices for unsafe pesticide poisoning practices. In the media coverage of technological-focusing events there is the assumption that media distorts "the real risks," either over- or underplaying them, this fixation on bias rests on an underlying pragmatic orientation toward real-world goals of either removing risks or protecting the interests of technology users (Gunter, 2005).

This study suggests that race is a contributing factor to experiencing pesticide poisoning by the fact that half of the participants of this study where NZ Maori despite their lower representation in the population. Pesticide is a form of environmental injustice (Fritz, 1999) found within New Zealand society. The power of social contextual factors, such as race and socioeconomic status do influence and contribute to health issue is well acknowledged within Critical Health (Lyons & Chamberlain, 2006). Many believe that the disparities in health that you see within the same country are from the differential distribution of economic and social factors that influence health (Robson, 2008).In the U.S.A. Hispanic workers and low-income workers were more likely to experience pesticide poisoning. Environmental problems are more frequently experienced by those who have the least power such as minority and low-income populations (Fritz, 1999, Lyons & Chamberlain, 2006), and in some case has been called environmental racism. The disparities between Maori and non-Maori in New Zealand are significant for a number of key indicators in health such as life expectancy, cancer mortality and cardiovascular illness (Robson, 2008) and how much environmental influences have added to this disparity has yet to be determined. The search for environmental justice is of great concern to activists and scholars in many countries around the world (Fritz, 1999)

T: but ah you know we weren't said to that it was harmful, all they said to us you got to drink it to be, to do any harm to you, but you know you could also feel it in the, in the air you breathing it in, in and out so you knew it wasn't, it wasn't doing you any good but it was your job, and you were sort of glad to have a job, you didn't want to say no to your boss in case he tells you where to go from there

As discussed previously in chapter 4, overseas studies found that overlooking or misdiagnosing pesticide poisoning was common, therefore it is likely that the consequences

of 70 years of pesticides use is not being reflected in our health statistics and therefore have not become a focus for health care funding by the government. One of the reasons that this is not happening is because our public health funding is largely based on what health issues are costing the health system the most. There's a reason why the government campaigns people to exercise more, stop smoking, drive slower, eat less or wear helmets and that's because they are able to quantify the health dollar that is actually spent on the health outcomes from these factors.

S: and um effectively what it does is it forces the sick person who, who is trying to deal with all of this, new things, and what what's happening to their body, it puts the onus on them to fight and to prove, when something has gone wrong, and it's just a terrible social injustice, I suspect that a lot of people in this situation they're not capable of it they don't have the strength to do that and um, and there should be some form of watchdog or something whose actually in there advocating, because were dealing with sick people, and sick people shouldn't have to fight and prove that there sick

When you look at what's being targeted by government you can see how in these public health initiatives is that they are dominated by focusing on individual lifestyle choices that influence's our nation's health (Lyons & Chamberlain, 2006). The focus the government continues to reflect the dominant medical narrative that focuses on individual factors for health. The government continues to exert its control over the authority of knowledge within this nation and in doing so increases the suffering of those with environmental illnesses. If the government of New Zealand used their power to educate the public about pesticides then the power over knowledge would be given back to the public and they can make an informed choice about the use of pesticides. This is similar to the approach taken with the tobacco industry where government regulated that health warnings needed to go on their products, giving people the choice in knowing the risks they take with their health.

E: you see ahh and ahh that's the mataurangi Maori that I'm talking about, I when I talk about our vision because when, when, when you see our vision and mission statement, it's actually telling you the whole journey anyway, our vision was really, was a bringing together of the mataurangi Maori concept, the Western science concept, medicine and a whole lot of people, ordinary people just like me, well people who bit more I don't know, um bringing them all together on our waka, telling them about the waka's going over there you want to come

Underlying all of the relational power dynamics between Government and Industry, and the health of the nation, has been their ability to use the powerful institution of Science to undermine stories of pesticide poisoning. When you consider why Science allowed this to happen a number of key factors emerge. The traditional and modernist views that dominated science at that time placed their authority over what represented truth, reality and knowledge and based on this, rejected the illness narratives of people who had been poisoned as too "subjective" to study because of essentially a philosophical stance. Opposing viewpoints on epistemological issues on what is knowledge to investigate were typically denigrated by traditional and modernist scientists (Murray, ?) If these illness narratives had been accepted as valid knowledge and worthy of investigation when the stories of pesticide poisoning first emerged in society back in the 1940's then awareness of the negative impact on health could have been recognised so much sooner.

T: like I said it's too late it's too late for us not a lot can be done for us now cause there's nobody expert enough in the field to know, that those chemicals did this to us, ah nobody only you've had the same experiences in your in your upbringing so you know where we are, and it and its you know it does impact on you the amount of people that don't take any notice of what your trying to achieve but you trying to tell them something ,but they sort of turn away you know that sort of thing so you gotta go in that way that sort of thing

Another contributing factor was both Medicine and Science were also so focused on individual factors that influenced health (Lyons & Chamberlain, 2006) that they were blind to the growing harm from pesticides in the environment. When it comes to making sense unexplained bodily experiences it is Medicine that controls the means of production of knowledge of the body (Nettleton, 2006). Medicine was dominated by searching for biological causes to illness and since the biological mechanisms were not yet understood for pesticide poisoning, medicine took the position that it didn't exist showing their powerful authority over knowledge of the body and in determining what is an illness.

N: but at the time when I got poisoned there, it wasn't treated like a big deal, it was just like, you know you've had too much sun or something like that you'll come right, you know, they didn't sit down and say look this is what happened to you this is what could happen to you

The domination of the biomedical model and the authority that this gave to medical knowledge, gave it precedence and therefore more power, than the knowledge of people who were being poisoned, even though the biological mechanisms were poorly understood. Today it is recognised that there is a considerable amounts of illness, pain and suffering that is not medically explained or well understood (Nettleton et al, 2004) but medicine consistently denied the experiences of people who had experienced poisoning because they were unable to recognise the symptoms of pesticide poisoning and diagnose it. This was to the detriment of Medicines health as well since today it is known that health care workers who treat cases of pesticide poisoning are at significant risk of getting exposed themselves (Sanborn et al, 2002).

Eventually science and medicine were provided with empirical explanations that did prove the "cause and effect" between pesticides and health, but only after strict verification procedures were used, so that finally an unambiguous "objective" truth was provided that allowed Medicine and Science to accept that pesticides were indeed dangerous to your health, decades after lay knowledge had first described pesticide poisoning.

S: um so basically you know when your dealing with pesticide poisoning there's just all these other factors on top of actually dealing with the sickness and that I find really frustrating that society can't accept these things and address them because really a sick person needs to um, you know have some quiet time, and, and just you know take things easy, you know, um, society is pretty tough, we need to make a little bit of an easier go of it, you know because all of these things, as I said to you, you know you have to fight, you have to face this disbelief and you have to find a way to work and make an income and stuff, and yeah it's just the disbelief out there, it's a hard illness to live with

The theoretical assumptions held within traditional and modernist science, and the medical profession, impeded the growth in knowledge about pesticide poisoning, denying and prolonging the suffering of people who had been poisoned. It has been shown that having knowledge of illness and disease is an important factor in accepting and managing chronic

health issues (Berntsson et al, 2007). It is perhaps ironic for the institute of Science that challenged the beliefs of religion's that sought to impede the growth of knowledge during the Age of Enlightenment, only to become entrenched themselves in a dogmatic set of beliefs that again impeded the growth of knowledge on health (Fox, 1999).

The institution of Psychology, which was also dominated by positivist views of traditional science (Murray, 2004), played a powerful role in placing their authority over pesticide poisoning that sought specifically to delegitimise the experiences of people who had been poisoned. Psychology used their power as an institution to prevent the growth of knowledge on pesticides and have played a key role in increasing the suffering of people who have been poisoned.

Critical Health Psychology has highlighted how the bias within Psychology have impacted on how Psychology has perceived illness and what they have investigated (Lyons & Chamberlain, 2006; Murray, 2004). To some researching environmental health is essentially being a dissident scientist (Brown, 2007) because within Science and Psychology in particular it is asking the questions no one else asks and do the studies that no one else does. However within the fields of Psychiatry and Psychology there are deeper issues that have prevented growth on knowledge on pesticides. When recruitment began for this study a consistent reaction I came against was suspicion and anger at how could a student of Psychology could do such a study considering the harm done by my institution to people who had been poisoned. The conceptions about what the scientific research is for has been shown to constrain what a participant say, how they say it, and the attitudes towards the research context (Gudmundsdottir, 1996). This perception of harm by Psychology was further reinforced when I made contact with a person who had been poisoned who couldn't be included in my study because he wasn't exposed in his workplace, but who gave me his psychiatrist report, for use in this study, where he had been diagnosed with schizophrenia because he believed he had been poisoned by pesticides. Years later an overseas psychiatrist overturned this decision stating this person had been exposed to pesticides and their fear of being poisoned was genuine. Diagnosis and recognition of the impact of illness symptoms from pesticide poisoning is considered by some an essential part to learning to manage and cope with the illness experience (Davies et al, 2000).

When you look closely at the fields of Psychiatry and Psychology you can identify that they both have a long history within their institutions of delegitimising people's experience of harm from a dangerous environment. For example, in the 1900's Freud came across women who had been sexually abused from living in an unsafe environment. Instead of acknowledging the damage of living in such an environment, he created a complicated theory that basically said that all children wanted to have sex with their parents (Briere, 1988). These ideas had such influence on mental health for so many decades that sexual abuse was either ignored or minimised, which sought to perpetuate the suffering of people who had been abused. It wasn't until 70's and within the feminist movement that female

survivors started talking about their experience within encounter groups (Bass & Davis, 2002) and that the fields of Psychology and Psychiatry started to pay attention to how an unsafe environment can affect a person's health, and even then they tried to medicalise the experience of sexual abuse, which is currently hotly contested within Critical Health Psychology.

Sexual abuse is similar to pesticide poisoning because they are both caused by living in an unsafe environment and therefore are both *environmentally injuries*. I am able to take this perspective because I had been sexually abused as a child and was poisoned by pesticides as a young adult. When I was in the height of my fight for recognition of my pesticide poisoning experience I was seeing a counsellor who said to me I can see why you are fighting so hard they both are the same for you aren't they, and there are striking similarities. For example they both are caused by the environment; they both have had total denial and minimisation in all areas of society as to whether they even exist, and both had the construction of elaborate theories within Psychology and Psychiatry that sought to deny peoples experiences.

When you seek to understand why Psychology consistently does not exercise the ethical principle of precaution when faced with environmental injuries it is likely that arguments focused at Medical Professionals are equally valid. This suggests that individual variables in health are far more easier to understand, control, and the professional is more able to alleviate suffering, and that environmental injuries are not well understood, or controllable, and therefore the professional has little to offer to alleviate suffering, and that this causes anxiety to health professionals.

Considering the large contribution both fields could make to the experience of pesticide poisoning, the decision to largely delegitimise emerging environmental injuries has been a detriment to these institutions, for several important reasons.

Several years ago I worked as a counsellor with a young man who was struggling with depression. He worked on a farm. He was struggling in his work, so he was put on pesticide spraying because it was considered an easier task to do. Two weeks after I last saw him, he shot himself in the head. After his death I learnt that he had been spraying pesticides. Death from mental health disorders is associated with exposure to pesticides (Sanborn et al, 2007). This leads to the question whether people who are already experiencing mental health issues such as depression, anxiety and rage even be around pesticides when the evidence suggest that this will intensify any underlying mental health condition. Do pesticides take a person just one step closer to committing acts of violence. In my personal experience of pesticide poisoning it certainly did. Suicide rates are higher in rural than urban areas pesticide poisoning is the most common form of suicide in rural communities around the world Chronic exposure to pesticides can increase depression leading to suicide (Beeson, 2000). Commonplace and culturally accepted rural elements, such as firearms and pesticides, may contribute to suicide through increased lethality (Hirsch, 2006). We have to

start considering whether the massive use of pesticides in this country is linked to our extremely high family violence rates (Snively, 1994) as well as high suicide rates, especially amongst farmers and in rural communities.

R: What's it like having a group of people explosive, like that? What would happen?

C: What would happen?

L: Back in those days you just, I'm mean you had, cause you always, always had a nutter that just went off eh

C: yeah

L: You know, they just went off, so we sort of walked away, from the, walked away from all the others, you know you would grab them and say hey settle down you know and of course tomorrow that same guy would be working beside you, and ahh, and we had those flare ups

L: yeah

Science also has much to learn about the interaction of pesticides with the neurotransmitters in the brain to influence mental health. Acetylcholine (Ach) has already been implicated in the production of anxiety (Sadock & Sadock, 2007) but has largely been ignored in contrast to other neurotransmitters such as Dopamine and Serotonin. As stated previously, the mechanisms of some pesticide's poisoning causes Ach to be over produced in parts of the brain that are involved in emotions and increases dreaming. In contrast the psychoactive substance THC which is in cannabis (Schofield et al, 2006) reduces the production of acetylcholine reducing dreaming and for some anxiety. This suggests that Ach could be manipulated to alleviate the mental health factors from pesticide poisoning while also raising the question as to how much the high use of cannabis in this country is linked to pesticide poisoning.

In previous chapters I have argued that pesticide poisoning induces strong emotions and deconstructs a person's identity. It was during the First World War that progress was made in understanding about head injuries from investigating the experiences of survivors from the war (Jones et al, 2007). Within the experiences of pesticide poisoning is the opportunity to understand both the complexities of identity and mood formation which could influence both theoretical ideas and applied practice.

R: What difference would, do you think it would have made if you had that knowledge 10, 20 years ago?

Z: probably I don't, maybe tried, um there wasn't a lot of alternative healing then either years and years ago but probably we would of, he would of tried something like that

R: so there would have been more choices

Z: more choices, just to ease the pain really and to know to under, to really understand what was going on and yeah

Finally considering the strong evidence in the narratives of this study of the psychological distress from pesticide poisoning much could be contributed from Psychology, Psychiatry, and Health Psychology to understand and seek to alleviate this suffering within their communities.

The narratives of this study are a testament to how the power dynamics between Government, Business & Industry, Medicine and the Science's, in particular Psychology, have sought to control the authority of knowledge over pesticide poisoning, that ultimately saw denial of the experiences of people who were being poisoned, that created untold suffering to people living with pesticide poisoning in New Zealand. Considering the amount of people in this country who have potentially died prematurely due to pesticide poisoning the effect of these institutions, to control knowledge over the body and dictate what health is, has truly worked against the health of this nation.

Chapter 7: Conclusion

This qualitative study explored the pesticide poisoning experience of 16 New Zealanders using narrative theory and method to understand the illness experience. The idea of narrative was employed throughout this study from collecting illness stories within unstructured interviews, to then combining the stories and analysing them from three different narrative perspectives, the thematic, structural and the performance/dialogical. Each perspective revealed a different way of understanding and knowing the illness experience from pesticide poisoning.

Thematic analysis of the narratives revealed themes that were typical of the *restitution*, *chaos* and *quest* narrative types, showing the threads that pull together all illness experiences together (Frank, 1995) The analysis found a linear continuity between narrative types as the participants progressed through different stages of their illness experience. The *restitution* type narrative was present in the stories from this study but they were not a common theme in contrast to other narratives of illness (Frank, 1995; Nettleton, 2006). This implies a lack of belief in the medical system within the narratives of people who have pesticide poisoning. In contrast the *chaos* type theme was more commonly found within the narratives, indicating the chronicity of this illness and the challenges in living with a contested illness. There were 5 layers of uncertainty revealed within the *chaos* theme and these were related to challenges with diagnosis; potential harm to family, the environment and genetic identity; and the uncertainty of having or getting an environmentally induced disease. Though the chaotic aspect of pesticide poisoning was evident (Frank, 1995, Nettleton, 2006) the narratives were more dominated by the *quest* type narrative (Frank, 1995) in particular the *automythological* type was a typical theme for this study.

The narratives revealed 5 distinct stages to the pesticide poisoning experience. These were exposure, realisation, struggle, integration and empowerment. Each stage was connected to different narrative types and the corresponding changes in identity. The exposure, realisation and struggle stages are distinctly *chaotic* as the participants experience a deconstruction of identity as a result of the pesticide poisoning experience. The integration and empowerment stages are clearly *quest* types. At the integration stage the participant makes changes in their personal situation that helps them adapt to their illness experience and reconstruct a new sense of identity. The empowerment stage is a step further from integration where the participants actively advocates for their illness experience and builds a strong identity based on the pesticide poisoning experience. The thematic narrative analysis reveals that rebuilding a strong identity is an important part of managing chronic illness.

The analysis from a structural perspective revealed that the narratives as a whole conceptually fit the Whare Tapa Wha model of health (Durie, 1994), suggesting that this is a way that people structure their stories that gives an embodied account of illness and how it impacts on identity. Conceptually the *restitution*, *chaos*, and *quest* types can visually be

perceived within the metaphor of a house showing the impact on health and deconstruction of identity from pesticide poisoning.

The principles of WTW were then applied to give an embodied and reflexive account of the research experience showing how conducting research can impact on your personal identity. The structural perspective of illness has revealed a promising theory from which to explore the embodiment of illness and identity reconstruction which has applied applications within health care. The connection of the WTW model to illness narratives highlights the strengths of the structural approach in narrative analysis, that it was able to identify an important topic and voice that might have been overlooked otherwise (Reissman, 2008)

The performance/ dialogical stage of analysis revealed how within the social context the authority of knowledge over pesticides considerably impacted on the illness experience. This stage of analysis revealed the relational dynamics (Moss & Teghtsoonian, 2008) between the participants and the powerful institutions of government, industry, medicine and the science's, as each struggled for authority over the knowledge of pesticides, that ultimately sought to deny the pesticide poisoning narratives of this study. The narrators of this study strongly resisted this authority and contested the knowledge of these institutions.

Contributing factors to this denial of knowledge of pesticide poisoning was the lack of ethical precaution within the institutions; powerful pressures from industry; attitudes within New Zealand that encouraged risk taking; a tunnel vision focus on productivity and the wealth of the nation; race and socioeconomic factors; traditional and modernist perspectives that dominated within Science; a focus on individual over environmental factors within Medicine and Psychology; the domination of the biomedical model; the history of denial of environmental injuries within Medicine and Psychology and the key role played by the institution of Psychology in delegitimising poisoning experiences.

The three narrative perspectives employed in this study can be experienced visually if you imagine the zoom icon on your computer and the light from a candle on your screen. The thematic analysis is the highest resolution for this study you zoom inside the flame of the candle as you absorb the reality of and maybe get burnt from the illness experience of the participant. The structural analysis zoom's out of the flame and instead captures the whole of the flame of the candle, perceiving the entirety of story that has been told. The performance/dialogical zooms out even further, now the candle is but a flickering light in the distance and around it you can now see all the powerful forces and energies that surround's an illness story.

The very strengths of this study are also the very same things that can seek to limit it. The author's personal experience with pesticide poisoning, and the inclusion of two participants in the study who are related to the author through marriage, influenced the perspective on pesticide poisoning presented in this study, which for some may enhance the perspective

put forward, for others it may seem too close to the embodied experience of illness. Other perspectives could enhance and contrast the understanding of pesticide poisoning narratives overall.

The focus on workplace exposures make this studies finding's practical to the health of people currently working with pesticides in New Zealand. The study was very fortunate in that most of the participants of the study had received a diagnosis of pesticide poisoning or acknowledgement of their exposure from government, and this allowed the biological view of pesticides to be contrasted with the embodied experience of this illness which is the strength of the narrative theory and methods (Frank, 1995; Reissman, 2008).

A limitation to this study then is that exposures to pesticides that have occurred in the home, by spray drift or overseas, or where the diagnosis with pesticides is more hotly contested such as chemical sensitivity, have not been explored in this study. Further research on the more contested aspects of pesticide poisoning would enhance the understanding of both this illness and the contestation of illness overall.

Being able to recruit both woman and men ,Maori and non-Maori, and retired and current workers with pesticides in New Zealand, was a strength of this study in being able to capture a variety of views from different perspectives, adding to the depth and the complexity of this study. At the same time the sample was not homogenous and contrasting narratives from more homogenous samples would considerably enhance our understanding of pesticide poisoning of the gendered, social and cultural understandings of pesticide poisoning in New Zealand.

This study has shown the importance of narrative theory and its methods to reveal new ways of knowing and understanding health as it is experienced living within a sick body, and demonstrates that the popularity of narrative is well deserved and this is because it is an effective tool to understand, in particular, emerging illnesses such as pesticide poisoning. The narratives of this study demonstrate that there is much to be learnt about the experience of pesticide poisoning and that from these narratives there is the potential to learn about the foundations of health, identity and the experience of illness as a whole, which is promising for the future of Health Psychology and for the people of New Zealand who have experienced pesticide poisoning in this beautiful nation for decades and decades now.

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R: What difference would, do you think it would have made if you had that knowledge 10, 20 years ago?

Z: probably I don't, maybe tried, um there wasn't a lot of alternative healing then either years and years ago but probably we would of, he would of tried something like that

R: so there would have been more choices

Z: more choices, just to ease the pain really and to know to under, to really understand what was going on and yeah