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# **Individuals' Perspectives of Causes and Influences on their Diagnosed Anxiety Disorders**

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## Abstract

Anxiety disorders are the most common type of mental disorder in New Zealand, as they are in the Western world. However, little research has been done on how persons with anxiety disorder conceptualize their respective diagnoses. This small community based, qualitative study interviewed seven individuals diagnosed with anxiety disorders and tried to capture the content and complexity of their disorder. Volunteer participants responded to a flyer placed at an anxiety disorders clinic, located in Auckland, New Zealand. Participants included one male and six females, aged from mid 20 to early 40s. Criteria for participation included being diagnosed with an anxiety disorder by a health professional. Participants generally spoke in terms of their problems in living, as well as the development and course of their disorder. All participants reported that (1) their disorder was chronic and pervasive; (2) their condition was debilitating at times; (3) their condition was complicated by depression; and (4) dysfunction or disruption was present in their early family life. Most participants talked about the early onset of disorder. Recognizing and acting on the need for help was problematic for most participants. Thematic analysis was undertaken to best account for the data, which unfolded as a coherent, consistent and holistic narrative. Three common broad developmental themes were identified: *traumatic early life*, *troubled school life* and *problems with living*. Two broad themes were created to capture participants' thoughts and feelings following diagnosis: *rationalisation* and *post-rationalisation*. Discussion specifically suggested the need for further research into the aetiology of anxiety disorders, including the role of maternal controlling behaviour and early onset of the disorder. Further research is also needed to understand and facilitate the help-seeking process for persons suffering from anxiety disorders. A need was identified for the accurate detection of anxiety disorders, particularly when masked by a presentation of depression or other symptoms. Findings suggest that a developmental/ social/contextual model may be most useful in conceptualizing and guiding prevention, intervention and treatment plans. In addition, the impact and meaning of the diagnostic event on people with anxiety disorders requires examination to fully understand all the dynamics and ramifications. Implications from this study include the need for initiatives to aid early recognition and generally to educate people about the nature of anxiety disorders, including the fact that they are common, serious and treatable.

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## Chapter One – Background and Introduction

According to epidemiological studies mental disorders are common in New Zealand. The latest Te Rau Hinengaro New Zealand Mental Health Survey (in 2006/07) interviewed seventeen thousand people and found that 46.6% of the population has had a mental disorder at some time in their life, and 20.7% has had a disorder in the past 12 months (Oakley Browne, Wells & Scott, 2006).

Anxiety disorders have been identified as the most common type of mental disorder, according to the New Zealand Mental Health Foundation (2011). Anxiety disorders are a collection of chronic, debilitating conditions as described in the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text revision; *DSM-IV-TR*, American Psychiatric Association, 2000). They include panic disorder (PD) with or without agoraphobia, specific phobias, social anxiety disorder (SAD), generalized anxiety disorder (GAD), posttraumatic stress disorder (PTSD) and obsessive-compulsive disorder (OCD).

In this country a prospective study by Moffitt et al., (2009) found the mean past-year prevalence of any anxiety disorder was 22.8% in a Dunedin cohort and 19.4% in the New Zealand Mental Health Survey (NZMHS). While these studies used different editions of the DSM and therefore had slightly different diagnostic criteria, the prevalence rates were similarly high. Moffitt et al. (2009) also made the point that these estimates are conservative, as self-report surveys tend to underestimate true prevalence rates.

Wells (2006) said that New Zealand's reported rate of anxiety disorders is second only to the United States (14.7% compared with 18.2%). In the United States, as in New Zealand, anxiety disorders have the highest overall prevalence rate among the mental disorders (Kessler et al., 1994). Their National Institute of Mental Health (NIMH) Epidemiologic Catchment Area (ECA) study found that 26.9 million individuals in that country are affected at some point in their lives (Mendlowicz & Stein, 2000).

Compared to our neighbour, Australia, 12 month prevalence are very similar for most disorders. However, social phobia and PTSD are more common in New Zealand than in Australia (5.1% versus 1.3% for social phobia; 3.0% versus 1.3% for PTSD) (Wells,

Oakley Browne, Scott, McGee, Baxter & Kokaua, 2006). The authors said it is likely that these differences reflect differences in the interview procedure.

In comparing rates of different disorders in New Zealand, the 1986 Christchurch Psychiatric Epidemiology Study interviewed 1,498 adults and found lifetime prevalence for generalised anxiety was 31%, compared to 19% for alcohol abuse/dependence and 13% for major depressive episode (Wells, Bushnell, Hornblow, Joyce & Oakley-Browne, 1989). Females report having higher rates of anxiety and affective disorders while males have higher rates of substance abuse disorders (Wells et al., 1989). They also found that anxiety disorders are more chronic than either affective disorders or substance use disorders.

In general, anxiety disorders have been found to be persistent and have large comorbidity and overlap with other disorders (Bystritsky, 2006). They are characterized as being associated with disability, chronicity and comorbidity (Belzer & Schneier, 2004). They cause considerable emotional and physical suffering and poor quality of life (Prins, Verhaak, Bensing & van der Meer, 2008). They interfere with basic activities of daily living and occupational functioning. Relationship satisfaction is lower when at least one member of a couple suffers from an anxiety disorder (Barlow et al., 2000, cited in Sheffield, 2010). So anxiety disorders affect not only the sufferer, but also their partners. However, according to Mogotsi, Kaminer and Stein (2000, cited in Barrera & Norton, 2009) research into how anxiety disorders impair quality of life has been slower to progress than assessments of quality of life in other disorders.

As mentioned, comorbidity is common with people affected by anxiety disorders. The most frequent comorbidity is between mood and anxiety disorders, and this comorbidity is well documented to be pervasive and substantial (Belzer & Schneier, 2004). Clark's meta-analysis (1989, cited in Mineka, Watson & Clark, 1998) found depressed patients had an overall rate of 57% for any anxiety disorder. New Zealand data similarly confirm mood and anxiety disorders are most likely to co-occur, with half (49.6%) of those experiencing a 12 month mood disorder also having experienced an anxiety disorder (Scott, McGee, Oakley Browne & Wells, 2006). Scott et al. (2006) noted that comorbid mood and anxiety disorders are strongly related to case severity. While they found that mood disorders involve substantially more role impairment than anxiety disorders, experiencing comorbid disorders at the same time was associated with major

impairment. Comorbidity is also associated with serious consequences for the individual, such as suicidal behaviour (Scott et al., 2006). In her qualitative study on depression, Bradley (2011) said her most significant finding was the pervasiveness of anxiety amongst her participants. She concluded that anxiety is likely to be under-diagnosed or diagnosed as depression when “depressive symptoms inevitably develop in adults” (p. 182). However, while the exact nature of the temporal development of anxiety and mood disorders remains less than clear, according to Silberg, Rutter and Eaves (2001), anxiety predates depression more often than the reverse in longitudinal studies.

It is well known that the majority of people with psychological disorder receive no professional treatment and that fewer yet receive treatment in the mental health specialty sector (Kessler et al., 1994). As Hirschfield et al. (1997) suggested in their investigation into the under-treatment of depression, individuals are being seriously undertreated even though effective treatments have been available for more than 35 years. Despite being associated with long duration of episodes, high rates of chronicity, relapse, and recurrence, psychosocial and physical impairment, and mortality and morbidity, with increased risk of death from suicide, the vast majority of patients with chronic depression are misdiagnosed, receive inappropriate or inadequate treatment, or are given no treatment at all. They found it disturbing that dramatic advances in the diagnosis and treatment of depression have not revolutionized treatment practice. Kaddam, Croft, McLeod and Hutchinson (2001) reported that several studies have shown that GPs fail to detect a significant proportion of cases with psychological and psychiatric distress. Wittchen et al. (2002, cited in Baldwin, Anderson, Nutt, Bandelow, Bond, Davidson et al., 2005) found the correct identification of anxiety disorders and subsequent active treatment may be more problematic than for mood disorders. Hirschfield et al. (1997) suggested that factors that rest with the medical profession may need to be identified and rectified, for example, they suggested medical schools may not provide sufficient education about psychiatric diagnosis, psychopharmacology and psychotherapy, or limited training in the interpersonal skills may lead to doctors’ avoidance of addressing depression, emotional problems and related disorders.

According to the latest Te Rau Hinengaro New Zealand Mental Health Survey (2006/07) only 58% of those with serious disorder made a mental health visit to the

health care sector (Oakley Browne et al., 2006). Of concern is that persons with anxiety disorders have been found to have particularly low help seeking behaviour (Mykletun & Dahl, 2006). In an Australian population with anxiety disorder and depression, less than half sought consultation for their mental health problems. Social anxiety disorder, in particular, is known to be associated with distinctive treatment barriers. Other research supports the popular belief that males are reluctant to seek help from health professionals. Men are less likely than women to seek help for problems as diverse as depression, substance abuse, physical disabilities and stressful life events according to Padesky and Hammen 1981, cited in Addis & Mahalik, 2003).

Anxiety disorders are also regarded as having economic as well as social consequences (Andrews, Henderson & Hall, 2001). However, the economic costs of anxiety disorders (such as decreased productivity) are difficult to measure (Bystritsky, 2006). While largely unmeasured, they are of relevance to individuals, their families, and to primary care and specialist mental health services (Patel, Knapp, Henderson & Baldwin, 2002). Although anxiety sufferers are often reluctant to seek help, anxiety disorders are still believed to have a serious impact on the health care sector. Andrews et al. (2001) said that impact is explained not by the cost of treatments of the disorder but by the high cost of frequent medical evaluations and treatment of physical manifestations of the disorder (e.g. muscle pains and aches). Mendlowicz and Stein (2000) found that the cost associated with anxiety disorders in the United States accounts for approximately 30% of total expenditures in that year for mental health.

While anxiety disorders are the largest and the most prevalent group of psychological disorders, they are also the most poorly understood, least recognized and inadequately treated, according to Bystritsky (2006). Anxiety disorders are also under-studied, according to Andrews, Henderson and Hall (2001). Most research into anxiety disorders is conducted as an adjunct to comorbid depression and relates to the provision of treatment of depression. Research is generally conducted under the auspices of healthcare providers, and does not necessarily consult or reflect the views of healthcare users.

Critics such as Thomas (2009) suggest a research bias may exist that favours clinical research into the biomedical causes and pharmaceutical treatment of depression. Granek (2006) also noted that the goal of modern psychological research is to test the efficacy

of treatments for various mental disorders, thus resulting in very little research on “no-treatment” outcomes for conditions such as depression (p. 192). She found very few studies aim simply to observe the process of a psychological condition. Law (2006) would argue this is a reflection of the influence and interests of psychiatry and ‘big pharma’ (the pharmaceutical manufacturing industry). Many, including feminist writers, have challenged society’s unquestioning acceptance of what they call ‘biopsychiatric rhetoric’ (p. 459) and say there is a need to raise awareness about how this discourse is perpetuated in direct and indirect ways (Cosgrove, Pearrow & Anaya, 2008). One such discourse is that mental disorder is a brain disorder and mental distress is caused by biochemical imbalances which can be corrected by prescribing psychiatric medications (Heifner, 1996).

Others lament how the biomedical model has become the dominant model in the explanation of emotional disorders, to the exclusion of other possible alternative socio-cultural, political or economic models and how this has come to be reflected in the research. Although dissatisfaction is frequently expressed with the biomedical model, it has become well entrenched in societal discourse on mental disorder (Granek, 2006). At the heart of the biomedical model is the process of diagnosis, which is integral to the theory and practice of medicine. According to Brown (1995) “diagnostic classification is the language of medicine” (p. 39). He also defined diagnosis as “representing the time and location where medical professionals and other parties determine the existence and legitimacy of a condition” (p. 38).

### ***The Present Study***

It seems likely, therefore, that receiving an official mental disorder diagnosis would represent an important and pivotal moment in a person’s life. However, there is a paucity of literature on what the conferment of a mental disorder diagnosis actually means to its holder (Frese & Myrick, 2010). This is very surprising given that diagnosis is not without controversy, and that it is purported to have many implications for the recipient, both positive and negative. Furthermore, there seems to be little research that adequately describes the personal experiences of people who have been diagnosed with anxiety disorders. Nor is there research that captures individuals’ reflections on their condition. As Kent and Read (1998) pointed out, having been educated about mental disturbance at first hand, clients and their families are themselves experts in their own right, with invaluable experience to contribute. Therefore is unfortunate that the

viewpoints of sufferers have not been well considered in all that has been written about anxiety disorders.

Therefore it is important to investigate how persons with an anxiety disorder conceptualize and understand their condition. The aim of this study is to explore the perspectives of people who have received a diagnosis of an anxiety disorder, rather than the perspectives of healthcare providers or the people who are conferring the diagnosis. It is hoped these individuals' shared experiences of anxiety and subjective accounts will promote greater understanding of how they view their condition. It is an objective of this study to gain a better understanding of the circumstances and symptoms experienced by anxiety sufferers and it is hoped the shared stories of the seven participants may assist in illustrating the nature of anxiety disorders.

## Chapter Two - Aetiology of Anxiety Disorders

Psychopathology, including anxiety disorders, is generally regarded to be the result of multiple influences and consideration of aetiology should include biological, psychological, environmental and social dimensions, as per the bio-psycho-social model (Sadock & Sadock, 2007). Suarez, Bennett, Goldstein and Barlow (2009) further proposed a model of 'triple vulnerability' consisting of generalised biological, or heritable vulnerability, generalised psychological and specific psychological diatheses.

In the case of anxiety disorders the generalised psychological vulnerability is based on early experiences that contribute to the development of a sense of control over salient events and the more specific psychological vulnerability is associated with learning experiences that focus anxiety on specific objects or situations (Suarez, Bennett, Goldstein & Barlow, 2009). Anxiety disorders are therefore differentiated by the specific perceptions of threat and avoidance (Hunter & Schmidt, 2010). These may include specific phobias such as the fear of needles, concerns about vague negative outcomes that are the content of chronic worry in GAD, or the 'fear of fear' that characterizes panic disorder (Hunter & Schmidt, 2010).

Muris (2006) pointed out there are a number of developmental pathways to disorder. A generalized or specific biological vulnerability has been discovered through family studies in that individuals with parents who have psychopathology are more likely to have some form of psychopathology themselves (Biederman et al., 1990). In this regard it is thought that certain biological character traits can be inherited, for example, shyness has been identified as a risk factor in developing phobias (Sadock & Sadock, 2007). Kagan (1994) found that the trait of inhibition or shyness can be evident as early as four months of age. However there is a complex interplay between biological and environmental factors, which has been called 'environmental biology' by Maxmen, Ward and Kilgus (2009). While genetics have some influence, the impact of other factors must be taken into consideration when contemplating the development of disorder.

Gender has also been implicated. Females are said to be more susceptible to internalising disorders such as depression and anxiety (Fergusson, Swain-Campbell &

Horwood, 2002). However the sex differential prevalence is one of the more controversial issues in terms of mental disorder diagnoses (Hartung & Widiger, 1998). Feminist scholars have suggested possible socio-cultural explanations, including the features of women's lives that undermine well-being (Pugliesi, 1992). Others further suggest that findings of gender differences in mental health are artifactual because of sexism of psychiatry (Pugliesi, 1992). In the case of depression, feminist critics warn against an ever increasing biomedical discourse that positions depression as a medical condition. Ussher (2010) referred to this as 'the medicalization of women's misery' (p. 9). In reviewing the research literature associated with depression and anxiety it seems that the integrative bio-psycho-social model has been replaced with competing biomedical, psychological and socio-cultural models. Bebbington (1998) said sex differences alone cannot adequately explain the phenomenon of depression. A number of researchers agree that not enough attention is paid to influences in one's physical and social environment.

Read, Hammersley and Rudegair (2007) proposed 'acquired vulnerability' as the propensity to develop disorder as a result of negative life events or trauma. Relatedly, parental psychopathology is purported to be one of the biggest significant risk factors (Bogels & Brechman-Toussaint, 2006). Research has established the trans-generational transmission of childhood adversity (Scott, Varghese & McGrath, 2010). Bowlby's (1977) attachment theory is relevant here. Attachment issues between the primary caregiver and child may lead to psychopathology such as separation anxiety disorder (Rikhye et al., 2008). McLaughlin et al. (2010, cited in Scott et al., 2010) found that maladaptive family functioning is strongly associated with the persistence of disorder. All forms of abuse (and witnessing abuse) have been related to severe emotional and behavioural problems and predict a higher risk of anxiety and depression (Evans, Davies & DiLillo, 2008).

Family research suggests the possibility of an association between childhood shyness and parental social phobia (Cooper & Eke, 1999). It has also been found that modelling of parental behaviour is somehow implicated in the maintenance of disorder, for example parents of individuals with social phobia are significantly more socially fearful and concerned with the opinions of others and pass this concern onto their children. Dadds et al. (1996, cited in Crawford & Manassis, 2001) found that parents of anxious children tend to promote cautious and avoidant child behaviour by modelling

avoidance, vocalizing doubt in their child's abilities and providing acceptance and comfort when their child displayed such behaviour. Through the processes of operant and classical conditioning, maladaptive responses as coping strategies are learnt and reinforced by avoidance of anxiety provoking situations. Other research has shown that parents of individuals with social phobia are less caring, more rejecting and more over-protective than other parents (Kaplan & Sadock, 2007).

As per Beck's (1994) cognitive theory, dysfunctional beliefs are developed then internalised by the person and these cognitive biases and maladaptive emotional responses are thought to maintain fears and anxiety. Beck noted that anxiety is characterized by beliefs around helplessness, whereas depression is centred on hopelessness (1994, cited in Mineka, Watson & Clark, 1998). Similarly, healthy emotional responses or what Greenberg (2004) called 'emotion schemas' are not developed or under developed. He proposed that healthy psychological growth is based on having adaptive emotional experiences.

A diathesis-stress model is often used to explain the development and maintenance of anxiety disorders. Both internal and external diatheses (risk factors) are recognised as implicated (Mineka, & Oehlberg, 2008). Internal diatheses include genetics, behavioural inhibition, personality or dispositional traits and external stressors include adverse circumstances, such as exposure to unpredictable and uncontrollable stress, or early aversive learning experiences (Mineka, & Oehlberg, 2008). Also implicated in the development and maintenance of anxiety disorders are physiological and somatic symptoms, such as muscle tension, headaches and insomnia and the attention to which, maintains levels of anxiety and nervous arousal (Bourne, 1999).

It is thought that critical contextual factors influence what an individual learns to fear, how the distress is interpreted, and beliefs about how to go about getting help (Hunter & Schmidt, 2010). Strong family and social support has been linked to mental well being, while inadequate family and social support systems have long been linked to emotional disorder (Murray, 2005). Research shows that lacking a social network is associated with intensified symptoms, while social support acts as a protective factor (Rutter, 2010). A lack of necessary social skills may maintain disorder (Rapee & Spence, 2004).

In addition, broader social and cultural influences also demand consideration. Negative or overwhelming life experiences, such as neglect, abuse or bullying are implicated but also socioeconomic inequality, problems linked to migration, and employment may be relevant. Unemployment is thought to have a major effect on self esteem and symptoms of anxiety, somatisation and depression (Linn, Sandifer & Stein, 1985). Lewis (2006) identified three major groups who make up the bulk of psychiatric consumers: women, the poor and minorities. He pointed out that the socioeconomic oppression of these groups of people is rarely acknowledged in psychiatry. Further, as Kent and Read (1998) note, the way professionals tend to conceptualise aetiology has implications for the approach taken to treatment and its possible outcomes.

### **Chapter Three – The DSM and the Diagnosis of Anxiety Disorders**

The *Diagnostic and Statistical Manual of Mental Disorders* has become the main classification system of mental disorders, used around the world over the past 50 years (Cooper, 2004). While there are other classification systems such as the ICD-10 (the *International Classification of Mental and Behavioural Disorders* (published by the World Health Organisation), the DSM is the most commonly used. The current version is the DSM-IV-TR (Text Revision) which was published in 2000. The DSM-V is due to be published in 2013.

The DSM contains comprehensive descriptions, symptoms, and other criteria for categorizing mental disorders. It uses a multi axial system to organize each diagnosis into five levels (axes) relating to different aspects of disorder or disability. The American Psychiatric Association (APA) started developing this system of psychiatric nomenclature in 1933 (Malik & Beutler, 2002). The DSM evolved from systems for collecting census and psychiatric hospital statistics, and from a manual developed by the US army and was first published in 1952. Since that time the DSM has been reviewed and revised several times.

Frese and Myrick (2010) described the publication of the DSM III in 1980 as a pivotal development. They say it signalled a shift from relatively subjective and primarily psycho-dynamically oriented perspectives to a more objective and scientific framework. Each subsequent version of the DSM has attempted to improve reliability and validity through a more clearly described approach to assigning diagnoses (Frese et al., 2010).

Over the years the DSM has refined its definition of mental disorder. The DSM III defined it as a clinically significant behavioural or psychological syndrome or pattern that occurs in an individual and that is typically associated with either a painful symptom (distress) or impairment in one or more areas of functioning (disability). In addition there is an inference that there is a behavioural, psychological, or biological dysfunction, and that the disturbance is not only in the relationship between the individual and society (Cooper, 2004). However the DSM IV notes that mental/psychiatric disorders cannot easily be precisely operationally defined and that no definition adequately specifies precise boundaries for the concept of mental disorder (Stein, Phillips, Bolton, Fulford, Sadler & Kendler, 2010).

Mental health professions are anticipating the publication of the next edition (the 5th edition) scheduled for publication in May 2013. According to David Kupfer, chair of the DSM-5 task force, the DSM-5 should facilitate more comprehensive diagnosis (APA, 2011). In addition to proposed changes to specific diagnostic criteria, the APA is proposing that ‘dimensional assessments’ be added to diagnostic evaluations.

The DSM-5 will enable clinicians to evaluate the severity of symptoms, as well as take into account ‘crosscutting’ symptoms that exist across a number of different diagnoses. “We know that anxiety is often associated with depression, for example, but the current DSM does not have a good system for capturing symptoms that do not fit neatly into a single diagnosis; for example, the work groups are determining how to better assess the severity of symptoms and how to handle psychiatric disorders that often occur together such as anxiety and depression” said Kupfer (2011).

Bradley (2011) concluded that not only is anxiety under-represented and under-reported in clinical presentations and in research, it is also under-diagnosed or is likely to be diagnosed as depression. As the lines can be somewhat blurred between anxiety disorders and other comorbid conditions, such as depression, it is important to study how they are related, developmentally and temporally and how they present themselves. It is hoped this study may be able to contribute to a greater understanding of how anxiety and depression develop and that participants’ observations will lead to a greater understanding and correct diagnosis and appropriate treatment.

## Chapter Four - Pros and Cons of Diagnosis

Ever since the introduction of the DSM there have been many ongoing arguments both for and against the use of diagnosis (Adams & Quartiroli, 2010). Many argue against the need for psychiatric diagnosis and the inherent disease assumptions of the medical model. Following on from Thomas Szasz (1960), many critics view psychiatric diagnoses as the unnecessary medicalization of personal or emotional or social problems or what Szasz called 'problems in living' (p. 114).

However, psychiatric advocates say there are several advantages of diagnosis, not just for mental health professionals, but for clients as well. For clients it is generally proposed that accurate diagnosis should lead to appropriate treatment and understanding of the course and prognosis. According to Shea (1991, cited in Fong, 1993) DSM diagnosis serves to discover and organize information into a diagnostic schema that should lead to more effective methods of helping the client. Diagnosis can help determine the services clients need and provides information necessary for treatment plans, whether it be counselling, psychotherapy or psychiatric treatment strategies (Othmer & Othmer, 1989, cited in Fong, 1993). Diagnoses may also help with effective referrals to identify those clients whose problems extend beyond the clinician's area of competence (Eriksen & Kress, 2006).

Eriksen and Kress (2006) suggested another benefit may be that sometimes clients respond positively from an ostensibly concrete explanation of their behaviour and experiences. They said that receiving a diagnosis may be personally comforting to some people as a way of explaining behaviours or feelings that are upsetting. A diagnosis may offer clients freedom from self-blame and the ability to invest their energy more productively in resolving or managing their problems (Houts, 2002, cited in Erikson & Kress, 2006).

In a similar vein, White (2002, cited in Adams & Quartiroli, 2010) said some clients may prefer the certainty of a diagnosis to the uncertainty of their symptoms. Clients may believe that after they have been diagnosed with a mental disorder, there may be a simple treatment that leads to a 'cure' for their illness. Often, this belief alone encourages the client to actively participate in her or his treatment, leading to a positive outcome. White (2002, cited in Adams & Quartiroli, 2010) proposed that externalizing the problem creates the opportunity to create a strengths-based personal narrative,

allowing the client to separate his or her sense of self from symptoms and the process may focus the families of those diagnosed onto an identified cause, and away from blaming one another or themselves.

Other benefits of using the DSM for diagnosis are for health professionals. One of the main benefits is that it provides them with a common language to use (Hohenshil, 1993). According to Kutchins and Kirk (1989, cited in Hinkle, 1999) it can also assist researchers and theorists to compare various treatment approaches to particular problems. They said the DSM system has been a major facilitator of research efforts in numerous diagnostic and clinical areas that might have remained obscure if they had not been included in the DSM nomenclature. Another benefit is that it provides a common educational base in teaching psychology programs (Mead et al., 1997, cited in Adams & Quartiroli, 2010).

Another often quoted consideration is that ascription of a DSM diagnosis is usually required for entry into almost any service in the mental health care delivery system (Eriksen & Kress, 2006). As a matter of course, the DSM provides the standard means for mental health professions to be reimbursed by third parties for services, thereby allowing many clients to receive services. However, this third party requirement for a diagnosis has also been a criticism of the diagnostic system. Many argue that because of its economic power, influence, and popularity, the DSM is “the key to millions of dollars in insurance coverage for psychotherapy, hospitalization, and medications” (Kutchins & Kirk, 1997, cited in Kress & Eriksen, 2006, p. 12).

This relates to the broader critique of the increasing medicalization of human nature. According to critics of the diagnostic system this may be attributed to ‘disease mongering’ by pharmaceutical companies and psychiatrists, whose influence has dramatically grown in recent decades. They say this criticism is highlighted by how each new edition of the DSM contains an increased number of identified diagnoses.

In responding to these criticisms, then American Psychiatric Association President, Steven Sharfstein, released a statement in 2005 which conceded that psychiatrists had “allowed the bio-psycho-social model to become the bio-bio-bio model” (p. 477). Others have similarly argued that the DSM emphasizes the medical aspects and traditionally ignores or minimizes relational, contextual and environmental factors,

cultural issues, and client perceptions of their own problems (Ivey & Ivey, 1998, cited in Adams & Quartriloi, 2010).

Feminist writers Cosgrove, Pearrow and Anaya (2008) said that few clinicians and lay people are aware that the ‘very instruments’ mental health professionals rely upon for diagnosing and treating their clients are compromised by conflicts of interest (p. 459). They said that until recently, the public did not know that the organization that produces the DSM, the American Psychiatric Association (APA), receives substantial drug industry funding or that the majority of the individuals who serve as diagnostic and treatment panel members also have drug industry ties (Cosgrove, Bursztajn, Krimsky, Anaya & Walker, 2009). They investigated the experts on DSM panels for mood disorders, and found that 100 percent were funded by the pharmaceutical industry. This link is regarded as particularly problematic because psychopharmacology is the standard treatment in these disorders. Although this investigation related to mood disorders, psychopharmacology (including anti-depressants) has also become a standard treatment in anxiety disorders (Baldwin, Anderson, Nutt, Bandelow, Bond, Davidson et al., 2005).

Over the years, a large group of scholars have argued there may be potential harm in imposing DSM values onto clients. Honos-Webb and Leitner (2001) said there is potentially a negative impact of psychiatric labels on clients’ self-esteem, self-efficacy and on the therapeutic relationship. The application of diagnostic labels has historically stigmatized and hurt those who are different from the mainstream according to Caplan (1995, cited in Kress & Eriksen, 2006). The DSM’s historical labelling of homosexuality as a mental disorder is often cited as an example of diagnosis being used as a form of social control in what is demarcated as normal or abnormal (Brown, 1995). Brown (1995) further described diagnosis as the “politics of definitions” (p. 35), whereby illness designations are created from social conflict and diagnosis provides a lens for viewing many of the social conflicts which revolve around issues of medicine and health.

Link, Struening, Neese-Todd, Asmussen and Phelan (2001) found that people labelled with mental illnesses have consequences of stigma on their self-esteem and that stigma is a barrier to recovery. The influential Carl Rogers (1951, cited in Honos-Webb & Leitner, 2001) and other humanistic psychologists have long argued that diagnoses do

not facilitate the therapeutic process. Rosenhan (1973, cited in Erikson & Kress, 2006) wondered if diagnostic categories lead people to accept a 'self-fulfilling prophecy' that their situation is hopeless and that they are sick. It has been often claimed that the DSM uses definitions and terminology that are inconsistent with a recovery model, and that can erroneously imply excess psychopathology, for example multiple "comorbid" diagnoses or "chronicity" (Lopez et al., 2006, cited in Adams & Quartiloi, 2010). Glasser (1998, cited in Adams & Quartiloi, 2010) believes that the diagnosis of disorders shifts the responsibility for life choices away from the individual. According to Goncalves, Macahdo, Korman and Angus (2002) the act of diagnosing may preclude a focus on the client's narrative construction of his or her personal experiences.

Others say that contextual behavioural assessment has become overlooked in preference for assessing signs and symptoms for the purpose of diagnosis. They say taxonomies (classification systems) are by nature descriptive, static, and uni-dimensional (Erikson & Kress, 2006). While the DSM has (in Axis IV) recognition of life stressors and the Global Assessment of Relationship Functioning, they provide relatively little context. They say the DSM's focus on signs and symptoms of disorders draws attention away from clients' subjective attributions about their life experiences and symptoms. Finally, the DSM system does not suggest or require contextual input into the diagnostic process itself.

According to Kress, Hoffman, and Eriksen (2010) there are also numerous ethical considerations inherent within the process of assigning a DSM diagnosis. They identified issues including accuracy of diagnosis, informed consent and confidentiality. Informed consent as it relates to diagnosis means that psychologists offer enough information about diagnosis for clients to responsibly consent to diagnosis and to treatment that is based on that diagnosis. Grover (2005) suggested that informed consent may not be truly informed in that the full implications of having the diagnosis and of having it communicated to others may not be adequately understood by the client at the time consent is granted. Welfel (2002) said that at a minimum, psychologists need to inform clients at the beginning of therapy that they may receive a diagnosis and subsequently inform them about what actual diagnosis is given.

Even the authors of the DSM have acknowledged that its diagnoses and criterion sets are highly debatable and have led to fundamental disagreements amongst clinicians

(Widiger & Clarke, 2000). In revising the DSM, work groups (made up of global experts in various areas of diagnosis) have looked at what elements of the DSM could be improved. With DSM-5 the public was invited to comment on its development via a website [www.dsm5.org](http://www.dsm5.org). Frese, Keris and Myrick (2010) pointed out that while consumers and families have been more and more involved in research and treatment policies, there has not been the same degree of consumer/family involvement in diagnostics.

The diagnostic process is therefore widely acknowledged as a critical and controversial process. The process is fraught with complexities for both the diagnoser and diagnosee and there are important ramifications such as access to healthcare services and treatment funding. However, in spite of continuing debate about the diagnostic system, its use is well established in the mental health profession and diagnoses are used daily (Eriksen & Kress, 2006).

The various debates in the literature highlight the various agendas that can conventionally impact the diagnostic process. The approach of this study is to understand the diagnostic process from the point of view of the client. This perspective should not only be free of any particular agenda, but may also create an opportunity for participants in the research to reflect on and draw attention to particular events which they see as significant or may have caused them concern.

## Chapter Five - Literature Review of Quantitative Research

Besides epidemiological and statistical surveys, very little research has been carried out specifically on anxiety disorders, which is surprising given that anxiety disorders represent the most prevalent type of mental disorder.

In New Zealand the most commonly quoted research is Te Rau Hinengaro New Zealand Mental Health Survey (2006) which, as already mentioned, has collected information on the prevalence, severity, impairment and treatment of major mental health disorders. New Zealand has long running world class longitudinal studies, namely the Dunedin Multidisciplinary Health and Development Study and the Christchurch Health and Development Study (CHDS). The CHDS has gathered information on the health, education and life progress of a group of 1,265 children born in Christchurch during mid 1977. The study has collected data on the rates of psychiatric disorder and has identified developmental and risk factors for mental health problems. The Dunedin study has a cohort of 1,037 people born over the course of a year (1972-3) in Dunedin. Using this cohort, Fergusson and Horwood (2001) established that adolescents with anxiety disorders are at an increased risk of subsequent anxiety, depression, illicit drug dependence, and educational underachievement as young adults.

Both in New Zealand and overseas the amount of research on anxiety disorders is minimal in comparison to that generated on depressive disorders. Even though they are distinct disorders research that has been done on anxiety disorders seems to be done as an adjunct to, or secondary to research on depression. One example of such research is that by Tylee (1999), who investigated unrecognized depression and comorbid anxiety in patients visiting their primary care physician.

Researchers' and clinicians' greater focus and emphasis on depression may have several possible explanations. Depression may be what motivates people to visit their doctor and this condition may be seen as requiring more urgent attention and treatment and therefore, naturally becomes the primary focus of research. Other factors include the high comorbidity between the conditions and that anxiety disorders are often treated with anti-depressant medications anyway. However critics such as Newnes (2004) say there is a research bias towards the investigation and treatment of depression and this

may reflect psychiatry's powerful and ever expanding medicalization of depression, which can be profitably treated with anti-depressant medications (Law, 2006).

It does seem that most of what has been written about anxiety disorders is largely embedded in the biomedical model and very little has been written with regard to the lived experiences of people diagnosed with an anxiety disorder. In addition because the majority of research into anxiety disorders (and other psychological conditions) is embedded in a psychiatric biomedical model, it is usually quantitative in nature.

Most of the research into anxiety disorders is generally carried out from the perspective of health care providers and is usually concerned with the management of people as patients. Typical studies look at access to healthcare services and treatment outcomes, for example, Prins, Verhaak, Bensing and van der Meer's (2008) review described the perceived healthcare needs of psychiatric patients and non patients. Beal et al. (2007) noted that while consumers of mental health care should have a vital role in contributing to the organization, delivery and evaluation of services and development of their plan of care, this is often lacking.

'Quality of life' surveys are another common methodology to quantify the lives of persons with anxiety disorders. Of benefit is that quality of life assessments have been instrumental in exposing the extent and seriousness of anxiety disorders. Mendlowicz and Stein (2000) found an almost uniform picture of anxiety disorders as markedly compromising quality of life and psychosocial functioning. They also found that significant impairment can also be present in individuals with sub threshold forms of anxiety disorders. Other studies such as Rapaport, Clary, Fayyad and Endicott's (2005) study found significant quality of life impairment, although the degree of dysfunction varied. Barrera and Norton (2009) showed similar degrees of quality of life impairment across generalized anxiety disorder (GAD), social phobia and panic disorder.

Specific research on people's experience of the diagnostic process is mainly concerned with medical disease diagnosis. In terms of psychiatric diagnosis, research is generally broad based and looks at the spectrum of psychiatric disorder. Jacob's (2006) paper highlighted the issues related to the diagnosis and treatment of common mental disorders in primary care. He found differing conceptual models and perceptions are used in different settings and that psychiatrists use medical models, whereas general practitioners focus on the psychosocial context, stress, personality and coping.

Although psychiatric diagnoses are made on a regular basis, research that deals with the process or outcome or utility of diagnosis from the service user's perspective is scarce. Given the controversies that surround the assignment of a diagnostic label it is surprising how little research has been done on how anxiety diagnoses are communicated, received and incorporated into a person's life. The views of the diagnosed have not been readily sought.

One type of research relevant to this study is that by consumers. A consumer is a person who has accessed psychiatric services and been given a DSM diagnosis. Articles have been written and published in professional journals by persons who have been diagnosed with serious mental illnesses (e.g. Baxter, 1998; Chadwick, 2007; Deegan, 2007; Frese & Davis, 1997, cited in Freese & Myrick, 2010). Many, such as Kent and Read (1998) advocate for greater consumer consultation and input in the decision making process. Some consumer advocates actively campaign against the diagnosis of mental disorders or its assumed implications. Others believe a bio-genetic explanation and medical diagnosis of 'mental illness is an illness like any other' approach, as enabling freedom from blame and possibly less stigma, although this is highly debated (Read, Haslam, Sayce & Davies, 2006).

Frese and Myrick (2010) lamented a dearth of research related to matters of diagnosis and how it impacts consumers. In their quasi-qualitative study into depression they collected opinions about the diagnostic process from a selected sample of consumers. Gathering information through personal stories from various consumers provided valuable insights into how a psychiatric diagnosis is constructed, deconstructed, understood and utilized. The themes they gathered clustered into the following areas: billing, insurance and 'big pharma', labelling and stigma, axis issues, multiple and/or changing diagnoses. These themes may be of relevance in this study.

Research of anxiety disorders is limited in general and, what little has been done is largely embedded in the biomedical model (Prins et al., 2008). As a result, the majority of research into anxiety disorders (and other psychiatric conditions) is usually quantitative and positivistic in nature and therefore limited to observable behaviours. Very little has been written with regard to how people diagnosed with an anxiety disorder experience, interpret and understand their disorder.

## Chapter Six – Literature Review of Qualitative Studies

Unfortunately there are very few qualitative studies into anxiety disorders, and, as found with quantitative studies, most studies tend to focus on people's experience of depression. Additionally the few qualitative studies that do involve anxiety disorders similarly focus on patients' perceived health care needs. An example of such a study is one from the United Kingdom by Kadam, Croft, McLeod and Hutchinson (2001) who explored 27 patients' perspectives and preferences in relation to their healthcare needs for their depression and anxiety. Interestingly, the authors point out that typically the doctor's perspective on these problems has been considered, yet in all these controversies the views of the patient have not been readily sought. They also said this is surprising given the vigorous debate on the contrast between biomedical and socio cultural definitions of mental problems.

A number of studies identified themes that may also be relevant to the qualitative study of anxiety. Epstein, Duberstein, Feldman, Rochlen, Bell, Kravitz, Cipri, Becker, Bamonti and Paterniti (2010) conducted focus groups on people's personal and vicarious experience with depression. However, again, the aim of the study was to better understand patients' inner experiences prior to and during the process of seeking treatment to improve recognition and management of depression in primary care. Participants described three stages leading to engaging in care for depression; knowing (recognizing that something was wrong), naming (finding words to describe their distress) and explaining (seeking meaningful attributions). The clinical and colloquial use of word 'depression' was noted as problematic. Some participants' narrow concept of depression interfered with recognition and acceptance of the diagnosis. In one focus group, women expressed confusion about why only one word, 'depression' was used to describe such diverse experiences, time courses, and treated disorders.

Granek (2006) has lamented the lack of in-depth qualitative research on the experience of depression (let alone anxiety). She said that because depression has been considered a medical disorder by psychiatry, it has been researched through "objective" positivist empirical methods (p.191). She investigated depression from a subjective perspective and found it to be a complex process that is largely a relational phenomenon, with the core experiences of participants being social isolation and alteration in relationships with others. Participants described being depressed as a feeling of being lonely and

isolated from others. They felt uncomfortable around people and were anxious and agitated in public, causing further withdrawal from others and more isolation, yet all participants talked about craving connection and a desire to be with other people while feeling unable to do so. Along with feeling disconnected, confused, fragmented and in great pain, participants also reported feeling anxious and nervous. She argued that the DSM-IV's list of symptoms tends to ignore such relational features. Anger toward others and 'cavernous self-loathing' also occupied the minds of the participants (p. 199). She noted that anger (which is not part of the DSM-IV definition) to be a very large part of participants' experiences of depression. She wondered why anger has been left out of the dominant discourse on depression and concluded that because anger is a relational feeling in that it is directed toward someone or something, it cannot be part of a DSM definition that considers only the individual in its scope. She concluded that the traditional medical, objective conceptualization of depression is inadequate for understanding the totality of the depressed experience and that more emphasis should be placed on the 'subjective' aspect of the condition.

Bradley (2011) also suggested that a more in depth understanding of individuals' experience of depression is required. Her study concluded that the current medical model of depression is insufficient to conceptualize and guide treatment pathways and that a social/contextual model might provide a more useful extension to the understanding of depression, with context and individual experience being paramount.

A number of other researchers have described current conceptualizations of depression as inadequate. Farmer (2002) found that approximately 70% of adolescents with major depression are not receiving adequate assessment and treatment due, in part, to an incomplete picture of the disorder. She said developmental principles, salient contextual events, and an adolescent viewpoint of precipitators, symptoms, and treatments are lacking. Her in-depth interviews found that participants focused on anger, continuous fatigue, and interpersonal difficulties as characteristic of depression. Eight themes were found, including a dispirited weariness (characterized by continuous fatigue) distressing physical symptoms (including headaches, dizziness, and insomnia), decreasing grades, loss of academic self-esteem and unrelenting anger which also included criticism of self and others).

Similarly Wisdom and Green (2004) said they were unable to find any explorations of teenagers' experiences of depression. They interviewed 15 adolescents with diagnoses of depression and found that adolescents reacted to their diagnosis in one of three manners: "labelers" reported hearing the diagnosis with relief. They saw it as confirmation that their distress had a name and that they were not the only person ever to experience these symptoms. The diagnosis provided a label that was helpful in categorizing their symptoms and in giving them new ways to make sense of their distress. These teens utilized it as a label that benefited their attempts to recover and tended to be interested in getting information about interventions to reduce symptoms; "medicalizers" took on a patient role consistent with the medical perspective of depression that required medical treatment and tended to view their health care provider as responsible for "fixing" the problem; "identity infusers" accepted the diagnosis as an immutable part of their personality that could not be changed and correspondingly, tended to be more pessimistic about the likelihood of recovery.

McCarthy, Downes and Sherman (2008) conducted a qualitative study involving semi-structured interviews of nine young adults who were diagnosed with and treated for major depressive disorder between the ages of 15 and 18. Five themes emerged from the interviews: talking to a counsellor about their depression was helpful; participants obtained relief in their counselling and expressed respect for their professional helpers; parental (and adult) partnerships are important; friends of the adolescent clients were usually helpful to them; and the adolescents possessed a realistic optimism concerning a possible subsequent depressive episode.

Again there is only limited research into clients' understanding of receiving a mental illness diagnosis. A study by Shergill, Barker and Greenberg (1997) investigated how communication of psychiatric diagnosis was perceived by psychiatrists and patients, and how it was influenced by diagnostic category. They examined whether psychiatric patients knew their diagnosis, the significance they attached to it, and the impact of being informed in a systematic fashion according to their wishes. They also assessed whether the nature of the psychiatric diagnosis influenced what patients were told by their psychiatrists.

A study into the subjective experiences of patients newly diagnosed with bipolar disorder was conducted by Proudfoot, Parker, Benoit, Manicavasagar, Smith and Gayed

(2009). They found participants had both positive and negative reactions to diagnosis. Patients often placed a subjective meaning on the diagnostic label of bipolar disorder and questioned in an existential way what the diagnosis meant about them as a person and their sense of self. Another possibly relevant theme was its implications for the future - what a diagnosis means in terms of the rest of their lives. Of particular concern to participants was the stigma associated with the label. The experience of stigma has been investigated by qualitative researchers. Dinos (2004) explored stigma in the experiences of health care of people with enduring mental ill health. Knight, Wykes and Hayward (2003) used Interpretative Phenomenological Analysis (IPA) to investigate stigma in schizophrenia. No study could be found on the phenomenon of stigma in relation to anxiety disorders.

One study that did incorporate the perspective of patients was that by Salmon, Peters and Stanley (1999), but in regard to somatisation disorders. They performed a qualitative analysis of verbatim records of interviews to describe distinguishing features of doctors' attempts to explain their symptoms. Results show that doctors' explanations were often at odds with patients' own thinking. The conclusion reached was that empowering explanations could improve these persons' wellbeing and help to reduce the high demands they make on health services.

A qualitative study by Haslam, Brown, Atkinson and Haslam (2004) investigated anxiety disorders in the work place. They found that many people experienced side effects from medication and felt poorly informed about these. Of interest they also found that the family practitioner is regarded as a focal point for help, but people find it difficult to disclose their distress.

Case studies are another medium for exploring the subjective experiences of people with psychiatric disorders. Rhodes and Smith's (2010) case study explored the experience of depression with the aim of describing what it is actually like to be depressed. Honos-Webb and Leitner's (2001) case study is said to illustrate the potential for the application of a DSM diagnosis to exacerbate clients' symptoms and inhibit the healing process in psychotherapy.

In conclusion, while there is an existing body of research that explores various aspects of the subjective experience of depression, there is surprisingly little research been undertaken into the subjective experiences of people diagnosed with anxiety disorders.

Research that has been done is typically set in a medical context and is generally from the perspective of service providers. The scant research that has been done from the perspective of service users usually focuses on their perceived needs and preferences for treatment, and is often without reference to the diagnostic event.

Interestingly research that has been done highlights how service users and service providers often have differing perspectives. Therefore first-hand accounts are needed as to what people with anxiety disorders say about the utility of diagnosis.

The limited number of quantitative studies is also mirrored in the few qualitative studies into anxiety disorders. Similarly, both kinds of studies into disorder tend to focus on people's experience of depression. The few studies that are about anxiety disorders also tend to focus on patients' perceived health care needs rather than focusing on the patient's perception of causes and influences on their condition. In addition most research has been conducted in the United Kingdom or the United States. With New Zealand having relatively high statistical rates of anxiety disorder, and with anxiety disorders on the increase in New Zealand, it is imperative that researchers build a literature base with reference to the New Zealand context.

## Chapter Seven - Overview of The Present Study

### *Methodology*

Social science research has arrived at an age of post-positivism, according to Ryan (2006). Epistemology is now grounded in the idea that reality exists but never can be fully understood or fully explained, given both the multiplicity of causes and effects and the problem of social meaning (Fisher, 2005). As a consequence it is commonly held that there is a multiplicity of theoretical perspectives and explanations that bear on a phenomenon. Therefore is generally accepted that a variety of research methodologies including both qualitative and quantitative and ranging from large-scale epidemiological studies to single case designs can be useful in providing insight into a particular phenomenon.

In her critical review of why women experience higher rates of depression than men, Ussher (2010) explained how the biomedical model adopts a realist epistemology and discourse of medical naturalism, to position depression as a “naturally occurring pathology within the woman, caused by biology, cognitions or life stress” (p. 9). While feminist critics argue that such a biomedical model negates the political, economic and discursive aspects of experience, Ussher (2010) made the point that the alternative model of social constructionism may appear to “dismiss the ‘real’ of women’s distress, and deny its material and intrapsychic concomitants, as well as negate relevant research findings” (p. 9). As an alternative, Ussher (2010) proposed ‘critical realism’ as an epistemological standpoint that lies between the two apparently oppositional positions of positivism/realism and constructionism, so that the materiality of somatic, psychological and social experience is recognized but conceptualizes how individuals construct their world or reality as mediated by culture, language and politics.

Such a standpoint seems applicable to the purpose of this study, which seeks to learn more about the real and felt experiences of people with anxiety disorders, while recognizing the social context and customs in which people exist. Not only are mental disorders societal constructions that can and have changed over time, but also are the research endeavours that attempt to study them.

Without doubt the concept of mental disorder is complex and highly contested. However it is relevant to talk to the people who have been diagnosed and hear their points of view. This research is primarily exploratory and descriptive in nature, with emphasis on how participants describe and explain their diagnosis and what their diagnosis means to them, therefore a discursive and contextual social inquiry is deemed appropriate.

The research is also designed to discover meaning in what emerges out of the participants' accounts and therefore the process is inductive. Exploring the data first, before developing theory, will hopefully provide different explanations and insight. The process of analysis necessarily involves interpretation from the researcher's part, while being aware that researchers interpret the meaning of their results against a range of explanations and understandings that themselves are products of other interpretations (Fisher, 2005).

### ***Rationale for choosing a qualitative approach***

Generally speaking, this research is in keeping with the aims of qualitative researchers who try to capture the experiences and perspectives of people. Willig (2008) described qualitative approaches as subjective, relating to experience or knowledge as conditioned by personal mental characteristics or states, and preferring language and description. Bryman (2008) said that qualitative researchers express a commitment to viewing events and the social world through the eyes of the people they study. It searches for meaning in the accounts and/or actions of participants' thoughts and feelings. Of relevance is that qualitative researchers are interested in exploring the meanings by which individuals understand their social circumstances (Hatch, 1985, cited Hatch, 2002). In addition, qualitative research allows for a great variety of perspectives, methods, and strategies and qualitative approaches are incredibly diverse, complex and nuanced (Holloway & Todres, 2003).

Qualitative approaches place much greater emphasis upon the way in which the world is socially constructed and understood (Blaikie, 2000, cited in McEvoy & Richards, 2006). The research methods are typically small-scale but intense, and the interaction between the researcher and the participants in the study is seen as an integral part of the research process (Philip, 1998, cited in McEvoy & Richards, 2006). Participants are selected

using purposive or theoretical sampling approaches on the basis of how useful they are likely to be for the pursuit of the inquiry.

As previously mentioned there is a paucity of qualitative research into anxiety disorders. This may not be surprising as the area of qualitative investigation within psychology has been under developed in general and quantitative studies have been the mainstay of psychological research to date. As Hammen and Watkins (2008, cited in Rhodes & Smith, 2010) said, qualitative studies offer an important way to explore phenomena in depth and can be thought of as complementary to quantitative work. In fact, personal descriptions of life experiences can serve to inform knowledge about neglected, but significant areas of the human realm (Polkinghorne, 2007). As Runciman (2002) proposed, qualitative research can be particularly useful where problems are “complex, contextual and influenced by the interaction of physical, psychological and social factors” (p. 146).

Instead of beginning with preconceived hypotheses, qualitative researchers seek to discover them in data collection and analysis (Hill, Thompson & Williams, 1997). This approach is especially useful in the early stages of previously unexplored topics (Hill et al., 1997). As mentioned, qualitative approaches allow for an open-ended starting point to the investigation (Holloway & Todres, 2003).

Qualitative researchers take the broad philosophical approach of person-centeredness (Holloway & Todres, 2003). As McAdams (2006) said a growing number of psychological theorists, researchers, and therapists agree that people create meaningful selves through the individual and social construction of coherent life stories. Neimeyer and Raskin (2000) also emphasized the importance of allowing persons to be the experts on their own experience. Honos-Webb and Leitner (2001) advocated strongly for the adoption of the credulous approach: taking what the client says at face value. In this way it is hoped this study will obtain a rich supply of idiographic and contextual data.

The starting point to Granek's (2006) research was that people have a consistent notion of a 'self' and can thus reflect and accurately report on their experiences. Her approach began by deconstructing mainstream psychology and the assumptions surrounding depression and looked at how depression is understood from the subjective experience of the person experiencing it. As such, this research aims to explore participants' life

experiences, their reality, exploring all possible factors from each participant's perspective in relation to the context of their anxiety disorder.

### ***Rationale for using thematic analysis***

Thematic analysis is a widely used method for analysing qualitative data in various fields of social science research, including psychology (Boyatzis, 1998; Braun & Clarke, 2006; Bailey 2007). It provides a flexible and useful method for identifying, reporting, and analyzing data for the meanings produced in and by people, situations and events (Silverman, 2006). Data can be minimally organised and described and at the same time provide a rich and detailed, yet complex account (Braun & Clarke, 2006).

Thematic analysis is also a flexible methodology in that it is not linked to specific theories. Holloway and Todres (2003) identify "thematizing meanings" (p. 347) as one of a few shared generic skills across qualitative analysis and offers theoretical flexibility. This level of analysis ensures that identified themes remain largely the perspective of the participants. This present research is an attempt to construct a psychological understanding of the participants' experience of their anxiety disorder through their use of narrative to construct, refer to and make sense of their experience (Tamboukou, Squire & Andrews, 2008).

Although thematic analysis is a useful tool for identifying, analysing, and reporting patterns (themes) within data it often goes further than this, and interprets various aspects of the research topic (Boyatzis, 1998). Discussion of the data involves deeper analysis and interpretation at which time the significance of the identified patterns will be theorized and compared to previous literature (Floersch, Longhofer, Kranke & Townsend, 2010.)

A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set. An inductive approach (from the bottom up) can be taken, meaning that the themes identified are strongly linked to the data themselves (Patton, 1990). Inductive analysis is therefore a process of coding the data without trying to fit it into a pre-existing coding frame, or the researcher's analytic preconceptions. In this approach, if the data have been collected specifically for the research, the themes identified may end up bearing little relationship to the specific question that were asked of the participants (Braun & Clarke, 2006).

Other analytical decisions revolve around the level at which themes are to be identified: at a semantic or explicit level, or at a latent or interpretative level (Boyatzis, 1998). A thematic analysis typically focuses exclusively or primarily on one level. With a semantic approach, the themes are identified within the explicit or surface meanings of the data and the analyst is not looking for anything beyond what a participant has said. The aim is to create a comprehensive account of significant themes. As with the nature of qualitative research these themes arise from the dialogue.

### ***Analytic procedure***

The analysis focuses on thematic discovery from the transcripts of interviews with participants. The analytic procedure adopted was in keeping with Braun and Clarke's (2006) six phases of thematic analysis. The first phase involved reading and rereading the transcripts many times to become familiar with the data. Phase two involved generating initial codes and then systematically examining, identifying and collating data relevant to each code. Codes identify a feature of the data that appears interesting to the analyst, and refer to "the raw data or information that can be assessed in a meaningful way" (Boyatzis, 1998, p. 83). This is time consuming as any text can contain a number of different codes. Pope (2000) described a process called 'constant comparison', in which each item is checked or compared with the rest of the data in order to establish analytical categories. The third phase was consideration of all possible themes. Patton (1990) formulated dual criteria for judging categories of internal homogeneity and external heterogeneity, meaning that data within themes should cohere together meaningfully, while there should be clear and identifiable distinctions between themes. Reviewing these themes made up the final phases of analysis to define and name the themes and refine the specifics of each theme. The final report aims to provide a coherent and interesting account of the data, within and across themes.

### ***Method***

Qualitative research allows for different types of interviews (e.g. structured, focused or semi-structured, unstructured and group interviews) (Moyle, 2002). For this study, it was anticipated that a face to face, unstructured interview style with open ended questions would allow for flexibility of response and facilitate responses that are somehow more meaningful to participants. Social researchers such as Reinharz (1992) advocated free interaction between interviewer and interviewee to give participants the freedom to express their own story in their own words.

Bryman (2008) outlined an appropriate style of unstructured interview which has a list of topics to be covered as an “interview guide” (p. 196). Interview guidelines for the present study appear in Appendix E. Introductory questions were designed to set up the interview and revolved around “What is your diagnosis and by whom and when were you diagnosed?” The main question was “Tell me how you came to be diagnosed with an anxiety disorder?” and was designed to encourage participants to use their own words to reflect on and describe their condition. This would allow for follow up questions and discussion on participants’ responses. The intention is for the discussion to be participant led as much as possible without being overly shaped by the nature of the questioning. Other questions were on hand to serve as prompts if needed and included: “What did the diagnostic process involve? How and what do they communicate to others about their diagnosis?” Of interest also is whether they have found receipt of a diagnosis to be helpful or harmful. Discussion would end with an enquiry “Is there anything else that we haven’t covered that you would like to share?” Another major consideration is participants’ comfort, for example they cannot be rushed in the interview process (Shreffler 1999; Haggerty & Hawkins, 2000; Strauss et al., 2001, cited in Moyle, 2002) so no specific time limit was put on the interview. However an indication was given that interviews could take about one to two hours. Participants were told they were able to discontinue the interview or terminate the interview at any time they wished.

### *Participants*

Prior to recruiting participants, approval for the research was sought and granted by Massey University Human Ethics Committee (MUHEC) (see Appendix A). Permission was gained from the Phobic Trust Anxiety Disorders Clinic for their support in recruiting volunteers for the study. A flyer was placed on the reception desk at the clinic (see Appendix B). Volunteers were screened according to criteria (see Appendix C) which included that participants be over the age of 25 and had been diagnosed by a healthcare professional as having an anxiety disorder as their primary diagnosis. Health care professionals included GPs, psychiatrists and psychologists. This requirement was to ensure participants had received an official diagnosis. No distinction was made in type of anxiety disorder but excluded anyone who had recently been diagnosed (within the past six months). To qualify participants must be satisfied that they are able and willing to talk about their disorder.

As part of the screening process the researcher discussed the aims of the study with potential volunteers. They were told they would be encouraged to discuss and reflect upon their anxiety disorder diagnosis. They were also told that the researcher was interested in their experiences related to their disorder. Following a brief description of the research aims, participants were given the opportunity and time to contemplate participation. An information sheet explaining the purpose of the study was sent to potential participants (see Appendix D). A list of the types of questions that might be used in the interview as prompts, was provided to assist potential participants determine if they would like to proceed (see Appendix E). Each person was told that questions would be kept deliberately open, allowing cues for participants to talk with a minimum amount of interruption or constraint by the interviewer.

Participants were informed they could withdraw from the research at any stage and would still be given a \$30 petrol voucher as thanks. Participants were assured confidentiality and anonymity in the report and written consent was provided by participants (see Appendix F). Participants were made to understand they were being interviewed for research purposes and were reminded that the relationship would be one of research and not therapy (Shreffler, 1999; Haggerty & Hawkins, 2000; Strauss et al., 2001, cited in Moyle, 2002). However support would be made available to participants by way of resources at the anxiety clinic if requested. Participants were told if they experienced any discomfort during the interview the recorder would be turned off and it would be discussed whether the interview would be discontinued. During and following the interview, participants were asked about their level of discomfort and no one indicated experiencing distress. No participant chose to withdraw from the study.

The limited number of participants (7) is in keeping with other examples of in-depth qualitative research. As in other examples of qualitative research, no attempt was made to gain a representative sample and no distinction was made between male and female participants, or attempt made to recruit equal numbers of each gender. Seven participants were sufficient to provide enough data to reach saturation point in the themes (Guest, Bunce, & Johnson, 2006).

One participant was in her mid 20s, five participants were in their thirties and one in their early 40s. All had been diagnosed with at least one anxiety disorder by a health professional; three persons had been initially diagnosed by their GP, one person had

been seen by a university counsellor, then a psychologist, another by a workplace counsellor then a psychologist and one person had been first diagnosed by a psychologist and one person first diagnosed by a psychiatrist. Four participants had comorbid anxiety conditions and five of the seven had experienced some type of depressive disorder. All participants had received treatment and had either completed a course of therapy or were in the final stages of therapy. In total, four participants worked part or full time and two participants were studying at university. Five of the participants were married or in long term relationships. Pseudonyms were allocated to protect the privacy and confidentiality of participants. Demographic details which could compromise the anonymity of the participants have been omitted.

The participants were

- 1) Ruth, a female aged 25, was self employed and had worked only part time for the previous three years due to her illness. Ruth was in a long term defacto relationship. She was diagnosed by a psychologist two years previously with Generalised Anxiety Disorder, Post Traumatic Stress Disorder and Dermatillomania. She reported that she was eventually diagnosed with Dysthymic Disorder one year later. Ruth had never taken medications but had received Cognitive Behavioural Therapy (CBT) and Acceptance and Commitment Therapy (ACT), which she reported as being helpful. She was currently seeing her psychologist once a month. She reported that her symptoms for each of her diagnoses had generally improved, although sporadically.
- 2) Irene, a female, aged 31, was first diagnosed 10 years ago with Panic Disorder and Major Depression. Irene was married and was a part time student and also in casual employment. She was on medication and saw her GP for her prescriptions. In the past 12 months she had been seeing a counsellor and reported having experienced a definite, yet fluctuating, improvement in symptoms.
- 3) Amy, a female, aged 37. Amy was married and worked part time and was a part time student. She was diagnosed by a psychiatrist with Generalized Anxiety Disorder and Panic Disorder when she was a teenager. Four years later she was also diagnosed with Bipolar Disorder. She reported she remained on medication

and was under the care of her GP. She was not in therapy and reported feeling well over the past 12 months.

- 4) Yvonne, a female, aged 36, who had been diagnosed with Panic Disorder and Emetophobia (vomiting phobia) one year ago. Yvonne was married and worked full time. She had been attending regular sessions of CBT and other psychotherapy since her diagnosis.
- 5) Elaine, was a single female, aged 36, who lived with her parents. Elaine was currently not able to work and was on the Disability Benefit. Elaine was diagnosed four years ago with Social Anxiety Disorder, Obsessive Compulsive Disorder, Panic Disorder with Agoraphobia and Major Depression. She was on medication and was being treated by her GP. She was no longer in psychotherapy but had a peer support worker she saw weekly. She reported that she no longer felt depressed; however, she reported that while she was more socially active, she had had no substantial decrease in anxiety or panic attacks over the past 12 months.
- 6) Nadia, a female, aged 35, had Generalised Anxiety Disorder. Nadia experienced panic attacks from age 19, but did not know what they were and did not seek help from the mental health system until several years later. She also reported that she had health anxiety in the past. She was not taking any medications. Nadia worked full time and was single.
- 7) Tony, a male, aged 41, who was in full time employment and was married. He was diagnosed with Social Anxiety Disorder and Seasonal Affective Disorder by his GP within the last two years. Tony was no longer on medication and was exploring various therapeutic options. He reported that his depression, panic attacks and insomnia had been improving, but new symptoms had been popping up and he was not sure if they were related to increased social activity. Tony's GP was currently tracking his progress.

All participants expressed enthusiasm for the research project and the opportunity to tell their story in the hope that their personal contribution may assist a broader understanding of anxiety disorders. This is in keeping with Moyle's (2002) research experience that the opportunity for people to tell their story is important. Participants

themselves were aware that there was little published on what it is like to live with an anxiety disorder, such as social phobia, and were keen to be consulted and participate in the research process.

## Chapter Eight – Findings

### *Overview of findings*

Analysis of participants' narratives revealed consistencies that could be organised into five overarching themes: a traumatic early life, a troubled school life, problems with living, *rationalisation* and *post-rationalisation*. The first three themes emerged as a reasonably straightforward narrative in a chronological order that followed the time from when participants were very young to the time they sought help as adults.

The final two themes, *rationalisation* and *post rationalisation* relate to help seeking and diagnostic stages. The rationalisation theme refers to how participants viewed their diagnosis. Post-rationalisation refers to how, on reflection, participants use the diagnostic information to review and reflect on the course of their lives.

Other similarities in participants' accounts emerged during analysis and have been identified as sub-themes which assisted in organising the data and seem important in understanding some of the issues associated with anxiety disorder. Within the five overall themes, a total of 18 sub-themes were identified.

These sub-themes are labelled: *anxious from an early age, dysfunctional family environment, controlling maternal behaviour, distress at school, being bullied, dropping out, feeling bad, need for perfection and control, mentally and physically exhausted, ruled by panic, limiting oneself, depressed, confused and desperate, fronting up, diagnosis versus disorder, validation, stigma, and regret* (see Table 1). Although these themes and sub themes are treated separately, they are interrelated.

All participants talked about how they thought their anxiety disorder emanated from early childhood. Four out of seven participants told of how they retrospectively recognised anxiety as forming part of their very earliest memories. Six out of the seven participants spoke about early life experiences in remarkably similar ways, including dysfunctional family life, hating school and being bullied. All participants similarly related how disorder developed and persisted over time, through childhood, adolescence and into adulthood. Most stories described dropping out of school or university, limiting oneself and experiencing a great deal of physical and/or emotional pain before desperately seeking help.

In regards to seeking help and the diagnostic process, participants' experiences varied widely in terms of when, why and how they sought and obtained help. For six out of seven participants the help seeking process was delayed and difficult. Most participants said they were confused about what they were experiencing and did not necessarily equate their suffering with having a disorder for which treatment could be available. Some participants said they were very reluctant to front up and talk openly about their problems.

However on receiving a diagnosis participants said they were relieved and able to make sense out of what they were experiencing and their diagnosis seemed to provide an important and understandable explanation. Moreover some participants felt liberated from the self blame or personal shortcomings that had previously attributed their symptoms to.

When asked to reflect on events as adults, some participants expressed regret, particularly if intervention and receiving treatment could have happened sooner. Some participants identified their own and parental ignorance as a contributing factor. All participants said they felt let down by the lack of knowledge they possessed about anxiety disorders and felt their knowledge had been ill formed. All participants wished there had been more information readily available to themselves and the general public. In addition some expressed regret or feeling they had lost a number of years to their disorder.

Table 1. Summary of themes and contributing sub-themes

<b>Theme</b>	<b>Sub-themes</b>
1. Traumatic early life	<p>Anxious from an early age</p> <p>Dysfunctional family environment</p> <p>Controlling maternal behaviour</p>
2. Troubled school life	<p>Distress at school</p> <p>Being bullied</p> <p>Dropping out</p>
3. Problems with living	<p>Feeling bad</p> <p>Need for perfection and control</p> <p>Mentally and physically exhausted</p> <p>Ruled by panic</p> <p>Limiting oneself</p> <p>Depressed</p> <p>Confused and desperate</p>
4. Rationalisation	<p>Fronting up</p> <p>Diagnosis versus disorder</p> <p>Validation</p>
5. Post Rationalisation	<p>Stigma</p> <p>Regret</p>

## *Theme One – Traumatic Early Life*

### *Anxious from an early age*

When asked to explain how they came to be diagnosed with an anxiety disorder, four participants identified their disorder as originating in early childhood and reported experiencing severe anxiety from an early age. All but one participant generally seemed to attribute their anxiety to being born with a shy and sensitive temperament. This is in keeping with literature proposing a wide range of predisposition or vulnerability models (Clark, Watson & Mineka, 1994). Many studies, such as Prior (1992), have identified inhibition, shyness and withdrawal as being characteristic of the style of temperament that can have an effect on the development of mood and anxiety disorders (Rapee, Schniering & Hudson, 2009) and there is recent literature that identifies shyness as a risk factor for the later development of socio-emotional difficulties (Rubin et al., 2009, cited in Karevold, Ystrom, Coplan, Sanson & Mathiesen, 2012). Their prospective study linked childhood shyness with a wide range of negative adjustment outcomes across the lifespan and said the link between shyness and social skill difficulties can be predictive of a host of social, emotional, and academic difficulties.

Data on the early onset of anxiety and mood disorders are not readily apparent in the literature and the age of onset has proven to be a very difficult issue to address, according to Rapee, Schniering and Hudson (2009). The literature is varied in regards to age of onset. Prior to 1970, children were dismissed as too immature to experience depression and, later, regarded as poor informants regarding their emotional states (Angold, 1988, cited in Farmer, 2002). Most research seems to suggest that anxiety disorders, such as specific phobias begin in early to middle childhood, social phobia in early to mid adolescence, obsessive-compulsive disorder in mid to later adolescence and panic disorder in early adulthood (Kessler et al., 2005; Ost, 1987). However, some researchers, for example, have argued that the average age of onset for social phobia is much earlier (Ballenger et al., 1998). Rapee and Spence (2004) found that high levels of social anxiety can be apparent in early childhood. A small number of prospective studies have noted the persistence of an established diagnosis of social anxiety later in life.

*I've been an anxious person all my life - ever since I was born. My mum says I was anxious from day one. I didn't sleep through the night until I was five years old. I couldn't be left in the dark or anything (Yvonne)*

*I've had severe anxiety all my life, ever since I can remember. I would have been seen as a really shy little girl. I've had social phobia for as long as I can remember. My first panic attack I was four years old. Even going to kindergarten I would never play with the other children. I sat in the corner and watched them play (Elaine)*

*I had anxiety as a child I just didn't know that's what it was. I was a very, very anxious child. I was terrified. From as early as I can remember I can remember being frightened, really frightened. I've had intense anxiety ever since I was four or five (Irene)*

*I think I've had anxiety all my life. I used to be terrified when I was little of realistic risks in my life, for example when I was four years old I was never afraid of monsters under my bed I was afraid of kidnappers coming to my house and kidnapping and murdering me. I was actually so scared because my bedroom was the first one at the top of the stairs and all the other bedrooms were beyond that I thought that I would be the first victim. I was obsessed about it all the time (Amy)*

*I would say that I was a depressed child. I certainly knew the world was a dangerous place. I wasn't exactly carefree and I had a lot of worries for a child (Elaine)*

### ***Dysfunctional family environment***

All participants reported coming from a dysfunctional family home and their accounts included mentions of difficult relationships, parental separation and sometimes physical and emotional abuse. This is consistent with extensive research which suggests that family factors and parental psychopathology are important contributors to the development and maintenance of childhood anxiety disorders (Hughes, Hedtke & Kendall, 2008). Paternal alcoholism, depression and nervous breakdown were specifically mentioned. Six participants mentioned their mother suffered from anxiety disorders, naming generalised anxiety disorder, panic disorder, dermatillomania and emetophobia or believed their mother had unspecified anxiety, depression or possible personality disorder. This is consistent with data that supports the familial aggregation of psychological disorder (Hettema et al., 2001). Research also suggests that family dysfunction is related to less favourable outcomes in children with anxiety disorders (Crawford & Manassis, 2001).

*Anxiety was part of my upbringing. My mother brought us up in an anxious way because she didn't know any better...she gets depression and anxiety and she possibly has histrionic personality disorder but she hasn't been diagnosed with that for sure so I'm not sure... My dermatillomania started at about age 10. My mum has got dermatillomania too- she unintentionally aggravated or encouraged it (Ruth)*

*My father was rather volatile. He drank a lot and was drunk a lot. He would yell and have anger tantrums. He was very unpredictable and I was frightened when he was around. He would verbally abuse my mother all the time. I felt I had to protect her. Weekends were the worst (Elaine)*

*My parents never fought in front of me, ever, so I thought we had a very calm and stable family. My parents had raised me in a very sheltered life ..I was very coddled when I was a child. They always looked after my fears so it was a real shock when my father had a nervous breakdown from overwork and disappeared. He had an affair and just left. So I went from what I thought was a calm, loving environment to a feeling of utter abandonment.....My mother and I didn't have enough money to live on. We moved twice to bigger cities so she could get a job... I had a sister who was seven years older. She acted as a second mother. She is much worse than me and has been hospitalised a few times (Amy)*

*Everyone in my family has panic attack disorder and emetophobia which is phobia around throwing up. My mother is afraid of throwing up too and my brother's afraid of throwing up in public...We have a very tight family but if there's something we don't do it's to cry in front of each other... I was so emotional but I didn't want dad to see me sad because we don't show emotion at home. We don't cry in front of each other (Yvonne)*

*My father is a depressive, an angry depressive as opposed to a catatonic type. He is definitely a product of his abuse that was done on him...Sometimes he'd hit me – but that was later. My mother was an emotionally unbalanced woman and she did go off the deep end. She used to make me feel really frightened. My mum didn't get on with her father and there were some issues with her being a rape victim, which would have changed her dramatically. She talked to me about that stuff from a very young age. I learnt that word rape from a very young age. She instilled in me this feeling that bad things were going to happen all the time. I am a combination of a vivid imagination, sensitive soul and her catastrophizing. She was a very intense woman and didn't have*

*any sense of personal boundaries. She would get into you very physically and tell me what to do all the time, and say no do it like that (Irene)*

*I had a very bizarre relationship with my parents. I felt resentment – why did they have me? The whole thing was messed up. It was a messed up dynamic. My mother had a messed up personality. My father was the nicest guy in the world away from that context. The normal thing is if there's conflict there's a direct relationship to the conflict and not a roundabout way of going about it – like an automaton or robot with a controlling figure. She would instruct him and the next thing I'd know was that he was coming at me. She would give very specific instructions e.g. summer's coming up and he's going to be outside so don't hurt him on the legs. I can't believe that was my life. It boggles my mind. It meant she could say 'I would never hit my child'. She could say that if someone asked. I was always trying to get my dad to take my side, but he never did. If I needed help defending my position as a child it didn't happen... For a long time I just thought it was me. Then later on finding out that's not really normal (Tony)*

*I had an unsettled childhood. My parents were from Europe and came here when I was 5... There were lots of big changes and I was brought up by my grandparents and my mother lived in another city. It wasn't a bad childhood, just very unsettling. I did feel quite out of control as a young girl and I did have a few OCD things as a child ...There were traumatic things in my early childhood.... My dad was quite abusive to my mum....I had a lot of resentment towards my mum. I couldn't understand her coming and going. Everything was hush hush and I didn't understand it....She had low tolerance level – she was very irritated easily - and was addicted to prescription drugs. She was a lot more secretive and quiet and found it difficult to express her emotions... She might have been depressed. She was really bad with money and maybe she had a gambling problem. She had her ways of coping (Nadia)*

### ***Controlled by threats of hell and damnation***

While one participant referred to being 'coddled' and over protected as a child, three participants described how their mother controlled them with threats of hell and damnation. Behavioural control in the family has been posited to be a key characteristic of families of children with anxiety disorders (Ginsburg et al., 2004). Van der Bruggen, Bogels, and van Zeilst (2010) say that of all parenting behaviours, parental control is considered most central to the development of anxiety in children. This parental control

may lead to an increase in the child's perception of threat and to a reduction of the child's perceived control. Soenens, Luyckx, Vansteenkiste, Luyten, Duriez and Goossens' (2008) longitudinal study established psychologically controlling parenting as a particularly strong and specific predictor of internalizing problems and maladaptive perfectionism. Parker (1983) identified affectionless parental control as implicated in the development of depression.

This particular type of controlling behaviour may somehow be related to scrupulosity on the part of the mother. Scrupulosity is a psychological disorder primarily characterized by the obsessional fear of thinking or behaving immorally or against one's religious beliefs and has been relatively understudied to date (Huppert & Siev, 2010). It is often accompanied by compulsive moral or religious observance (Miller & Hedges, 2008). Scrupulosity is often considered a moral/religious subtype of OCD and is highly distressing and maladaptive (Miller & Hedges, 2008).

*Around six or seven I started to get disturbing images in my head. My mother had brought me up rather religious so I just thought Satan was trying to get me, which was to be expected, although I did wonder whether this meant I was good or bad that I was being targeted (Elaine)*

*My mother became very religious in a very scary way. She used to force us to listen to her reading a bible passage every night and it wasn't to bring the family together. It was her forcing herself on us. She found religion very suddenly – it was really weird. I just happened to have the bible open and was flicking through it. She said to be careful reading that – people get funny ideas. Just a week later she'd been converted. She told me "there's a lot of good things in the bible and I stand corrected". She'd seen in the bible that you're not allowed to commit adultery and the bible's definition from the Old Testament was that you can't marry until after you're partner's died – so she said my dad can't get divorced as there's no such thing. She said she has to be dead before dad can get remarried. It was used to support her case against dad. She was the only one who went to church and she tried to force us. We went for a while because we wanted to please her. My development with Christianity developed my anxiety. I thought I might go to hell. It took me a while to unbelieve it (Irene)*

*My parents are very religious and I stay away from that as I get very emotional. Her religion is the right one and I'm going to hell (Tony)*

## *Theme Two - Troubled School Life*

### *Distress at school*

Six participants reported being very nervous at starting school and found school life extremely stressful. They experienced a great deal of ongoing debilitating distress which persisted all the way through their years at school, with some participants reporting that they hated school. Two of the seven participants reported that they now believe they suffered from selective mutism which was not investigated at the time.

Missing school due to migraines or not feeling well is mentioned. Behaviours such as disturbed sleep and truancy were described. Van Amerigen, Mancini and Farvolden (2003) found in younger children, that anxiety disorders are likely to result in chronic school refusal, resulting in significant social and academic difficulties. No participant mentioned parental or teacher or peer support as being available.

Participants said they saw themselves as sensitive to their surroundings and disliking attention, especially when having to perform in some evaluative way. This is in line with Albano et al.'s (1998) findings that this and having trouble speaking in front of the class were two of the most common reasons cited as reasons for not enjoying school and leaving school prematurely.

*I remember the first day of school it was so traumatic with everybody looking at me. I would scowl and get hostile to keep people away. I couldn't bear their attention, them looking at me and asking me questions...I hated school and for the first few years I refused to speak at school. I kept myself very still so as not to draw attention to myself. I often missed school because of headaches or migraines or not feeling well enough to attend.....The most debilitating aspect was my fear of speaking, after recent research I believe I suffered from selective mutism. I found it so hard to talk, what I wanted to say I would repeat over and over in my head but the fear was just too intense. I couldn't make myself talk even though I was physically capable... If people asked me questions I could usually answer yes or no or at least nod or shake my head but if someone asked something that required more than that I felt too overwhelmed with fear (Elaine)*

*They thought I was autistic when I was a child as I didn't speak for a long time. I must have had selective mutism. I would talk at home but not at school. Eventually I grew out of it and became a top student. I was encouraged in the academic area but I never liked*

*sports as I was very fearful of competition and always afraid of being humiliated so never participated in sports. At school I was just seen as very smart, getting A+, but people did not see the distress of getting an A- (Amy)*

*Going to school was awful, on especially horrible days like sports day or some sort of performance I would say I was sick. I thought it was wrong to lie so I would make myself sick so then it would be true. Anticipatory anxiety has been a huge problem and also causing vomiting, diarrhea and excessive urination. I had to stop eating breakfast around eleven years old because the nerves would take over and I would vomit before leaving. I would still be sick but there a big difference between vomiting liquid and recently chewed solids...*

*When I was 15 and anxiety started to kick in I told my mum but she brushed it off. She didn't want to deal with it because if I went to therapy that would mean she's a bad parent. So unfortunately I didn't get the opportunity to go to therapy and get the help when I was younger (Ruth)*

### ***Being bullied***

The same participants described their distress and inhibition continuing through primary school and into high school. Life became more confusing and anxiety intensified around the time of puberty with participants reporting problems in peer relationships. Six participants experienced social anxiety and difficulty in peer relationships which led to them being isolated or excluded or being the victims of bullying. The literature shows that peer victimization is strongly related to social anxiety. Siegel, La Greca and Harrison (2009) found peer victimization was both a predictor and consequence of social anxiety over time, including relational victimization.

*I wanted to have friends but if I was frightened I was really withdrawn and not want to play with anyone. I didn't think of not having friends as a major issue as that's all I knew. I was convinced that nobody liked me. I'd have the odd conversation with people but I wouldn't stay around. It's not that I tried really hard to make friends I was scared of being rejected. I never had friends and they bullied me anyway – pretty much the whole class did. They would purposely move away from me. I was that girl who always went wandering off on her own. At high school if you don't gravitate to people in the first year you miss the boat – and I missed the boat. I didn't stay in the common room at school – I didn't know what to say or do so I would play the aloof card (Irene)*

*When I was 15 and being bullied at school I got sick and missed two weeks of school and refused to get out of bed and go back to school. They got the school counsellor in and as soon as I had strangers enter my house I started to bawl my eyes out. After years of pent up emotion I cried for nine hours straight...*

*I had got to the point where I was cowering in the corner if anyone looked at me. When people tried to interact with me it was physically painful to accept that kind of interaction. For the first two weeks I refused to speak. If I speak up and nothing gets done about it that means there's no way out. Then I started talking. The biggest revelation was that everyone is telling me 'it's not you. You're not the one with the mental problem, we're trying to deal with your parents...*

*...From that point everything became much easier. For the first time in my life someone was on my side. For 15 years none was on my side. I thought that was normal. I thought I just had to take it...My parents were given instructions to keep going with my therapy, but they didn't follow through (Tony)*

### ***Dropping out***

Six out of seven participants described how their anxieties continued as they got older, with a seemingly increased burden of adolescent emotional turmoil and when they could not cope began to withdraw from school and social life. Van Amerigen, Mancini and Farvolden (2003) found epidemiological evidence that persons with psychological disorders, especially social phobia, are at increased risk for premature withdrawal from school. Anxiety disorders in particular are the most important psychiatric determinant of dropping out for females, according to Kessler et al. (1995, cited in Van Amerigen, Mancini & Farvolden, 2003).

Communication apprehension, as mentioned by participants has been identified by Monroe et al.(1992, cited in Van Amerigen, Mancini & Farvolden, 2003) as an important determinant of high school drop-out and it has also an important determinant of whether or not those who graduate from high school will go on to postsecondary education. This was identified as a reason why participants could not continue with their education.

*I started withdrawing over the years and I stayed in my room for four years from the age of 15-19. My parents seemed OK with me living in my room. The internet has been*

*my companion and kept me sane. I still like computers and being alone but I had a sense of mortality - that I can't keep it up forever. I've done it for years but I can't keep it up forever. My parents were not proactive and I had to ask if I could go back to see the doctor (Tony)*

*At age 16 I temporarily dropped out of high school. I was diagnosed with depression and then later on GAD and panic disorder. My parents both decided together to take me to the doctor because they had unexpectedly got divorced and the family house was sold and my father moved to another city. Because of the shock of these abrupt changes I got depression and temporarily left high school. I got treated for depression but not anxiety as the focus was the depression but over the next 6-12 months I started to develop the anxiety and panic attacks typical of panic disorder, so the continued care evolved more into the treatment of anxiety rather than depression as the depression had subsided (Amy)*

*On leaving school I wanted to keep on with music but I hadn't addressed how to deal with performing. Anything to do with performance and I couldn't focus...it caused me to say to myself I need to have a serious think about whether I'm going to continue doing this (Irene)*

*At university my anxieties came out more - right after my depression when I was in a relationship my parents didn't approve of and wouldn't support. I studied at a large university and I didn't thrive in that environment, it was hard to keep motivated and go to classes (Amy)*

*Having anxiety disorders – not that I knew what they were - prevented me from doing the things that other people were doing and didn't give me much hope for the future. Upon reaching the end of high school I desperately wanted to go to university but because of the anxiety disorder there was absolutely no way that I could (Elaine)*

### ***Theme Three – Problems with Living***

#### ***Feeling bad***

Participants reported feeling bad - both emotionally and physically, and also reported feeling demoralised and discouraged. In their meta-analytic review Henningsen, Zimmermann and Sattel (2003) suggested that the designation “common distress

disorders” might be more appropriate than “common mental disorders” as the word “distress” refers equally to bodily and mental suffering.

A wide range of somatic symptoms including fatigue, tension headaches, insomnia, sore throats, migraines, irritable bowel, and generalised bodily pain were mentioned as adding to their distress. While somatic symptoms are readily identified, it is more difficult to recognise how they are related to anxiety. At the most basic level, some participants did not recognize that they had symptoms of anxiety. They focussed instead on various somatic concerns, such as gastrointestinal complaints, fatigability, and headaches.

A great deal of research, such as that by Haug, Mykletun and Dahl (2004) has investigated the strong associations between anxiety, depression and functional somatic symptoms. They reported that while these somatic symptoms are prevalent in the community, at least one third of the symptoms lack organic explanation. Somatic symptoms that are not well explained by general medical conditions are very problematic for Western medicine, according to Mayou, Kirmayer, Simon, Kroenke and Sharpe (2005). They reported that such symptoms account for a quarter to a half of presentations in both primary and secondary care and that despite the size and importance of this problem they are difficult to classify. A number of studies, such as Schur, Atari, Furberg, Olarte, Goldberg, Sullivan and Buchwaid, (2007) have investigated the overlap in symptoms among medically unexplained and psychiatric conditions and named conditions include chronic fatigue syndrome, low back pain, irritable bowel syndrome, chronic tension headache, fibromyalgia and temporomandibular joint disorder.

Mayou, Kirmayer, Simon, Kroenke and Sharpe (2005) said that “conceptually, these illnesses lie in an ambiguous area of medical thinking somewhere between medicine and psychiatry” (p. 847). Although some participants reported having distressing somatic symptoms, it is not the case that they were necessarily heavy users of medical services, and they possibly preferred to avoid medical attention. This is of interest because the research literature, such as that by Barsky, Orav and Bates (2005) suggested that there is a positive correlation between somatisation, psychiatric disorder and medical utilisation.

Similar to Granek's (2006) findings in her qualitative study of depression participants expressed harsh sentiments of self-criticism. They also described being physically and mentally drained by their anxiety, leading to limitations on their activities. However panic attacks (see later) seem to be particularly dreaded and act as a motivating force for some (but not all) participants to seek medical attention or be close to a location where medical attention is available.

*Each day was a battle but people acted as though I was cowardly. Not being able to do things, made me feel really bad about myself because I couldn't do the things people wanted me to do and things I wanted to do...In the real world people tell you there's nothing wrong with you, basically you're a loser or lazy and you know that's not true, but when you have low self esteem you kind of believe it. I was made to feel like I was lazy and not living up to my potential...*

*..I'd say to myself "I hate myself. I'm a terrible person" I was consumed by guilt. I thought I as the worst person that has ever lived... I was in a bad way, at rock bottom...*

*...If I have been out high anxiety through to panic attacks leave me feeling wrecked the next day and often the day after that. I feel like I have been run over by a truck. It makes managing my week very difficult. I think I might have chronic fatigue syndrome but I have not officially diagnosed yet (Elaine)*

*Last year since going back to uni I've had tension headaches. I felt like I've lost a lot of days due to depression and pain and at times am unable to walk, due to back pain caused by tension (Irene)*

*I often feel nausea after I eat, before I eat and nausea to do with anxiety. I have Irritable Bowel Syndrome. I would go around eight times a day with a lot of discomfort and wind. It feels very sore like the inside is inflamed. Now I have an issue with constipation since I started on anti-depressants. If I don't eat soon enough I feel like vomiting and a headache will come on suddenly. I get dizzy and things start to turn black. If I don't drink coffee I can get quite dizzy and my balance isn't so good (Yvonne)*

*I very strongly believe something else is happening inside. I do believe I have a hormone problem not just because of the anxiety but because of frequent acne outbreaks and I have bloating, weight gain in my stomach areas in my 20s. I also had my fallopian tubes removed due to appendicitis surgery when little. The scarification overtook my*

*tubes and they got infected and they had to be removed three years ago and I didn't realise how important hormones are to anxiety. I am going to get my hormones tested (Amy)*

### ***Need for perfection and control***

Four female participants talked about their perfectionism and need for control. The literature has long proposed a relationship between perfectionism and psychopathology and talks about adaptive and maladaptive perfectionism, which is defined as the desire to achieve the highest standards of performance, along with undue self critical evaluations (Frost, Marten, Lahart & Rosenblate, 1990).

Similarly, beliefs about control have been postulated to be important to anxiety and mood disorders. Moulding and Kyrios (2006) said the phenomenology of OCD suggests that it may be an example of an anxiety disorder where control issues relate to the self (behaviour and thoughts) and world (the external environment). They suggested that discrepancies between an individual's desired level of control and their perceived level of control could contribute to OCD.

*People with anxiety are very conscious of the need to look perfect. We need to look perfect because we don't feel perfect inside, then you're not approachable because your miss prim and proper, so it makes it hard to connect with people. You are judged as that perfect girl and you have to work harder and harder to keep the perfection (Amy)*

*I need to feel in control - if things are perfectly organised it gives a sense of control as if I've mastered it. You must do all this and you must do it amazingly well and you must do it perfectly and must do it by yesterday! (Yvonne)*

*I'd get up in the morning and put on full makeup - I always like to present well on the outside - I dress nicely and I was really good at putting on a mask - I smile a lot - even if I'm miserable. I'm a perfectionist- I'm really hard on myself. I would apologise a lot - I was a real people pleaser I wanted approval all the time, but I would put a lot of what I thought about myself into other people's hands and I lost a lot of self esteem...I had to please people to gain approval - I did that with my grandparents they were real churchgoers. Good Irish Catholics. If I acted the good little girl I got the rewards. If it works you keep doing it. My appearance was a way to get approval and later on attract*

*guys. ... I was looking for validation. I hated feeling alone and vulnerable. I couldn't bear it (Nadia)*

### ***Ruled by panic***

Most participants spoke of high levels of anticipatory anxiety and panic which considerably added to their depression, impairment and isolation. Panic is compounded by performance demands and social anxiety. If part of a couple, panic impacts on both partners. Four out of seven participants had been diagnosed with panic disorder, and panic attacks were mentioned by two other participants.

Panic disorder has been the subject of considerable research and controversy and little is known about the natural history of panic attacks and the factors predicting the prognosis of panic (McNally, 1990). Prospective longitudinal studies indicate that elevated anxiety sensitivity may be a risk factor for panic and perhaps panic disorder (McNally, 1990). As noted in the literature, many people who develop panic attacks and panic disorder go on to develop agoraphobic avoidance of situations in which they fear or expect they may have a panic attack in the future and is related to significant impairment.

*When I was 19 and overseas I had a really bad panic attack one day – it came completely out of the blue. It was massive then I started getting a lot of them. Most of my panic attacks happen from sleep – I'd wake up in full fledged panic and phone up for an ambulance because I was convinced I was dying. Because they were very physically draining they really freaked me out. I would go and sit in the hospital waiting room without checking in just in case something did happen. My panic attacks went on for two years without really being told what they were and I had little understanding. I managed to get through my nursing studies but things were really bad - I'd have a panic attack a couple of times a day - and if I hadn't had a best friend I probably would not have been able to finish (Nadia)*

*An Asian lady in the bank told me when she came to this country it was really frightening not being able to communicate, not being able to get a taxi or ask the whereabouts of a toilet. I thought that sounded similar to what I experience with panic in that it's scary and you feel trapped. I just couldn't function – getting cash out of ATM - part is social phobia of people watching me, part is feeling trapped as I can't get away as the machine has my card... For me the difference is the 'freak out' part. I think the*

*anxiety has got to the point where I am going to act crazy and 'freak out' or start running around in circles, start screaming or act crazy. I have the usual symptoms, rapid heartbeat, chest feels like it is being crushed, choking sensation, sweating and getting really hot, nausea, shaking, going completely blank. Sometimes I can't remember my own name or basic information. And the screaming urge to run or oddly freeze (Elaine)*

*I couldn't go to the grocery shop. I tried but I'd stop at the door as I would worry about having a panic attack... but you can't just get better because you want to get better (Yvonne)*

*When you have anxiety you have low energy and don't have motivation in seeking treatment...If you get another panic attack you get discouraged and a feeling of hopelessness – when am I going to get better? (Ruth)*

*Even for my husband, I told him on our third date that I'm falling quickly for him so I told him "I have to tell you something I have an anxiety disorder – can you deal with that because I have to know. If you can't I have to know right now because I have to leave so I won't get hurt. He said yeah fine, but he had no idea what an anxiety disorder meant when he saw my first panic attack he got pretty frightened and said, what say I do? Call the ambulance? (Amy)*

### ***Limiting oneself***

Of the four participants who had been diagnosed with panic disorder, only one had been diagnosed with agoraphobia, but other participants spoke of limiting themselves to 'safe' environments. Research on the relationship between sensitivity to anxiety, panic and agoraphobic avoidance shows complex interactions, and according to Wittchen, Gloster, Beesdo-Baum, Fava and Craske (2010) studies remains incomplete and partly contradictory. One participant said her agoraphobia is complicated by social anxiety.

*I started limiting myself more and more and the anxiety just got more generalised...I found a lot of situations cause high anxiety or panic attacks, not just because of their social component but the feeling that I'm trapped. I can't get away or calm down or make my way to a safe place, being at a sales desk in the middle of a transaction, at the money machine and my card is in it, being at the supermarket with a trolley – I can't leave an aisle quickly, being in the middle of a conversation as it would look rude or*

*odd to exit...I began to lead the life of a hermit, not participating in life...I don't want to be in that situation again where I have a panic attack at home and I'm scared all the time. My only safe place was my bed. I was just a sobbing thing that couldn't do anything and I started avoiding everything...I was exhausted and I became very depleted...everything was such a struggle, so I was depressed, mildly moderately then severely (Elaine)*

*I'd always thought that agoraphobia was to be scared to be in a crowd, but it's not. It's to be scared to do something in case you have a panic attack (Yvonne)*

*In my early 20s I felt exhausted and drained from my anxiety. I didn't work for 5-6 years. Time had stopped and I was depressed about the 'lack' in my life (Nadia)*

### ***Depressed***

Five out of the seven participants had also been diagnosed with one of the mood disorders: two had clinical depression, one with seasonal affective disorder, one with bipolar disorder and one with dysthymia /depression. As noted previously, high comorbidity between anxiety disorders and depression is commonplace.

Of possible relevance is that Wilhelm et al. (2008) found that early onset anxiety disorders were an indicator of early onset depression and recurring episodes. Sandi and Richter-Levin (2009) found that being a highly anxious person is a risk factor for depression, but they said exactly how the depression develops is much more complex. In their 30 year longitudinal study Wilhelm et al. (2008) found that of those who reported a lifetime history of anxiety, 70% had experienced the onset of anxiety before the onset of depression.

*Part of the depression got worse because I felt if I removed myself from the world more that I wouldn't have anxiety - but I did, my OCD got worse, so I thought 'what can I do? I can't live in the world like other people so what's left for me? So I questioned how long I could go on for. Everything had become very difficult like moving through mud. I had no real interest in doing anything other than sleeping, which I found very hard to do. I had this awful sense of dread all the time. I would wake up after three hours of sleep and just couldn't do anything. I would just lie on my side staring at the wall as the tears just wouldn't stop - on your side they fill your ears up with tears.... I had no*

*friends, I didn't want to go anywhere, couldn't use the phone, didn't even want to go into the garden (Elaine)*

*I was depressed about how anxiety is going to limit me and how I would cope. I do have trouble not blaming myself that I'm an anxious person – that it's my fault in that I created my reality with my thoughts. I really beat myself up that I'm not as productive as what I'd like to be. It's very easy for me to say I'm not going to bother today because I feel so bad (Irene)*

*I was feeling mildly depressed all the time, constantly apathetic. I couldn't get up and get motivated but it wasn't bad enough that I clicked that there was something wrong. I just lived with it. It was so constant I'd have a few days or a week out of the month when I wasn't depressed. It's so complicated –even psychologists have a hard time identifying it. It cycles for me. I didn't know what to do with the double depression. The thing that upset me the most about the second major depressive episode was that I was doing everything right – eating well, sleeping, going for walks and I still got a major depressive episode (Ruth)*

*I was depressed for 3-4 years. It's a long time to lose motivation for everything... one of my big problems is performance issues – thinking I can never do enough work and setting unrealistic expectations and then beating myself up for not meeting them –it's perfectionism poking its head up (Amy)*

### ***Confused and desperate***

Participants' own suffering was not necessarily sufficient to initiate seeking help and extended delays in taking action were reported. For some participants it took problems to become severe or a precipitating event before action was taken. Sometimes intervention by a family member was necessary. This reflects Biddle, Donovan, Sharp and Gunnell's (2004) finding that the need for help is located with 'real' (i.e. extreme) distress only. Two of the participants mentioned the option of suicide, while two others wondered how they would survive. Mojtabai, Olfson and Mechanic (2002) found that impairment in role functioning or suicidality act as strong predictors of perceived need.

As mentioned previously, a number of studies show that the majority of adults with common mental disorders do not seek professional help. In one study of help-seeking in a U.S. university population, there was a median delay of 11 years between onset of

disorder and accessing services (Eisenberg, Golberstein & Gollust, 2007). Biddle, Donovan, Sharp and Gunnell (2004) developed a Cycle of Avoidance model (COA) to account for this. Their model shows that young adults' illness behaviour in response to mental distress usually involves accommodating or denying illness rather than resolving it, even when symptoms become severe. Jorm et al. (1997, cited in Jorm, 2000) described this as poor 'mental health literacy' (a term that has been associated with an increase in time between onset of symptoms and service utilization). Persons with anxiety disorders are known to have particularly low help seeking behaviour and it is thought that avoidant behaviour as a coping strategy is a distinctive barrier to treatment (Mykletun & Dahl, 2005). Participants also mentioned the fear of the unknown or requirement to change as a barrier to seeking help. Perhaps previously having had their problems minimized or dismissed by others also contributed to their reluctance to seek help.

Another important factor is the unrecognized component and lack of clarity into the nature of the problem, which, in psycho-analytic theory, are hallmarks of psychological disorder (Pols, 1984). Low awareness in problem recognition was mentioned by participants. This may be similar to Feely, Sines and Long's (2007) findings in their study of depression, in which participants described "a sense of 'unknowingness' which presented to most of the participants as a felt, social phenomenon and which added to the experience of depression" (p. 398). Feely's study also mentioned the paradox that living with 'not knowing' occurred in tandem with the grounded reality of living with depression.

*My mother was worried about how depressed I was as she had never seen me that depressed before... for a long time I denied it and thought it was something else – if I just tried harder...but on my own there was no way I could actually seek help as my agoraphobia had got so bad but my mother talked me into going and so I went... I'd reached the point where there was nothing left. I saw only three options 1. To die 2. to keep living how I was, which I couldn't do and 3. to get help. I thought about suicide a lot, even though I was convinced everybody would be better off. I thought my mum would find it too hard to handle. I couldn't do that to her (Elaine)*

*In March last year I lost my grandmother to cancer really quickly. Around July last year I started having panic attacks again, I would go to the movies and have to go out,*

*felt tired, stressed, started having two or three panic attacks per week. We went on holiday which was a disaster with panic attacks twice a day, upset tummy, diarrhea and I couldn't eat...all I wanted to do was sleep and sleep and sleep, hours and hours. I lay on the couch like a vegetable... I had stomach problems for a long time but I never thought about anxiety and the GP wouldn't have picked up on it... It was a vicious cycle the more sick I felt the more anxious I became and the more sick I felt...I thought there's something wrong with me but I thought it was something physical... the whole time I didn't know what was happening to me. I was in bed sleeping and crying and not eating I had massive crying fits, couldn't get out of bed. . I started to lose weight and lost 6 kilos. If I was a lonely person I don't know how I would have survived (Yvonne)*

*I couldn't deal with the elevated stress levels of being bullied at work and it brought on a major depressive episode, not quite to the point of being suicidal, but when you are thinking about hurting yourself you know something is wrong, I realised I shouldn't be thinking like that - even if you don't do anything to carry it out..... I was starting to hear voices and have nightmares and was anxious all the time (Ruth)*

*I'd worn myself out trying to analyse my anxiety...I like to solve things, I'm very analytical... if I could solve these things from my past, if I could just get to the answer - but I kept going round in circles... I did a lot of reading and research and my world revolved around my anxiety (Nadia)*

#### **Theme Four – Rationalization**

##### **Fronting up**

As seen above, most participants were confused as to what was happening to them. Some were reluctant to seek help and seemed to really struggle with the decision to seek help. By the time they took action they all had experienced a great deal of distress. Biddle et al. (2004) described the help-seeking process as not a simple decision about professional help but a multi-faceted, protracted career composed of a plurality of strategies and people consulted during the process of coping with symptoms and trying to negotiate and renegotiate often increasingly severe symptoms such as panic and agoraphobia. Of interest is that Rickwood and Braithwaite (1994, cited in Biddle et al., 2004) found that as few as 17 per cent of young adults with mental distress (and less than a third of those with a clinically defined disorder) actually seek healthcare. It seems many people struggle to interpret the meaning of even severe symptoms and continue

various ways to try to normalise them. Prior et al. (2003, cited in Biddle et al., 2004) said that deciding what constitutes 'illness' may be challenging for people with mental disorder. Barriers include recognizing the need for help, knowing where to go for help and being willing and able to disclose.

One participant's response to her situation was in keeping with Wisdom and Green's (2004) description of 'medicalisers' (those people who look to their healthcare provider as responsible for 'fixing' them).

*I'm 36 years old but I only started talking about these problems four years ago, so my medical records don't mention my history of anxiety disorders. I hadn't talked to anyone about anything because of my anxieties. I don't know how other people behave if they've got problems. I guess if you've got problems it's assumed that you'll talk about them, but I wouldn't tell anyone anything. ...I was terrified I'd go seek help and they'd tell me there was nothing actually wrong with me and then I wouldn't know where to turn...*

*...When I had to go to the doctor to get a referral it was a really traumatic event – I was sobbing the whole time. I would only go to the GP for really serious things. I would have panic attacks about going to the doctor and hated going. I never mentioned my migraines I didn't think there was any point... I'm there to see the doctor but I'll say everything's fine. I don't want to break down in front of a stranger. Why didn't he ask more questions? I think a lot of people don't get diagnosed properly. I needed to be asked very direct questions...*

*...It had taken a long while to get the courage to seek help then I had to wait, wait, wait, to see someone. Part of me didn't care as I didn't want to go. To have to talk about something so important but I couldn't talk about it kept me awake for weeks...For me the seeking help process was very traumatic, very difficult, especially involving the family. I felt very exposed, very ashamed of telling my story. I was like a wild animal ready to bolt as the door was closing. I was very pleased when it was over (Elaine)*

*I went to the doctor because of not being able to sleep and panic attacks. I didn't know about social anxiety at that point. It was more agoraphobia and depression and regression to isolation. I hadn't had panic since I was 19 years of age. What do I do now? (Tony)*

*My dermatillomania was the thing that made me look into getting help. I knew it wasn't right....It took me ages to find out that dermatillomania has a name (Ruth)*

*I never thought it was anxiety...I made an appointment at the medical centre. I had a panic attack before I went in. I just want someone to fix me –I started crying in front of the doctor – I saw her as my saviour, you are going to fix me (Yvonne)*

### ***Diagnosis versus disorder***

For most of the participants the diagnostic event coincided with a critically low point in their lives and happened at a time when they felt debilitated, and so the professional attention and assistance, once received, was well appreciated. All but one participant reported reacting positively to being given a diagnosis.

Most participants reported relief at having a medical explanation of their problems as a recognized disorder. They could comprehend and evaluate their symptoms against this new information they had been given. Their symptoms were no longer inexplicable but were diagnostic criteria that were part of a well recognised disorder that they found out is actually common and treatable. The diagnosis seemed to turn 'disorder' of unexplained, terrifying feelings and sensations into the 'order' associated with the criteria of a legitimate and well documented condition. The diagnosis seemed to provide a meaningful and acceptable way of explaining to themselves and others what was happening to them. The conferment of a diagnosis provided a framework upon which they could now interpret their experience and make sense out of their confusion. This reflects Gonçalves, Henriques, Alves and Soare's (2002) analogy that psychopathology can be understood as a narrative that is unable to provide a rational and coherent account of sensorial, emotional and cognitive stimulation. These researchers suggested that the diagnosis enables the construction of a more understandable narrative.

It seems for some participants a diagnosis enabled them to externalise the condition as something to work on. Participants also said it meant they could then commence a search for more information and go on and educate themselves about their diagnosis. For some a diagnosis also provided the basis for which they could go on and receive treatment. While the literature had detailed that a diagnosis is important to the process

of allowing persons to receive services and for mental health professions to be reimbursed by third parties, this aspect was not mentioned at all.

Strong feeling around receiving a diagnosis was noted and the meaning of that diagnosis. For one participant the diagnostic label became her identity.

*When I returned home to New Zealand, aged 23, I went to the public mental health system as my panic and anxiety started building around my health....when I found out about a bit more about anxiety I became the diagnosis – I was enmeshed in my own anxiety. It was like “hi I’m Nadia and I’ve got GAD” If you’re given a label you can live up to it (Nadia)*

*When I was diagnosed with GAD I went away and did some research and found yeah that’s exactly like me. It explained all the fatigue, tiredness and irritability (Ruth)*

*Once the words ‘social anxiety’ were used - in my head everything fell into place. Knowing how to define it felt good. I chose to approach it as social anxiety instead of introversion and externalise it rather than view it as just me, which I couldn’t change (Tony)*

*The biggest breakthrough was when I heard the psychologist say she sees plenty of people with GAD and you’re going to be fine, it’s curable. “So I asked, I’m not going to be like this for the rest of my life?” ...*

*...After I got diagnosed a friend who was studying psychology leant me a case studies book and I read the case scenario of Lisa who has GAD and when I read it I said ‘Oh my God that’s me’. If what I’ve got is common enough to be in a casebook, then surely there’s a lot that can be done (Yvonne)*

### **Validation**

As mentioned in the introduction, many experts believe there are benefits to receiving an official diagnosis and participants’ experiences mostly endorse this. Participants could look to the future with some hope for change. In addition some participants expressed thoughts and feelings of validation and vindication. The provision of a professional diagnosis not only provided a much needed explanation for what they were experiencing but also acted to provide an alternative to previous styles of blaming by themselves or others for being ‘weak’ or ‘flawed’.

Participants also seem to greatly value the validation of their own personal experience and acknowledgment of how difficult their lives had become. Participants appreciated it when their experiences were received, acknowledged and communicated in a caring manner by their healthcare professional.

*Getting a diagnosis was helpful – when filling in forms you can't write "I can't cope with the world" but you can put down your diagnosis...I used to think I was just a dud and couldn't function in life and everyone else could so it was good to be validated - the fact that I was feeling terrified all the time and that I just don't need to pull up my socks, and no wonder your life's been so bad, because you've been so terrified...I'd done enough research to know about the disorders and everything I read said the same thing but you might go to see a professional and they might say "no you don't fit in" so I was relieved to get a confirmation that a professional agreed that's what I had... it was nice to have someone validate you....I'm not a dud I've got this....*

*...People talk about depression and anxiety but I like to use the word 'disorder' in the description, because if you say I've got anxiety they'll say 'so?' or to have OCD is considered cute description of how people like things a certain way such as clean, and that is not what real OCD is, but that's how its described in TV shows or in the movies (Elaine)*

*... I really liked getting the diagnosis as I learnt I wasn't the only one, it wasn't some horrible thing I'd just made up myself (Ruth)*

*When I got to see the psychologist it was good to tell my story to someone who understands and knowing that I wouldn't be alone with this and that she would be there to help me. Now I can talk about it without openly without overwhelming stress or emotion...*

*... ...When I first found out that I was having panic attacks and that I was not going to die, it was very reassuring. I have something! I'm not crazy. I have a disorder. Putting a name on those feelings and emotions was miraculous (Yvonne)*

## ***Theme Five – Post Rationalization***

### ***Stigma***

It was of interest what participants would say about stigma, as stigma has been well documented to be associated with various mental disorders. This topic was not brought up spontaneously by participants and so the researcher asked participants to reflect on this. While most participants said they were relieved to get a diagnosis, some participants said they were unsure about what the diagnosis would mean to others or expressed concern about being judged. Some participants said they were generally reluctant to share details with members of the public and some mentioned that they were not comfortable talking openly about their diagnosis because of people's perceived lack of understanding. This is understandable given that participants had been bullied in the past and had the experience of people not being sympathetic. Others said they were happy to share with interested and understanding people. Only one participant talked about stigma in depth. This participant may be characteristic of what Wisdom and Green (2004) called 'identity infusers' (p. 1237) where their condition is viewed as a stable part of their identity which they thought might make recovery more difficult.

*I was very disappointed when I got my diagnosis. It meant something was clinically wrong with me, that I was disabled – to me that wasn't good enough. I still don't feel at peace with it, that this is how it is going to be for the rest of my life. I accept it but I don't want my identity based on it. If I fully accept it I might be giving myself excuses not to do things better... It's not that I perceive it as a sign of weakness as I feel the people I meet with anxiety disorders are some of the strongest people I've ever met, because they are so determined to make it in life despite the issues...I think that anxiety could be seen as a weakness and I don't want people to judge me. I don't want them to perceive me as weak and flawed. (Amy)*

*With PTSD people don't understand how something so long ago can still affect you. I don't tell many people about that...I used to be quite embarrassed about the depression – you get told to buck up and be happy all your life when feeling sad. People just don't get depression. Oh I felt sad once. Do you know what it's like to feel slightly sad for 3-4 years? (Ruth)*

*You need to be open enough to talk to your GP about it in order to get a referral... there are still some negative aspects to asking to see a psychologist. (Yvonne)*

*Anxiety doesn't just mean a little bit anxious. It just seemed like a very mild word. Others don't understand. Oh you mean you don't think you'll pass out. That's another reason why I gave up trying to tell people about the craziness in my mind. It's hard telling people and expecting them to understand. (Irene)*

### **Regret**

Once diagnosed, participants reported that they then did extensive research via the internet and self help books and generally became well informed about different psychiatric diagnoses and became familiar with different types of therapies and treatments.

When asked to contemplate the diagnostic process in retrospect, some participants reflected on how their lack of knowledge about anxiety disorders or available services or treatment had let them down. They also went on to contemplate what their anxiety has caused them to miss out on and how their life might have been better if they had sought and received help earlier. There was a sense of frustration that valuable time had been lost and that a large part of their lives could have been used more productively.

*If I'd known about anxiety disorders I might have been able to identify it a bit earlier. I wish there were more information around in the public domain. It doesn't seem that doctors know much about anxiety disorders and they can't accurately identify it. I think they need a bit more training in this... There have been ads on TV about depression but New Zealand hasn't had a long public education promotion of anxiety (Yvonne)*

*Even at this stage in my life aged 35 I feel like I'm a bit behind – I've got friends who are married etc I missed a big chunk of my life - when I didn't work for 5-6 years (Nadia)*

*In general I feel as though I've lost more than eight years of my life – that time when I was not studying because of my anxiety disorder but giving up made my anxiety even stronger and because there was no reason for it, it gained in strength... but for all those years I could have been doing what I'm good at, what I enjoy (Irene)*

## Chapter Nine – Discussion

### *Background*

This study set out to explore and describe how people diagnosed with anxiety disorders think and feel about their diagnosis. This is important given that the literature on anxiety disorders has rarely consulted consumers' perspectives. As an exploratory study the researcher was interested in the subjective experiences of participants as well as what participants chose to relate as meaningful and important to them. A 'realist' epistemological stance was adopted, as recommended by Ussher (2010) which endorses the 'real' of participants' emotional distress and how they conceptualise it while remaining aware of how modern society, through culture, language and politics, influences discourses on how that emotional distress is expressed as mental illness including, for example, established discourses around depression.

All participants expressed a genuine willingness to share their stories, mainly because they felt their own lack of knowledge had let them down and hoped that sharing their stories may help inform and educate others. Some participants were also generally aware that very few first-hand accounts have been published and they felt their experiences should be told in case they could be of benefit or interest to other sufferers. All participants spoke movingly about their disorder and described their emotional suffering and pain, which are genuine and heartfelt. Participants' stories brought to life a far more real and vivid portrayal of anxiety disorders than is possible via studying a list of DSM diagnostic criteria.

Many of this study's findings are in keeping with the literature outlined in the introduction including the chronicity and comorbidity of anxiety disorders, delays and reluctance to seek help and disclose distress. Most participants reported anxiety as having pervaded every aspect of their lives, throughout their entire lives. All conditions had been debilitating and exhausting to greater or lesser degrees and impacted participants' lives and required active management. While participants did not talk in terms of quality of life, participants spoke of how their lives were limited; and keenly felt to be more limited than need be in a number of different spheres, including socially and occupationally. A large overlap among anxiety disorder diagnoses was found, yet distinctions were made between the qualitative experiences of the different disorders. A complicating factor for all participants was in relation to the accompanying experience

of depression, which for most, seemed to develop after years of trying to deal with living with anxiety disorder.

While this study did not set out to gather participants' life stories or conduct any type of narrative interview, the data gathered took a biographical turn and participants related meaningful events that had occurred over their life time which they used to illustrate their condition. This is consistent with other qualitative research which emphasises process and how events and pattern unfold over time and in context (Bryman, 2008).

Although interviews started with an enquiry into the present day situation, participants reflected on how their anxiety had unfolded over time and this seemed to provide a framework for their understanding. Participants' accounts were also in keeping with Riessman's (2008) observation that narratives are typically characterised by sequence and consequence, meaning that life events are selected, organised, connected and evaluated as meaningful. They contained key narrative elements, as identified by Gonçalves, Henriques and Alves (2002) being; structure, process and content. These elements are instrumental in helping understand how participants have constructed their personal experiences.

Participants' stories shared many common elements and all participants gave strikingly similar and coherent accounts to explain and describe the evolution of their disorder. The common elements gave rise to what have been identified as five main themes and are based on the 18 contributing factors or sub-themes which emerged during the interviews.

When asked how they came to have an anxiety disorder participants tried to explain and make sense of their condition. On reflection as adults, disorder was explained in terms of being born with a shy and sensitive temperament along with the critical role of their upbringing. While not necessarily blaming their parents, they recognized their family circumstances as somehow contributing to the development of their disorder and this led to the theme of *traumatic early life*.

It was striking that all participants described coming from what only could be considered a disrupted or dysfunctional family life. It seemed that many problems originated in how participants were raised, in less than ideal circumstances, in situations

over which they had no control. Upon starting school most participants were ill prepared and without the knowledge or tools to cope with the burden of anxiety and being unable to successfully socialize with peers seemed to compound the problem.

Participants' accounts point to the surprisingly early onset of problems. As mentioned previously, there is limited research on the early onset of anxiety disorder but conventionally onset is regarded as occurring later during childhood or adolescence. Some participants recalled feelings of depression and severe anxiety from the age of 3 or 4 and it is not known if participants were suffering from social phobia or separation anxiety or both. At least two out of the seven participants suggested they may have had selective mutism, indicating a severe form of childhood disorder that had gone undetected. Given the rarity of selective mutism, it was very surprising to have two participants with it in such a small study.

Participants' stories also seem to support the proposition that people with anxiety disorder may be the children of parents with their own psychological problems. The identification by three participants of pathological maternal controlling behaviour involving threats of hell and damnation was noteworthy, along with a couple of participants' expressed beliefs that their mother was reluctant to seek help in case she were exposed as a 'bad mother'.

It was saddening to learn of the amount of distress that participants endured during their years at school and the various contributing factors have been summarised in the observed theme *troubled school life*. Participants widely experienced being shunned or bullied and this in turn contributed to participants eventually dropping out or not being able to pursue their educational or vocational aspirations.

Participants adopted strategies of limiting their lives, in the hope that they would be able to contain their anxiety, but this did not work and participants described being subjected to anxiety and the terror of panic even in the safety of their home environments. It is evident is that participants came to live a greatly reduced life, one totally dictated to by the vagaries of anxiety. Panicky symptoms were keenly felt and another reason to withdraw from the world, part of what has been described in the theme *problems with living*.

It is regrettable that participants took a long time to come to the realisation they could get help. While participants were well aware they suffered from anxiety and had that communicated to them in various ways at various points in their lives by different people, they were still confused about what they were experiencing and did not necessarily equate their suffering with having a disorder for which treatment could be available.

Perhaps as people with anxiety disorders, they were reluctant to face feelings they had been actively avoiding for years, and given this background it is understandable that some avoided or resisted seeking help. Some participants delayed seeking help, viewing their symptoms as being emotionally based or simply part and parcel of on-going social problems. Some were ashamed or embarrassed about their condition and found it very difficult to summon the courage to disclose distress of a psychological nature to their GP. However, for most, things deteriorated so that the situation could no longer be ignored. Perhaps reflecting a lack of knowledge at the beginning of the process, some participants talked of how they sought a medical explanation for physical symptoms such as irritable bowel. This suggests that in the absence of recognizable and potentially treatable physical symptoms, people may just carry on believing their suffering is an inevitable part of their lives. There seems to be a genuine lack of understanding or knowledge about anxiety disorders which is compounded for people who do not feel able to ask for help or have learnt avoidant style coping strategies. The results are in keeping with research which has identified low rates of recognition, intervention and reluctance to seek help and use services. As mentioned in the introduction, Kessler et al. (1994) found that fewer than half of people with three or more lifetime comorbid disorders ever obtained mental health specialty sector treatment. It may point to what Biddle, Donovan, Sharp and Gunnell (2004) called the 'iceberg' of untreated psychiatric morbidity in young adults.

If people are somehow unaware or reluctant to disclose their distress then the role doctors play in detecting the presence of anxiety disorders in their patients is very critical. As Hirschfield et al. (1997) suggested in their investigation into the under-treatment of depression, factors that rest with GPs need to be considered. Kadam, Croft, McLeod and Hutchinson (2001) suggested that, perhaps medical schools do not provide sufficient education about psychiatric diagnosis, and wondered if limited training in

interpersonal skills may lead to doctors' avoidance of addressing depression and related disorders. Another factor mentioned was that psychological disorders may take more time to diagnose and treat than other medical conditions and that GPs find such consultations difficult to address in routine consultation times. From these participants' accounts it is not clear how a GP's environment acts to encourage or discourage the disclosure of emotional problems.

In the literature review it was mentioned that anxiety disorders have been found to have a serious financial impact on the health care sector but, in this study, only one participant seemed to have been a heavy user of services and this was in relation to panic attacks. In contrast to conventional understanding, it may be that people with particular types of anxiety disorders, such as social phobia or OCD are active avoiders of health sector assistance rather than being heavy users of services.

Once the diagnostic process was activated, participants had to assimilate the new information they were given and re-evaluate their circumstances in light of their new knowledge. In terms of the diagnostic event, appraisals related to a number of factors such as participants' own awareness of their disorder, whether intervention happened earlier or later in life, who made the diagnosis, how the diagnosis was communicated and whether there were various or repeated interventions. Some had come to the suspicion or realisation of having an anxiety disorder before the anxiety disorder diagnosis was confirmed. Although some were initially ambivalent about seeking help, participants said they mostly found a diagnostic assessment to be beneficial in a number of different ways, including learning that their symptoms were part of a well recognised disorder, which is common and treatable. An explanation of their symptoms in terms of a medically recognized disorder also provided participants with an objective rationale for what they were experiencing and was helpful in categorizing their symptoms and allowing new ways to make sense of their distress. For some it meant they could conceptualize their diagnosis as something to work on and educate themselves about. Comprehending the facts of their symptoms and having them explained in terms of a diagnosis is the basis of the theme described as *rationalisation*. A diagnosis seemed to enable participants to reframe their experiences and provide them not only with the information that helped them understand their symptoms but also gave them information that could be shared and be acceptable to others.

A variety of emotions were generated on being given a diagnosis, or having a diagnosis confirmed, ranging from a sense of relief as to having an explanation for what they have been experiencing through to feeling positively validated. This sense of ‘relief’ echoes Wisdom and Green’s (2004) finding that some participants (whom they named labellers) reported hearing their diagnosis with relief. These participants regarded the diagnostic label as confirmation that their distress had a name and that they were not the only person ever to experience these symptoms. Some of this study’s participants reported that the diagnosis also served as a validation of participants’ experiences and acknowledgment of their suffering and allowed them to stop blaming themselves.

On learning about anxiety disorders participants expressed frustration with the colloquial use of the word ‘anxiety’ as having had the effect of minimizing their suffering or being insufficient to describe the extent of their suffering. Some participants’ said that everyday usage of the word ‘anxiety’ interfered with recognition of disorder. This echoes Epstein et al.’s (2010) finding about the colloquial use of the word ‘depression’.

After diagnosis, and with the benefit of hindsight, a number of factors emerged which have been thematically named *post rationalisation*. There were some mixed feelings and ambivalence expressed towards sharing the diagnosis with others and stigma was identified as an important issue for some. Perhaps this fear of stigma is understandable and also complicated by the fact that participants had been bullied and found people to be unsympathetic in the past.

Retrospectively, all participants said they felt let down by the lack of knowledge they possessed about anxiety disorders and felt their knowledge had been ill formed. The findings, therefore, raise an issue related to the need for greater access to relevant information. There are people who are suffering from anxiety disorders but who do not have any knowledge about anxiety disorders that may be helpful to them. This lack of knowledge may also include having no real concept of what professional help might entail. Interestingly, following receipt of a diagnosis, it is clear that participants made a real effort to investigate and educate themselves about their disorder.

Although participants were specifically asked about their diagnosis or diagnoses, the DSM was not mentioned in relation to the provision of the diagnosis, nor as source of

information about different disorders. As Kraemer (2007) pointed out it is health care providers who think of diagnoses in terms of the DSM, while patients think in terms of disorders, therefore the different perspectives of patients and health care providers are understandable. The DSM's focus and concern has always been on 'diagnosis' that is, a clinical expert's opinion as to whether some disorder is present in a particular person. In comparison a 'disorder' is something wrong in a patient that is of clinical relevance and is something problematic for the patient for which s/he would like help with (Kraemer, 2007).

Of interest is that while participants could articulate how their lived experiences had contributed to the onset and development of their disorder, this did not necessarily lead participants to then draw a direct link between, say, troubles in their early life and their current disorder. While growing up and immersed their own lives they were not really able to assess how their life differed from the lives of other people. Where that was possible, however, they may have thought of differences as being caused by some other factor, for example their shy nature.

This study, like many other studies, demonstrates the complexity of mental disorder. The findings clearly highlight the huge influence of developmental, contextual and social issues in contributing to the development and maintenance of adult disorder. A person who has had a traumatic early life, had trouble at school and has experienced on-going problems with living as an adult presents a far more complicated case than an individual who is readily treatable with a pharmacological solution.

The complexity of anxiety disorders points to the need to fully understand and accurately diagnose the real condition, before deciding how to proceed with a treatment plan. While the biomedical model and diagnosis offers a convenient and useful explanation for sufferers, any treatment plan would also need to take into account social and contextual contributing factors.

### ***Limitations***

This study was limited by a number of factors, including having only one male volunteer. This may be an indicator of the difficulty of recruiting male research participants for a study of this nature. The research also included participants with a

variety of anxiety disorders, and so the nature of any one particular disorder could not be investigated in depth.

Although the seven interviews provided a rich source of data, the nature of a one-off interview and its time constraints limited the amount and type of data that could be collected in one sitting. Although no time limit was put on the interview, a single interview can only scratch the surface of participants' experiences and could not hope to capture the entirety or complexity of a person's life. Perhaps more information could have been gained from follow up interviews which would allow topics to be explored in more depth.

As well as the limited number of participants, this sample was a community sample of volunteers. Being self selected and willing to participate in research and the necessary process of disclosure may mean that this sample would be different from another sample of people who are not as willing to participate in research. Therefore, the generalisability of the results may be limited.

Another consideration is that while participants were forthcoming with information, it is must be assumed that not all pertinent information was disclosed. The researcher did not seek to go beyond what information participants freely volunteered in the interview. It has to be acknowledged that in a research interview there was a difficulty inherent in discussing personal subjects in depth and sensitive topics were talked of broadly.

As with any data collected via interview, they are open to different interpretations and the researcher had to analyse the data to reveal themes and draw conclusions and it is hoped that what was expressed and the meanings comprehended have been represented in the way participants intended.

### ***Future studies***

Considering that anxiety disorders are the most common type of mental disorder, they are truly under-represented in the research literature, particularly in comparison to the large body of research that exists on depression. While epidemiological surveys provide an understanding of the scale of the problem, research on how anxiety disorders impact lives is sparse.

This research framed the experience of participants within five themes: *traumatic early life, troubled school life, problems with living, rationalisation and post rationalisation*. The themes recognise the consistency of what the participants said but, having acknowledged the limitations of the current research, it would be of interest to explore the robustness of these themes in further studies.

It is certainly the case that much work remains to be done on understanding the aetiology of anxiety disorders. The findings raise the age old question about nature versus nurture. Although most participants suggested they thought they were born with a shy or sensitive nature, there were also remarkably consistent findings regarding *traumatic early life*. Research that further examines the family's role in the early development of anxiety disorder would therefore be worthy of further investigation. It would be of interest to carefully investigate the relationships between family dysfunction, marital discord, trauma and all forms of abuse (or what Read, Hammersley and Rudegar (2007) called 'acquired vulnerability') and how it contributes to the development of anxiety disorders. Family and longitudinal studies could be of assistance in providing a developmental perspective. Further study is necessary around how anxiety in children is related to parental mental health. Participants have drawn particular attention to maternal controlling behaviour. It was surprising in such a small sample that three of the participants spoke of how they were controlled by their mothers' threats of hell and eternal damnation. The constructs of maternal religiosity and/or scrupulosity and how they relate to controlling behaviour along with the possible impact on young children requires further investigation.

There is also a serious need to investigate cases of the earliest onset of disorder, which, as mentioned, the results of this study seem to indicate as being far earlier than suggested in existing literature. Additionally, a longitudinal study could track the temporal development of anxiety and depression and explore the stability or change of these conditions over time.

The design of the study was a generic investigation into anxiety disorders and participants had different diagnoses which were not contrasted. Research into the experiences of people with each type of anxiety disorder could be informative. Social phobia was identified as a significant problem for most participants, impacting key stages of childhood, adolescence and persisting into adulthood. Understanding anxiety

and social phobia in early childhood, and how distinguishable these conditions are in the young, also needs further exploration as a research topic. Over the lifetime social phobia can cause much distress, including isolation, loneliness and depression. Research has found that social phobia is a common and seriously impairing disorder that is seldom treated unless it occurs in conjunction with another co-morbid condition. Perhaps the impact of social phobia has been under-recognised and under-treated and further research into this could be of interest. It would also be of interest to research the qualitative experience of social anxiety.

Anxiety disorders result in significant disability and burden in both social and occupational functioning and there is a need for both qualitative and quantitative studies to provide better information on these spheres. Participants did not talk of how partners or family members or colleagues were affected and this could be another area for further investigation.

While help-seeking behaviour has been studied generally, it would also be of value for in depth research to be conducted in relation to the help seeking processes for each of the different types of anxiety disorders. Participants seemed to be well practiced in using avoidance as a coping strategy and this needs to be addressed. Participants seemed prepared to tolerate significant symptoms and impairment that accompany social phobia or OCD, for example, and it seemed to be severe depression or panic attacks which ultimately motivated participants to seek help.

The extent to which underlying anxiety disorders are being undetected by GPs and other health professionals must also be quantified. It needs to be known how often a presentation of depression, in a patient who is unaware or reluctant to talk about anxiety, obscures the existence of an anxiety disorder. It would also be of interest to find out if people diagnosed with depression, were also asked about anxiety symptoms. From participants' accounts it is not clear how a GP's environment acts to encourage or discourage the disclosure of emotional problems and this information could be useful.

Diagnosis of anxiety disorder can be a pivotal event in the lives of anxiety disorder sufferers. However the impact and meaning of the diagnostic process on people with anxiety disorders has not been well studied to date and requires further examination to fully understand all the dynamics and ramifications. It is not known how participants conceptually reconcile the impact of their upbringing and social context with the

provision of an anxiety disorder diagnosis as a type of medical condition. This aspect would be of interest to explore in depth.

### ***Recommendations***

It seems children raised in dysfunctional homes are at elevated risk for the development of anxiety disorders and depression and parents cannot necessarily be relied upon on to remedy. If the surprisingly early onset of symptoms reported by these participants can be replicated in other studies, it may warrant steps being taken to identify at risk children with the goal of early intervention to help prevent the development of debilitating disorder.

There may be a need to find ways of enlisting the help of carers or other health professionals working with families in the identification of children displaying signs of developing anxiety disorder. However, this would require an overall strategy to be determined and put in place by governmental and other organisational and community stakeholders, well beyond the scope or understanding of this study.

Perhaps it seems self evident, but parents need to be encouraged to create healthy and nurturing home environments for their children to reduce risk and provide some protection. Community programmes, or perhaps organisations such as New Zealand's Plunket Society could help educate parents or parents-to-be about issues such as secure attachment, anxiety and appropriate discipline. Children with multiple or unexplained somatic symptoms should be investigated as these are strongly associated with anxiety disorders. No doubt family doctors or GPs already play an important role in the recognition of unexplained somatic symptoms in youngsters, plus they are in the advantageous position of knowing something of the family history. GPs need to take a proactive role in uncovering anxiety disorders, as symptoms are often masked and patients or their parents lack awareness or are reluctant to disclose.

Almost certainly, strong warning signs seem to be present within the school environment. Understanding the meaning of some key behaviours could lead to timely intervention and could avert the risk of many years of future suffering. Given the prevalence of a troubled school life among the participants, it would seem appropriate for schools to play a role in identifying children at risk. In addition, the surprising early onset of the disorder, means even primary school teachers could play a part in

identifying children already in the early stages of developing anxiety disorders. Repeated absence or being bullied at school may be early indicators of risk. At high school, intervention programmes could be tailored to meet the needs of adolescents. While there are many factors that determine whether or not students will drop out, anxiety disorders, such as social phobia, may be an important, yet under recognised factor.

For healthcare professionals, one important implication seems to be that by the time people with anxiety disorder ask for help they have already endured much suffering and are quite depleted. When disclosing their problems, it is really appreciated when clinicians acknowledge the validity and importance of their personal experiences and communicate in a caring manner and impart a message of hope.

Sufferers themselves, once diagnosed, generally wished to actively learn as much as they could about their diagnosis and become informed consumers. Networks of support and connectedness could be helpful for providing psycho-education and promoting consumer advocacy.

Participants did raise the question of community understanding and it would be reasonable to conclude that greater public awareness of anxiety disorder could be helpful in building a supportive environment for sufferers. Some participants indicated they would like to see some type of public education campaign in New Zealand. Perhaps this could be similar to, or an adjunct to this country's National Depression Initiative (NDI) which is an integrated national project to raise awareness of depression, with the goals of aiding early recognition, appropriate treatment and recovery (Ministry of Health, 2005). Initiatives include a mass media public education campaign, community based education and GP education. It is not known what impact the NDI may be having on existing levels of anxiety disorder, considering their comorbidity. Perhaps the NDI is having a spin off effect and helping the mental health of anxiety sufferers who have depression. It may also help anxiety sufferers in general to see that a mental health issue such as depression is being openly discussed in the media as a part of a major education programme. Some of the other NDI initiatives around community programmes and education may be appropriate or already having an effect and it would be of interest to research this. At the same time, however, anxiety is not the NDI

campaign message and the suggestion of the participants is valid in that the public still needs to be informed that anxiety disorders are similarly common, serious and treatable.

### *Conclusions*

This study set out to understand how persons with anxiety disorder conceptualize their respective diagnoses. It was of particular interest to explore this area, particularly given the lack of research in this area. In general terms, existing research has a primary focus on depression, with anxiety disorder mentioned due to comorbidity or as an adjunct. Equally, research on anxiety disorders is often embedded solely in the biomedical model, an approach that has obvious limitations, given that so many social and contextual issues are implicated. While the biomedical model has utility by way of providing a convenient and acceptable rationale for disorder, the myriad of contextual and social issues involved mean it has limited utility for developing a treatment plan capable of successfully addressing all of these issues.

The research approach was based on community based interviews with clients and revealed clear and consistent factors. It was noted that participants reported that (1) their disorder was chronic and pervasive; (2) their condition was debilitating at times; (3) their anxiety disorder became complicated by depression; and (4) their dysfunction began in their early family life. Most talked about the early onset of disorder.

Findings of this study also suggested the need for further research into the aetiology of anxiety disorders, including the role of maternal controlling behaviour, family dysfunction and early onset of the disorder. It is clear that there is an issue in how to best address the needs of people who are suffering from anxiety disorders but who do not have any knowledge about anxiety disorders that may be helpful to them. It seems rarely the case, however, that a sufferer is able to self diagnose. Thus the responsibility for detection is necessarily transferred to other parties, but this need not necessarily lie with the medical system alone. The symptoms and behaviours of sufferers can be apparent from an early age, which means that there are a number of opportunities for detection and intervention during a person's life, including through school.

For adults, the opportunity to identify and diagnose the disorder often lies with the medical profession. However, it seems that if the sufferer does present to the GP, they may describe symptoms for something of an apparently different nature. Sufferers have

years of practice in compensatory or avoidant behaviour and the anxiety disorder diagnosis may be 'masked' leading to problems of detection. Given the chronicity of anxiety disorders and the high co-morbidity between anxiety and depression, it seems any mention of depression could well signal a need for further probing to assess the existence of anxiety disorder symptoms. Enquiry into the development of depression should try to establish a time line for the development of disorder. A review of school life, family history of psychological problems or trauma, history of panic attacks and coping strategies may quickly provide clues as to whether an anxiety disorder may be implicated and needs to be addressed.

Once accurately diagnosed, persons can start a process of improving the quality of their lives in at least two different ways. Firstly, understanding that they are suffering a recognised condition can be very helpful. It removes doubt, validates their experiences as real, and explains their symptoms in a way that can be readily comprehended. Diagnosis enables a framework of understanding and a reframing of their life experiences to date as explained by living with the symptoms of anxiety disorder. Secondly, it means they can initiate a process of dealing with the anxiety disorder and activate the hope of improving their lives.

Despite the limitations of the present research, it has provided an opportunity to gain insight directly into the real life experiences of people who have suffered anxiety from a young age. Working in conjunction with anxiety sufferers is an area of research that is currently under represented in the literature. Their reflections have been illuminating and thought-provoking. It has been a privilege to have talked with the group participants and to have shared their experiences with them. It is hoped their reflections and some of the issues raised in this study may provide inspiration for further research.

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## Appendix A: Massey University Human Ethics Committee (MUHEC) Approval



### MASSEY UNIVERSITY ALBANY

30 July 2012

Lynoor Birrell  
c/- Dr D Clarke  
College of Humanities and Social Sciences  
Massey University  
Albany

Dear Lynoor

#### **HUMAN ETHICS APPROVAL APPLICATION – MUHECN 12/050**

#### **Diagnosis Stories: How Individuals with Anxiety Disorders Describe and Attribute Meaning to Their Diagnosis**

Thank you for your application. It has been fully considered, and approved by the Massey University Human Ethics Committee: Northern.

Approval is for three years. If this project has not been completed within three years from the date of this letter, a reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Dr Dianne Gardner  
Acting Chair  
Human Ethics Committee: Northern

cc: Dr D Clarke  
College of Humanities and Social Sciences

Te Kunenga  
ki Pūrehuroa

Research Ethics Office  
Private Bag 102 904, Auckland, 0745, New Zealand Telephone +64 9 414 0800 ex 9539 [humanethicsnorth@massey.ac.nz](mailto:humanethicsnorth@massey.ac.nz)

## **Appendix B: Participant recruitment flyer**

### **Have you been diagnosed with an anxiety disorder?**

**Would you like to participate in a research study?**

**Have you got a couple of hours to spare?**

My research focuses on anxiety disorders and what it means to live with an anxiety disorder.

I am looking for people to interview who are willing to share their experiences with me.

Your identity and information will be treated with utmost respect and confidentiality, according to Massey University's Ethical Guidelines.

You must be over the age of 25 and have been given an anxiety disorder diagnosis

(eg OCD, GAD, Panic Disorder etc) as your primary diagnosis

(but not within the past 6 months)

*A petrol voucher of \$30 will be given as thanks for your participation*

Phone the researcher directly. For further information call Lyn:

021 104 3023

email: [lynnoor.birrell.1@uni.massey.ac.nz](mailto:lynnoor.birrell.1@uni.massey.ac.nz)

## **Appendix C: Screening Questionnaire**

How old are you?

Have you been given an anxiety disorder diagnosis?

What is your diagnosis?

Do you have any other diagnosis?

By whom were you diagnosed?

When were you diagnosed? (within the last 10 years)

## **Appendix D: Information Sheet about the Research Project**

### ***What does your anxiety diagnosis mean to you?***

Hi! My name is Lyn Birrell. Some of you may know me as the facilitator of the Phobic Trust's Support Groups. I am also a mature student and am undertaking a research project as part of my MA (in Psychology) at Massey University, Albany.

I am interested in researching anxiety disorders from your perspective. To date very little research has been published from the consumer's point of view and most people don't really understand what it means to have been diagnosed with an anxiety disorder. It is very important to research this because anxiety disorders are one of the most common mental health conditions in New Zealand, with approximately one in four persons suffering from an anxiety disorder at some stage in their life. Plus anxiety disorders are on the rise in our society.

I am looking for volunteers who would allow me to interview them in depth and in confidence about their diagnosis.

The sort of information I am looking for is: What is your diagnosis? How did you come to be diagnosed? What were the events leading up to your seeking help and getting a diagnosis? What was involved in the process? Did it make sense to you? What has happened since you were diagnosed? What does your diagnosis mean to you? If you could change anything about the process what would it be? Was the process helpful or harmful? In what ways? What does it mean to you to have an anxiety disorder? What do you tell people about your condition? How does your condition affect your day to day life?

These questions may lead into other questions or discussion. You are free to decline any question. I am generally interested in any other information you think may be relevant and would like to share about your condition. You will be asked to give only as much information as you feel comfortable with. Has any question been overlooked?

### **How you can be part of this study**

You are eligible to participate in this study if you are over the age of 25 and fluent in English. You will have been given a diagnosis by a clinician of at least one anxiety

disorder at some stage (but not as recently as the past 6 months). An anxiety disorder must be your main diagnosis. Your diagnosis may include phobia, such as social phobia, agoraphobia or Generalized Anxiety Disorder (GAD), Post Traumatic Stress Disorder (PTSD), Panic Disorder, Obsessive- Compulsive Disorder (OCD) etc.

The interview with me will take place at a pre-arranged mutually convenient day and time. It is anticipated that the interview will take between one and two hours.

With your permission the interview will be audio-recorded. I will later transcribe all the interviews looking for common themes.

**A \$30 petrol voucher will be given to you to cover the cost of transport for attending the interview.**

The most important thing is that you are freely able to talk about your diagnosis and condition. While it is not anticipated that the interview will make you feel uncomfortable, it is possible that perhaps talking about your diagnosis may bring up some unintended discomfort. If that does happen I will stop the interview, turn off the recorder and you can decide whether or not you wish to continue. All decisions will be entirely your choice. Equally you can ask for the recorder to be turned off at any stage during the interview. You are also entitled to withdraw from participation at any stage for any reason and have your recording erased (during the interview and up to two weeks following the interview). If you would like to participate but are unsure about any unintended impact perhaps you may wish to discuss it with your therapist first.

### **Your rights**

Your identifying information will be kept strictly confidential to the researcher only (i.e. myself only). No-one else will have access to any identifying information. Real names and personal details will not be used in the recording or transcription. Pseudonyms will be given. Although brief excerpts from the transcripts will be used in the thesis for illustrative purposes no identifying personal information will be used. All recordings and transcripts will be stored in a secure place at Massey University for 5 years after which the recordings will be erased and the transcripts destroyed by my research supervisor.

Please phone me directly if you are interested in participating in the study. I am happy to answer any and all questions you may have and any concerns or questions you have will be treated with confidentiality, care and respect.

Please phone – Lyn Birrell on 021 014 3023 or email:  
[lynoor.birrell.1@uni.massey.ac.nz](mailto:lynoor.birrell.1@uni.massey.ac.nz)

If you have concerns about this project please contact my supervisor

Dave Clarke, PhD, Registered Clinical Psychologist, School of Psychology, Massey University Tel 414-0800, ext 41214 [d.clarke@massey.ac.nz](mailto:d.clarke@massey.ac.nz)

*This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application 12/503. If you have any concerns about the conduct of this research, please contact Dr Dianne Gardner, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 41225, email [humanethicsnorth@massey.ac.nz](mailto:humanethicsnorth@massey.ac.nz)*

## Appendix E: Interview prompts

It is intended that the interview will be designed to give participants the freedom to express their own story and experiences in their own words, without being overly guided by the interviewer. The interview will be conducted in the manner of a conversation along the lines of “can you tell me about how you came to be diagnosed with....”

There will not be a long list of specific questions that require answering but instead questions will be used only as prompts to promote discussion if needed. Questions may change in the interview based on what unfolds in the interview process.

The main type of questions that will be used to stimulate discussion in the initial stages of the interview are:

What is your diagnosis? Or diagnoses?

How long have you had this diagnosis?

Who gave you this diagnosis?

Who else was involved in the process?

How did you come to be diagnosed (ie the events leading up to the diagnosis?)

Did the process make sense to you?

If you could change anything about the process – what would it be?

What has happened since your diagnosis?

What does your diagnosis mean to you?

Has it been helpful or harmful experience? In what ways?

What do you tell other people about your condition?

Has it changed the way you feel about yourself?

How would you describe what is it like to live with your condition?

Is there anything else that we haven't covered that you would like to share?

## Appendix F: Participant Consent Form

Diagnosis stories: How individuals with anxiety disorder describe and attribute  
meaning to their diagnosis

I have read and understood the Information Sheet dated July 30, 2012.

I agree to be contacted by the researcher as necessary for her to complete her study.

I have had the opportunity to discuss the study with the researcher (Lyn Birrell) and my questions have been fully answered to my satisfaction. I understand my right to ask further questions throughout the study.

I agree to the interview between the researcher and myself being audiorecorded.

I understand my right to decline any question asked by the researcher. I also understand my right to ask for the recorder to be turned off at any time during the interview.

I understand that participation is entirely voluntary and I may withdraw at any stage before, during and up to two weeks after the interview.

I understand that the interview will be transcribed and excerpts may be used in the study.

I understand that the data from the interview is confidential.

I understand that my real name and identifying personal information will not be used in the data and I will be given a pseudonym for the purposes of the study.

I hereby agree to participate in this study.

Full name printed: .....

Signature.....

At the conclusion of the research project I would like a copy of the findings YES/NO

Please provide your address (email or physical) to which a copy of the findings can be sent

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