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PARENTS BATTLING THEIR CHILD'S ANOREXIA:

What is it like For a Parent to Care for a Child with an Eating Disorder?

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Abstract

Anorexia nervosa is a serious and life-threatening mental health issue which needs to be given more attention. Qualitative research on parents' experience in caring for a child with an eating disorder is lacking around the world, and is almost non-existent in New Zealand. Parents of a child with an eating disorder have a huge and difficult role in caring for their child. Resources and facilities for treating eating disorders around the world are limited, and support for carers is minimal, which means the distressing experience of caring for a child with an eating disorder can become more difficult to manage. By giving parents in New Zealand an opportunity to voice their experiences, others may be educated about anorexia nervosa and the experiences of parents. A qualitative approach was employed in this project to explore the experiences of parents in caring for a child with an eating disorder. Twelve parents of nine daughters suffering from anorexia nervosa consented to participate in this research and were interviewed. Interviews were recorded, transcribed and analysed using phenomenological approaches. Descriptive, interpretative and hermeneutic phenomenological methods were drawn on to provide a detailed and in-depth explanation of what it is like for a parent to care for a child with an eating disorder. Analysis revealed that the parents experienced three stages during the struggle for the salvation of their child, which I have labeled the insidious stage, the tenacious stage and the recovery stage. Across the stages it was apparent that the battle against the eating disorder was never-ending, and full of uncertainty, contradiction and emotion. So coping was essential for the physically, emotionally and psychologically exhausted parents. The findings from this research can help raise awareness in society, assist in nationwide education around eating disorders and contribute to improving parents' experiences of caring for a child with an eating disorder. This research has established a good foundation for understanding the experiences of New Zealand parents, regarding what it is like to care for a child with an eating disorder.

Preface and Acknowledgements

The purpose of this research was to explore what it is like for a parent to care for a child with an eating disorder in New Zealand, and fill the gaps in current research. This research gave parents the opportunity to voice their very own experiences.

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Introduction

Background

Anorexia nervosa (hereafter, anorexia) is characterised by refusal to maintain a minimally normal weight for age and height, an intense fear of becoming fat or gaining weight, perceptual disturbances in how weight and shape are evaluated or experienced by the individual and, amenorrhea in females (APA, 2000).

Attempts to achieve one's goal weight include restricting food intake, excessive exercise and purging of calories (i.e. self-induced vomiting or laxative or diuretic abuse) (APA, 2000; Bryant-Waugh, 2000; Grilo, 2006). The intense fear of gaining weight does not alleviate by weight loss and instead, fear usually increases as weight is lost. The extent of perceptual disturbances or distortions relating to one's weight or body shape varies among individuals suffering anorexia (APA, 2000). The pursuit of thinness represents achievement and self-discipline and is thought to provide the individual with a sense of control and success as well as increased self-esteem. Weight gain is viewed by these individuals as failure of self-control and results in huge emotional distress. In addition, some research suggests that having an eating disorder may be a way to cope with or numb emotions that are perceived as distressing by the individual (Kyriacou, Easter, & Tchanturia, 2009).

Those suffering anorexia usually deny the serious medical consequences of their malnourished bodies (APA, 2000; Bryant-Waugh, 2000; Garfinkel & Garner, 1982; Grilo, 2006). Amenorrhea is possible in females, while in prepubertal females delayed menarche is possible. There are two subtypes of anorexia which classify the symptom patterns during the episode of anorexia, restricting type and binge-eating/purging type (APA, 2000; Grilo, 2006).

Bulimia nervosa (hereafter, bulimia) is characterised by a cycle of recurrent binge-eating episodes, recurrent inappropriate weight compensatory behaviours and over-evaluation of body shape and weight. A diagnosis of bulimia is given when the individual does not meet the criteria for anorexia. The characteristics of bulimia must occur at least twice a week for three months. Bulimia also has two subtypes classifying symptom patterns, purging type and non-purging type (APA, 2000).

Binge-eating episodes involve the individual eating an abnormally large amount of food in a relatively short amount of time, considering the circumstances. Binges are believed to occur after hours of food restriction and the body being deprived of nutrients. Emotional distress and feelings of lack of control are experienced during binge-eating episodes. Following this, compensatory strategies are used and include food restriction, self-induced vomiting, laxative abuse, diuretic abuse, excessive exercise and less frequently, misuse of diet pills. Compensatory strategies relieve fear of weight gain and physical discomfort. Individuals suffering bulimia usually experience embarrassment and shame of their disturbed eating patterns which encourages them to keep their symptoms secret. Individuals place an extreme emphasis on their weight and body shape when judging themselves on self-esteem and self-worth. Sadly, self-evaluation and self-esteem are typically negative and low (APA, 2000; Grilo, 2006).

Anorexia is thought to be the third most common health problem among adolescent girls where adolescence is typically the age of onset (Ball & Ball, 1995; Wakeling, 1996). In comparison to anorexia, bulimia is four to six times as common (Abraham & Llewellyn-Jones, 2001). Bulimia also occurs frequently among adolescents and often goes undiagnosed until late adolescence or early adulthood (Hoek & van Hoeken, 2003; APA, 2000). Females are at greater risk of suffering from anorexia and bulimia than males. The prevalence of anorexia among young females is estimated 0.5% (APA, 2000), while that of bulimia is estimated to be 1% (APA, 2000; Hoek & van Hoeken, 2003). It is estimated that between five and ten percent of sufferers of a clinical eating disorder are male (Crisp & Burns, 1983; Hoek & van Hoeken, 2003; Wakeling, 1996).

Eating disorders are a serious problem in New Zealand which remains unrecognised by many people. Research has emphasised that the incidence of anorexia and bulimia has increased over past decades (Hoek & van Hoeken, 2003; Wakeling, 1996). Furthermore, reports are likely to underestimate incidence rates for many reasons such as, the secretive nature of eating disorders and common methodological issues of research (Clarke, & Polimeni-Walker, 2004; Hoek & van Hoeken, 2003; Wakeling, 1996). This emphasises that eating disorders are a growing problem over New Zealand and the world (Hoek & van Hoeken, 2003; Wakeling, 1996).

Eating disorders can put the lives of its sufferers in danger and are one of the highest risks of premature death (Harris & Barraclough, 1998). Anorexia is a chronic illness in which recovery is thought to be slow. It is reported that between 25% and 50% of patients never recover fully (Grilo, 2006; Strober, Freeman, & Morrell, 1997), and are at risk of developing symptoms of bulimia (Tozzi et al., 2005). The course and outcome of bulimia is thought to be more positive compared to that of anorexia. However, the course of bulimia can also be chronic (Grilo, 2006). After a decade of bulimia presentation, roughly 30% still had problems with bingeing or purging behaviours (Keel, Mitchell, Miller, Davis, & Crow, 1999).

Anorexia and bulimia are associated with high rates of morbidity due to the serious physical and psychological harm that sufferers put themselves through. The symptoms of these eating disorders are considered harmful or risky as behaviours include; starvation, excessive exercise, purging and self-harm, as well as drug and alcohol abuse (Bryant-Waugh, 2000; Tan, Hope, & Stewart, 2003). Consequently, the list of the potential complications resulting from anorexia and bulimia are long.

The physical complications of anorexia are the most serious of all eating disorders and can be fatal where the complications may be irreversible in children (Neiderman, 2000; Nicholls, de Bruyn, & Gordon, 2000). Physical complications include, dehydration, extreme constipation, erratic glucose metabolism, amenorrhoea in females and complications in reproductive function, osteoporosis, dermatological implications and, problems with organ functioning including, cardiac abnormalities and brain abnormalities, particularly enlarged cerebral ventricles (Grilo, 2006; Nicholls et al., 2000). Anorexia affects the growth and development in children due to the conditions the body is subjected to (Nicholls et al., 2000).

In addition, anorexia is considered to be related to serious dysfunction in various areas in life when sufferers are seriously underweight. Factors of dysfunction include, irritability, insomnia, social isolation, problematic attitudes toward marriage and sexuality and relying heavily on their families (APA, 2000; Garfinkel & Garner, 1982; Ratnasuriya, Eisler, Szmukler, & Russell, 1991). Individuals also become more at risk of other mental health problems which is thought to be due to the eating disorder. Problems that may manifest are; depressed mood, obsessive compulsive features and

personality disturbance that often meet the criteria for one personality disorder at least, most commonly borderline personality disorder. Other impulse control problems have been found to develop such as, drug and alcohol abuse and an increased frequency of suicide attempts (APA, 2000).

The physical implications of bulimia are most apparent in hormonal and metabolic functioning (Nicholls et al., 2000). Medical problems occur as bulimia worsens and include, renal and electrolyte problems, cardiac problems, dehydration, gastrointestinal problems, dental damage, dermatological consequences and problems in pregnancy for females (Grilo, 2006). Those with bulimia are believed to experience deficits in interpersonal relationships and social anxiety. This means sufferers of bulimia have difficulty seeking treatment or support (Grilo, 2006).

Sadly, suicide attempts are common among those suffering from anorexia (Keel et al., 2003; Garfinkel & Garner, 1982), as are deaths resulting from starvation and cardiac events (Grilo, 2006). Consequently mortality rates among sufferers of anorexia are high. What is of great concern is that some research shows anorexia has the highest mortality rates among all psychiatric disorders (Harris & Barraclough, 1998; McMaster, Beale, Hillege, & Nagy, 2004; Neiderman, 2000; Wakeling, 1996). Suicides can and do occur in bulimia sufferers but are rarer (Keel et al., 1999).

So it is clear that anorexia and bulimia are serious psychological problems which can lead to social complications and dangerous physical consequences for sufferers and their families. Furthermore, these eating disorders are occurring more commonly than is known by society. This highlights the need to pay more attention to the area of eating disorders.

Research up until now

Previous research has explored the views of the patient with the eating disorder, such as that of Pettersen and Rosenvinge (2002). However, research argues that the patient's perception regarding eating disorders differs from that of the parents (Halvorsen & Heyerdahl, 2007). Qualitative research which explores the experience of parents caring for their children with eating disorders is limited (Cottee-Lane, Pistrang,

& Bryant-Waugh, 2004; Perkins, Winn, Murray, Murphy, & Schmidt, 2004; Tierney, 2005; Whitney et al., 2005; Winn, Perkins, Murray, Murphy, & Schmidt, 2004).

Only recently, interest in the care-giving experience of eating disorders has grown (Grilo, 2006). Much research has blamed or suggested particular categorisations of parents and family as contributing to the development and maintenance of the child's eating disorder (Hoste, Doyle, & le Grange, 2011; Minuchin, Roseman, & Baker, 1978; Romi & Kowen, 2006). Such suggestions not only make parents feel negatively about their role as a parent, they also paint a negative picture of the parents of children with eating disorders (Hillege, Beale, & McMaster, 2006; McMaster et al., 2004).

Other research has acknowledged that family dynamics which are considered dysfunctional may actually be a result from the pressure the eating disorder puts on the family rather than the family being part of the aetiology of the eating disorder (Hoste et al., 2011; Sim, et al., 2009; Stern et al., 1989; Kent & Clopton, 2002). Morbidity and mortality rates of eating disorders are highly distressing for a parent of a child with an eating disorder (Cottee-Lane et al., 2004). Other research points out that family are capable of being part of the solution to the individual overcoming the eating disorder rather than the problem (Kamerling & Smith, 2010; Hoste et al., 2011; Sim et al., 2009).

In the relatively limited amount of qualitative international research (Gowers & Bryant-Waugh, 2004); some parents of children with eating disorders have reported their experiences. The majority of the research that has been carried out has generally focused on carers' or parents' experiences of treatment or coping (Cohn, 2005; Honey & Halse, 2006b; Poser, 2005; Tan, Hope, Stewart, & Fitzpatrick, 2003; Tierney, 2005), but not extensively on, what it is like for parents to care for their child with an eating disorder. Much more research of a qualitative nature is needed to fully understand the experience of parents (Barker, Pistrang, & Elliot, 2002; Britten, 1995; Perkins et al., 2004; Pope & Mays, 1995). Despite the limitations of previous research, the perceptions of the parents are important, valuable and, worth exploring for a number of reasons (Honey & Halse, 2005; 1999; Tierney, 2005).

Research has generally been carried out in Australia and Europe (Keitel, Parisi, Whitney, & Stack, 2010) and suggests that there are huge implications for parents that have a child with an eating disorder (Cohn, 2005; Cottee-Lane et al., 2004; Haigh &

Treasure, 2003; Kyriacou, Treasure, & Schmidt, 2008a; Kyriacou, Treasure, & Schmidt, 2008b; MacDonald, 2000; McMaster et al., 2004; Perkins et al., 2004). To my knowledge, research on eating disorders in New Zealand is minimal while research on the parents of children suffering eating disorders is almost non-existent despite the apparent need. This is of concern as it is obvious that the role of the parents is complex and extremely stressful in a variety of ways (Honey & Halse, 2006a; Honey & Halse, 2006b; Keitel et al., 2010).

My research will be carried out more extensively than the majority of the previous qualitative research. Much of the previous research favours or only focuses on certain aspects of the parents' experience, such as their experiences with treatment (Tierney, 2005). This is not to say that such aspects are not important, but rather that other aspects of the parents experience have not been paid a lot of attention. Furthermore, the experiences of parents have hardly been explored in New Zealand. My research aims to cover a wide variety of aspects about the experience of caring for a child who has an eating disorder in New Zealand. This will provide an awareness as well as greater knowledge and understanding of what it is like for a parent to care for a child with an eating disorder.

It is now much more widely recognised that parents play a critical part in their child's recovery from an eating disorder (Goddard, Raenker, & Treasure, 2011; Hoste et al., 2011; Sim et al., 2009; Lock, le Grange, Agras, & Dare, 2001; Tierney, 2005). Eating disorders are typically diagnosed in childhood or adolescence which means, one or both parents provide primary care to their child (Grilo, 2006; Haigh, & Treasure, 2003).

Due to the typical lack of insight or denial of the individual suffering an eating disorder, it is often family members that bring the individual to the attention of health professionals (APA, 2000; Ball & Ball, 1995; Brown, 2011; Goddard, Macdonald, & Treasure, 2010). This makes the parents an important resource to collect information from (APA, 2000; Brown, 2011; Kamerling & Smith, 2010; le Grange, 1999; Sim et al., 2009). Parents' experiences can inform health professionals regarding the features and degree of the eating disorder (APA, 2000; Brown, 2011; Kamerling & Smith, 2010; le Grange, 1999).

Once the eating disorder is identified, parents are usually the people who are constantly encouraging their child to engage in or continue treatment, and who are involved in their child's treatment (Honey et al., 2008; Paulson-Karlsson, Nevonen, & Engstrom, 2006; Tierney, 2005). Parents facilitate and support the treatment delivered by health professionals (Honey et al., 2008). Parents must cope with their child suffering the eating disorder every day (MacDonald, 2000), and provide the necessary care in the home and family environment (Honey & Halse, 2005; Tierney, 2005). This involves managing the child's eating, as well as their challenging moods and behaviours associated with the eating disorder (Hillege et al., 2006; Kamerling & Smith, 2010; le Grange, 1999; Tierney, 2005). In other words, parents can influence the outcomes of treatment and are important sources of recovery (Kamerling & Smith, 2010; le Grange, 1999; Paulson-Karlsson et al., 2006).

Due to the vital role a parent has in their child's recovery, research recommends that clinicians include the parents as important members of the treatment team (Hillege et al., 2006; Sharkey-Orgero, 1999). This is thought to lead to improved outcomes for patient and family (Hillege et al., 2006; Tierney, 2005).

In support of this, those recovering from eating disorders have reported that empathetic relationships with significant others are crucial (Pettersen & Rosenvinge, 2002). Wood (2004) found that the turning points for male and female sportspersons suffering eating disorders were due to their supportive and empathetic parents or surrogate parents intervening. Parents were described as essential in continuing recovery from an eating disorder. Supportive and nurturing parents were associated with great recovery outcomes and shorter duration of an eating disorder. Greater prognosis in adolescent anorexia due to the parental support of treatment has also been suggested by other research (Halvorsen & Heyerdahl, 2007).

As parents are primary caregivers that can influence treatment outcomes, this makes the views of parents an important area of exploration (Honey & Halse, 2005; Nicholls & Magagna, 1997). Without the invaluable input, involvement, time and dedication of parents, one wonders what the outcome for their child suffering an eating disorder would be (McMaster et al., 2004). Exploring parents' perceptions and experiences of their situation provides knowledge for and understanding to other people

including health professionals (Honey & Halse, 2005; Nicholls & Magagna, 1997). Clinicians have found learning about parents' experiences helpful and useful when building a positive therapeutic alliance for the treatment of the child (Nicholls & Magagna, 1997).

It is emphasised that parents are the best resources in the recovery of their child (Cottee-Lane et al., 2004; Hillege et al., 2006; Lock et al., 2001; Sim et al., 2009). However, despite parents being an important resource, the lack of involvement the family has in the treatment of the eating disorder is of concern and reflects a gap in research (Ball & Ball, 1995). McMaster and colleagues (2004) point out that the importance of parental involvement is becoming more recognised, but that it is not yet viewed as essential to the recovery of the child with the eating disorder. The latter may be why little is known about parents' experiences of caring for a child with an eating disorder (Cottee-Lane et al., 2004). My research will help fill this gap and describe the inevitable and valuable role parents have in caring for their child with an eating disorder.

The inevitable role of the parents leads to another important area of research in eating disorders which highlights that the parents of children suffering eating disorders experience caregiver burden or high physical and emotional strain (Graap et al., 2008a; Graap et al., 2008b; Hight, Thompson, & King, 2005; Loukissa, 1995; Whitney, Haigh, Weinman, & Treasure, 2007). Some research found an underlying sense among parents of, "hoping for the best while fearing the worst" (Tierney, 2005, p. 377).

Caring for an individual suffering and eating disorder evokes a rollercoaster ride of emotions and, the majority of emotions are negative and very distressing (Abraham & Llewellyn-Jones, 2001; Cottee-Lane et al., 2004; MacDonald, 2000; Perkins et al., 2004). These intense emotions are endured by parents throughout the continuous care of their child suffering an eating disorder (Honey & Halse, 2005; MacDonald, 2000; Perkins et al., 2004; Tan, Hope, Stewart, & Fitzpatrick, 2003; Winn et al., 2004). The emotions reported by parents reflect their extreme concern and distress (Cottee-Lane et al., 2004; MacDonald, 2000), and emphasise the lonely and intense struggle of caring for an individual with an eating disorder (Ball & Ball, 1995; Cottee-Lane et al., 2004; Hillege et al., 2006).

Fear, anxiety, helplessness and frustration are commonly experienced by those caring for an individual with an eating disorder (Ball & Ball, 1995; Brown, 2011; Cottee-Lane et al., 2004; Grilo, 2006; Highet et al., 2005; Whitney et al., 2005). The limited knowledge and understanding among parents and health professionals regarding the seriousness of eating disorders as well as their management contributed to a lot of fear and concern for the child (Ball & Ball, 1995; Tierney, 2005). Much research explains how the chronicity of eating disorders and the intense negative emotions can contribute to caregiver mental health problems (Ball & Ball, 1995; Highet et al., 2005; Martin et al., 2011; Winn, 2004; Whitney et al., 2005).

Intense emotions are frequently evoked in carers of anorexia (Honey & Halse, 2005; Tan et al., 2003), from family members including parents, right through to the majority of mental health professionals (Grilo, 2006; Morgan, 1977; Strober, 2004). Intense emotions are due to the extremely low weight of the frail and fragile person (Ball & Ball, 1995; Cottee-Lane et al., 2004; Grilo, 2006; Highet et al., 2005). The high morbidity and mortality rates of anorexia and its chronicity are obviously very concerning (McMaster et al., 2004). What makes it worse is that the patient typically disengages themselves from treatment of the life-threatening anorexia (Cottee-Lane et al., 2004).

Parents' are desperate and typically unsuccessful in their attempts of trying to get through to their child who is starving themselves (Cottee-Lane et al., 2004). Some parents perceived their child as committing a slow suicide (Highet et al., 2005; MacDonald, 2000; Sharkey-Orgnero, 1999), and feared for their child's life as they encouraged their child to stay alive (Ball & Ball, 1995). Numerous unsuccessful attempts often contributed to carers sometimes feeling angry, in denial, helpless and powerless (Highet et al., 2005; Sharkey-Orgnero, 1999; Tan et al., 2003) and often leave carers feeling completely drained (Strober, 2004). Not surprisingly, anorexia is described as one of the most challenging and distressing physical and mental illnesses to care for, even more distressing than psychotic episodes or schizophrenia (Sim et al., 2009; Treasure et al., 2001; Whitney et al., 2007).

Caring for an individual with bulimia can also evoke powerful negative emotions and considerable distress for the carer as the role is also challenging (Perkins et al.,

2004; Winn et al., 2007). Winn and colleagues (2007) found that the difficulties in caring for bulimia sufferers were comparable to many of the difficulties of caring for an individual with anorexia or psychosis. Detection of bulimia and caring for the illness can be difficult due to its secretive nature and denial of a problem by the sufferer (Perkins et al., 2004). Furthermore, research suggests that the role of the carer can be quite difficult and distressing due to a significant percentage of those suffering bulimia also engaging in self harm or, drug and alcohol abuse (Winn et al., 2004; Winn et al., 2007).

Unfortunately, bulimia and anorexia are both hard to detect during adolescence due to the typical adolescent behaviours and changes that resemble eating disorder symptoms (Ball & Ball, 1995; Cottee-Lane et al., 2004; Highet et al., 2005). When parents and health professionals attribute the behaviours or symptoms of an eating disorder to adolescence, treatment is delayed (Ball & Ball, 1995; Cottee-Lane et al., 2004; Highet et al., 2005). Many carers reported underestimating the seriousness of eating disorders, felt helpless and were uncertain how to manage the eating disorder (Abraham & Llewellyn-Jones, 2001; Ball & Ball, 1995; Perkins et al., 2004; Whitney et al., 2005).

Disbelief, guilt and blame are commonly felt by many parents of children with anorexia and bulimia (Ball & Ball, 1995; Highet et al., 2005; Hoste et al., 2011; MacDonald, 2000; Winn et al., 2004). Guilt was felt by many parents, for not being aware of the eating disorder that their child was suffering (Abraham & Llewellyn-Jones, 2001; Ball & Ball, 1995; Cottee-Lane et al., 2004; Winn et al., 2004). Parents thought that perhaps if they had recognised the eating disorder sooner, then they might have been able to get their children to treatment sooner (Abraham & Llewellyn-Jones, 2001; Cottee-Lane et al., 2004; Winn et al., 2004).

Some parents initially avoided the fact that their child had an eating disorder and needed time to accept this. Many parents were frightened and shocked; they wondered why their child had developed an eating disorder and expressed concern for their child (Ball & Ball, 1995; Brown, 2011; Cottee-Lane et al., 2004; Highet et al., 2005; Tierney, 2005). Parents blamed themselves for the situation; they wondered how they had contributed to the situation and spoke about failing as a parent (Abraham & Llewellyn-

Jones, 2001; Ball & Ball, 1995; Cottee-Lane et al., 2004; Sharkey-Orgnero, 1999; Whitney et al., 2005).

However, once parents realised their child's health was in danger, parents sought to deepen their knowledge of the eating disorder (Sharkey-Orgnero, 1999). Parents realised that dwelling on responsibility was not productive or helpful so tried to avoid thinking about it (Honey & Halse, 2006b).

Parents having to adapt to the fact that their child had an eating disorder was hard and distressing for parents (Gilbert, Shaw, & Notar, 2000; Shapiro, 1983; Whitney et al., 2007). Many parents were bewildered by the seriousness and complexity of anorexia (Whitney et al., 2005). Parents described their child having been consumed or possessed by the eating disorder and reported noticing a change in their child's personality (Abraham & Llewellyn-Jones, 2001; Ball & Ball, 1995; Cottee-Lane et al., 2004; Hight et al., 2005). Parents feared for their child's development and acknowledged experiencing grief and loss over their child missing out on normal life (Hight et al., 2005; MacDonald, 2000; Treasure et al., 2001; Whitney et al., 2007).

But despite these feelings, parents eventually realised that the eating disorder which had developed in their child was never their fault (Perkins et al., 2004). Likewise, parents came to the realisation that the responsibility of recovery belonged to the individual with the eating disorder. It was important for parents to support their child but also step back and let their child recover and become independent (Cohn, 2005; Sharkey-Orgnero, 1999).

When it came to recovery and treatment, dealing with health professionals was sometimes another stressful experience for parents (Keitel et al., 2010; McMaster et al., 2004; Ross & Handy, 2007). Health professionals have often lacked knowledge and understanding of the seriousness of eating disorders and what kind of management the eating disorder required (Hillege et al., 2006; Sim et al., 2009; Keitel et al., 2010; Tierney, 2005). Many general practitioners have been known to misdiagnose eating disorders, minimise the symptoms of eating disorders and/or disregard the concerns of parents (Keitel et al., 2010; Tierney, 2005). Parents were often treated as if they were overreacting to the symptoms of their child's eating disorder (Tierney, 2005).

Once their child was diagnosed and receiving treatment, parents commonly experienced criticism from health professionals (MacDonald, 2000; Tierney, 2005). Some parents have mentioned having had difficulty being involved in their child's treatment (Hillege et al., 2006; MacDonald, 2000; Sim et al., 2009; Tierney, 2005). Parents identified some common obstacles of treatment which include, the negative attitudes of health professionals towards parents including blaming the parents and secrecy of treatment (MacDonald, 2000), communication problems and, issues with confidentiality (Kamerling & Smith, 2010; MacDonald, 2000; Winn et al., 2004). For instance, when children were over the age limit and considered an adult, parental involvement was limited to what the patient desired (MacDonald, 2000; Winn et al., 2004).

In addition, poor communication between health professionals and parents led to parents feeling isolated and uncertain about their child's treatment progress (Highet et al., 2005; Tierney, 2005). This leaves many parents feeling frustrated as they usually have useful information to share about their child's eating disorder (McMaster et al., 2004; Winn et al., 2004). Parents sometimes felt their concerns were not being heard (Ball & Ball, 1995; McMaster et al., 2004), or taken seriously (Ball & Ball, 1995; MacDonald, 2000), or they felt demoralised (Tierney, 2005).

Furthermore, many parents attributed exclusion to being held responsible and blamed for their child's situation (McMaster et al., 2004; Sharkey-Orgero, 1999), which was another element of parental distress (Keitel et al., 2010). Some parents believed that excluding the parents prevented their child from communicating with the family and therefore leading to their child isolating her/himself (McMaster et al., 2004).

When parents searched for advice about how to care for their child, sometimes health professionals were unable to give advice or sometimes the advice given was potentially detrimental (Keitel et al., 2010). Parents often found that the advice they were given conflicted (Ball & Ball, 1995; Cottee-Lane et al., 2004), which made understanding the eating disorder very difficult (Gilbert et al., 2000). This contributed to confusion and frustration (Cottee-Lane et al., 2004; Honey & Halse, 2005; Kamerling & Smith, 2010), and made it difficult for parents to cope (Ball & Ball, 1995). Many parents perceived anorexia as a 'mysterious illness' (Honey & Halse, 2005).

Despite the many difficulties that can arise relating to limited treatment and understanding, parents have highlighted the positives from their involvement in their child's treatment (MacDonald, 2000; Keitel et al., 2010; Tierney, 2005; Winn et al., 2004). Parents reported that their experiences varied and differed among service providers where some were more supportive and understanding of the parents (Keitel et al., 2010).

Specialist services in eating disorders were reported as helpful or beneficial by parents (Cottee-Lane et al., 2004; Winn et al., 2004). Also preferred by parents was a supportive style of treatment and open communication as this was reported to reduce tension and the negative emotions experienced by those involved (Winn et al., 2004). Family therapy was perceived as helpful as it provided a safe place for emotions to be expressed and invited the family to be involved with treatment (Paulson-Karlsson et al., 2006; Tierney, 2005). Parents also acknowledged that there was at least one health professional involved in the treatment of their child, which they found helpful (Tierney, 2005).

Parents experienced relief once treatment was found and utilised (McMaster et al., 2004; Whitney et al., 2005), and also during progress and improvement (Cottee-Lane et al., 2004; Perkins et al., 2004). Parents wish to be a part of their child's treatment and perceive involvement as valuable (Halvorsen & Heyerdahl, 2007; Winn et al., 2004).

But sadly, treatment has been referred to as lengthy and intense where parents often feel powerless, hopeless and inadequate (Highet et al., 2005). Parents were also aware of the possibility of their child relapsing in the future (Tierney, 2005). Such negative experiences, related to treatment, contributed to unnecessary distress experienced by the parents (Keitel et al., 2010; McMaster et al., 2004).

Another potential element of distress may be due to the limited understanding of eating disorders in the general public (Holliday, Wall, Treasure, & Weinman, 2005; Winn et al., 2004). This creates the possibility of the parents being unfairly stigmatised (Highet et al., 2005). The lack of understanding and comments made by others was frustrating for many parents (Hillege et al., 2006). Research shows that lay people have optimistic perceptions of eating disorders in relation to treatment outcomes and regarding the control the patient has over the eating disorder (Holliday et al., 2005). The

pressure upon parents who were struggling already was intensified as they came to realise they had to cope on their own because the illness was not understood (Hillege et al., 2006). Social isolation and significant distress often resulted for parents due to lack of support (Highet et al., 2005; Hillege et al., 2006).

Parents report that the public notice their child suffers anorexia where some talk about it and others avoid talking about it (Ball & Ball, 1995). Many parents feel this and not having daily contact with an eating disorder suggests a potential lack of awareness and understanding of eating disorders in the community (Ball & Ball, 1995; Highet et al., 2005). Parents have highlighted that even themselves who are in daily contact with eating disorders have difficulty understanding them (Ball & Ball, 1995). Some expressions from the public or onlookers suggest that they believe the parents are responsible for the child's ill health and allow the presence of the eating disorder (Highet et al., 2005). Stigmatisation like this, leads to parents experiencing unwarranted shame (Highet et al., 2005; Winn et al., 2004). This often discourages parents from sharing their experiences (Ball & Ball, 1995; Whitney et al., 2005).

Aside from treatment and public perceptions, parents have reported feeling that their identity and own life had been consumed by the eating disorder (Highet et al., 2005; Kamerling & Smith, 2010; Kyriacou et al., 2009; Loukissa, 1995). Parents previous personal and social lives had to be put on hold for a period of time, while they put all their energy into caring for their child in need (Cottee-Lane et al., 2004; Highet et al., 2005; Honey & Halse, 2006b; Kamerling & Smith, 2010; Keitel et al., 2010). Sometimes as a result, other opportunities in life had to be given up (Honey & Halse, 2006b; Keitel et al., 2010; Loukissa, 1995; Perkins et al., 2004), and caring for the child became the main priority in these parents' lives (Highet et al., 2005; Kamerling & Smith, 2010). This often left parents feeling emotionally drained or exhausted (Gilbert et al., 2000; Kamerling & Smith, 2010).

Parents that have experienced caring for a child with an eating disorder often realise that they must look after themselves and have time to themselves to be able to care for their child (Ball & Ball, 1995; Cohn, 2005; Honey & Halse, 2006b; Perkins et al., 2004). Parents have reported trying all kinds of strategies in attempt to remain physically and psychologically healthy (Honey & Halse, 2006b). Parents making time

for themselves is very important as eating disorders can display intense selfishness (Abraham & Llewellyn-Jones, 2001; Ball & Ball, 1995). However, this proves to be easier said than done, carers report that those suffering an eating disorder are dependent on them and that sufferers were unable to cope on their own (Kyriacou et al., 2009; MacDonald, 2000; Perkins et al., 2004; Whitney et al., 2007). Many parents had to see a counsellor themselves as many became depressed with the pressures of trying to manage the eating disorder and care for their child (Ball & Ball, 1995).

On top of the many stressors and strains of having a child with an eating disorder, parents had to be positive and knew it was important to encourage and support their child in recovery (Honey & Halse, 2005; Tierney, 2005). Parents would frequently try to portray a positive and confident image while hide their negative emotions from their child (Honey & Halse, 2005). At the same time, parents had to tolerate deviant attitudes and behaviours from their child with the eating disorder as to avoid further conflict with their child (Honey & Halse, 2005).

Parents also had to cope with often being rejected by their child with the eating disorder and cope with the accusations of not caring as well as being blamed by their child (Ball & Ball, 1995; MacDonald, 2000). For instance, many parents worried that after convincing their resistant child to have treatment; their child would feel betrayed or abandoned by them (Abraham & Llewellyn-Jones, 2001).

Ultimately research shows that caring for an individual suffering an eating disorder takes its toll on the physical and psychological health of the carer, where the majority of carers are parents (Abraham & Llewellyn-Jones, 2001; Cottee-Lane et al., 2004; Highet et al., 2005; Martin et al., 2011; McMaster et al., 2004; Perkins et al., 2004; Tierney, 2005; Zabala, Macdonald, & Treasure, 2009). Over 50% of carers of eating disordered individuals have reported experiencing significant distress or mental health problems (Winn et al., 2007). It was found that carers of anorexia are subject to higher psychological morbidity than carers of other mental illnesses or parents of healthy controls (Kyriacou et al., 2008a; Kyriacou et al., 2008b).

Common health problems of carers are, anxiety, feelings of helplessness (Highet et al., 2005; Kyriacou et al., 2008a; Martin et al., 2011; Zabala et al., 2009), a depressed mood (Graap et al., 2008a; Graap et al., 2008b; Kyriacou et al., 2008a; Martin et al.,

2011; Zabala et al., 2009) and exhaustion (Cottee-Lane et al., 2004; Perkins et al., 2004; Whitney et al., 2005). Kyriacou and colleagues (2008b) reported that more than 50% of carers suffered clinical anxiety while 13% suffered clinical depression. This is hardly surprising considering how challenging the role of a parent is (Haigh & Treasure, 2003).

So it is apparent that the amount of emotional distress parents and the family of a child with an eating disorder experience is considerable and frequently minimised or disregarded (Sim et al., 2009). More attention needs to be given to the challenging role parents have. If parents' views and experiences can be understood, then services or interventions could be implemented to assist parents in their challenging role (Honey & Halse, 2005). Interventions could encompass coping strategies as well as practical and emotional support, which would likely relieve some distress and improve the physical and psychological well-being of parents (Goddard et al., 2010; Haigh & Treasure, 2003). This emphasises the need for my research, to further explore what it is like to care for a child with an eating disorder.

Another important part of the challenging and distressing role the parents have involves trying to maintain family functioning and relationships (Honey & Halse, 2006a). Parents have expressed concern regarding the impact the eating disorder has on the entire household (Brown, 2011; Cottee-Lane et al., 2004; Tan et al., 2003). Eating disorders place many demands on other members in the family where routines, relationships and practically all aspects of family life are affected (Ball & Ball, 1995; Brown, 2011; Dimitropoulos, Carter, Schachter, & Woodside, 2008; Goddard et al., 2010; Hight et al., 2005; Kyriacou et al., 2009; Ross & Handy, 2007; Tierney, 2005).

Anorexia has been described as disruptive, draining and devastating to the well-being of the family (Abraham & Llewellyn-Jones, 2001; Brown, 2011; Cottee-Lane et al., 2004; Kyriacou et al., 2009; Ross & Handy, 2007; Sim et al., 2009). Anorexia emotionally upheaved the family and put the family at psychological risk (Garfinkel & Garner, 1982; Shapiro, 1983). An eating disorder is a serious and chronic illness which places a huge amount of stress on everyone in the family (Gilbert et al., 2000; Hillege et al., 2006; Ross & Handy, 2007; Whitney et al., 2005; Zabala et al., 2009).

Family members often experience shock when they find out their family member has an eating disorder and go through a number of stages (Ball & Ball, 1995). Family

members often do not understand the behaviour and feel that they no longer know the individual which leads family members to react in various ways (Ball & Ball, 1995). Negative experiences within the family generally result due to the range of emotions and challenges the family are faced with (Gilbert et al., 2000).

For some time, the eating disorder becomes the central focus in the family where parents have had to put their child with the eating disorder first (Highet et al., 2005; Tierney, 2005). Parents would find themselves spending more time with their ill child and less time in relationships with others (Abraham & Llewellyn-Jones, 2001; Highet et al., 2005). The eating disorder frequently demands attention and energy (Abraham & Llewellyn-Jones, 2001; Whitney et al., 2005), and manipulates or controls the behaviour of family members (Cottee-Lane et al., 2004; Highet et al., 2005; Kyriacou et al., 2009; Whitney et al., 2005). Normality in family life is lost (Cottee-Lane et al., 2004; Hillege et al., 2006).

Parents feel that the bond with their child changes and describe their child being taken over by or possessed by the eating disorder (Ross & Handy, 2007; Tan et al., 2003). Parents have reported that their child becomes socially withdrawn, detached, self-centred and devious (Ball & Ball, 1995; Gilbert et al., 2000; Highet et al., 2005; Kyriacou et al., 2009). The eating disorder places a barrier between the child and parent, restricting their relationship and closeness (Ball & Ball, 1995; Perkins et al., 2004). Some parents have expressed difficulty in the form of communicating and interacting with their child (Goddard et al., 2011; Grilo, 2006; Perkins et al., 2004). Confrontations between the child and parent seem to occur more frequently when not avoided by parents (Ball & Ball, 1995; Perkins et al., 2004). The difficulties experienced within the relationship and managing the child's behaviour and demands make it hard for parents to maintain a relationship that is positive with the child (Ball & Ball, 1995; Cottee-Lane et al., 2004; Perkins et al., 2004).

Parents were aware that other members of the family shared similar experiences with the suffering individual (Gilbert et al., 2000). Relationships once had between family members and the eating-disordered individual change (Ball & Ball, 1995; Highet et al., 2005). Parents become aware that their other children may feel uncared for or neglected due to the demands of the eating disorder (Abraham & Llewellyn-Jones,

2000; Honey & Halse, 2006a; Tierney, 2005), and how their reactions might affect other members in the family (Honey & Halse, 2006a).

For instance, parents sometimes had to tolerate the deviant behaviours of their child with an eating disorder to avoid making the situation worse (Highet et al., 2005; Honey & Halse, 2005). But this can influence siblings to feel resentment toward particular family members (Highet et al., 2005; Honey & Halse, 2006a; Tierney, 2005). Siblings may resent their sibling with an eating disorder due to the disruption to what was once, normal family life (Highet et al., 2005), and due to the stress the eating disorder is inflicting onto their parents (Ball & Ball, 1995). Often parents realise this but find the child with the eating disorder is highly dependent (Perkins et al., 2004).

Siblings sometimes experienced, fear, anger and worry, where siblings sometimes found the eating disorder difficult to understand (Highet et al., 2005). Siblings have little opportunity to express their feelings regarding the situation and parents felt this was overlooked by many health professionals (Ball & Ball, 1995; Tierney, 2005). Siblings may act out their built up frustration, withdraw from the family or cope well with the situation (Ball & Ball, 1995; Gilbert et al., 2000; Tierney, 2005).

Parents reported attempting to minimise the negative impact of the eating disorder on their other children, parents tried to protect their other children and maintain normality within the family (Honey & Halse, 2006a). At other times, parents needed to manage the negative emotional impact the eating disorder placed on their other children which was sometimes by their children having counselling (Honey & Halse, 2006a).

Spousal relationships were also said to have been strained while the child had an eating disorder as parental support was required by the child. As the majority of the parent's time was spent with their child with the eating disorder, this meant time with others, including their spouse became very limited (Gilbert et al., 2000).

Strained relationships and lack of understanding on the part of other family members and feelings of neglect by a sibling can unfortunately also increase the stress experienced by the parent (Ball & Ball, 1995; Highet et al., 2005; Keitel et al., 2010). Parents often worried about the relationships between the child and other family members (Honey & Halse, 2006a; Keitel et al., 2010). Carers of those with anorexia

have identified taking large responsibility for the health of other family members (Graap et al., 2008a; Graap et al., 2008b; Honey & Halse, 2006a). Caring for all family members as well as a child with an eating disorder has been described by parents as mentally and physically exhausting (Cottee-Lane et al., 2004).

Many parents emphasise the importance of spending time with others in a space that is free of the eating disorder (Ball & Ball, 1995; Cohn, 2005; Honey & Halse, 2006a, Honey & Halse, 2006b). Likewise, it is essential for family members to continue on with their individual lives (Ball & Ball, 1995; Cohn, 2005). This is important as the eating disorder is self-centred and destructive (Abraham & Llewellyn-Jones, 2001).

In addition, practical problems of an eating disorder can place a strain on the family (Cottee-Lane et al., 2004). Most commonly, difficulties during food-related activities result, for instance, dining in, dining out and grocery shopping experiences all change to accommodate the eating disorder (Perkins et al., 2004). Meal times become a stressful and upsetting event for the entire family and have been likened to a battleground (Ball & Ball, 1995; Cottee-Lane et al., 2004), which is of course led by the eating disorder (Cottee-Lane et al., 2004).

Consequently, the family often give up many of their social activities such as, attending social events as majority involve food (Cottee-Lane et al., 2004; Gilbert et al., 2000; Hillege et al., 2006; Whitney et al., 2005; Keitel et al., 2010). Lack of social interaction and support outside the family increases reliance on family members for support, and this then increases strain on family relationships (Dimitropoulos et al., 2008).

The practicalities of getting the child to treatment and other appointments can also cause problems and stress for parents. Transporting the child to and from treatment and other appointments as well as treatment related costs and food fads can be difficult to cover. Parents often worried they would no longer be able to meet their child's needs financially (Hillege et al., 2006; Honey & Halse, 2005; Perkins et al., 2004). Although parents would not hesitate to save their child from the eating disorder, finances were a significant stressor for many parents as they often had to use savings or borrow money (Keitel et al., 2010).

So it is apparent that functioning and relationships within the family are strained in different ways (Ball & Ball, 1995; Hillege et al., 2006). However, despite the resentment and ambivalence experienced by many family members toward the eating disorder, family members tend to remain involved in their loved one's suffering despite the situation being difficult to understand (Ball & Ball, 1995; Highet et al., 2005; Loukissa, 1995).

An eating disorder affects many aspects of family life and family members (Dimitropoulos et al., 2008). This makes it important to research the experiences of parents who have the challenge of caring for a child with an eating disorder as well as holding the family together. My research will provide information from the personal experience of parents which may be useful to others including parents in similar situations, as current resources and support available to parents seems to be limited which leads to the next point made by research.

Parents have reported that support and understanding were essential in coping with a child with an eating disorder (Cottee-Lane et al., 2004). The experience of caring for a child with an eating disorder varies from parent to parent. However, many parents commonly described their experience as a lonely one (McMaster et al., 2004; Tierney, 2005). Support and understanding were often hard to find so many parents became resourceful through their attempts of finding support and understanding from a variety of sources (Ball & Ball, 1995; Cottee-Lane et al., 2004; McMaster et al., 2004; Sharkey-Orgnero, 1999).

Parents are the primary carers of their children yet; research shows that carers have many unmet needs that arise from caring for an individual with an eating disorder (Haigh & Treasure, 2003; Honey et al., 2008; Winn et al., 2004). Unmet needs often go unrecognised and contribute to significant carer distress (Haigh & Treasure, 2003; Winn et al., 2004). Winn and colleagues (2004) have outlined three major areas of need for carers which are; more information, guidance and practical advice and, the opportunity to speak to others regarding their own experiences. These areas of need have also been identified by parents in other research (Graap et al., 2008a; Honey et al., 2008).

Parents have admitted to initially having minimal, if any knowledge about eating disorders (Cottee-Lane et al., 2004). Lack of knowledge on the part of parents and

health professionals made it difficult to identify and get effective treatment for the child (Cottee-Lane et al., 2004; Honey & Halse, 2005; Keitel et al., 2010). These factors contribute to the difficult role parents have in caring for a child with an eating disorder, where there is a lot of uncertainty (Cottee-Lane et al., 2004; Winn et al., 2004).

Parents love their child and want to provide support (Treasure et al., 2001; Whitney et al., 2005). They want to understand and support their child completely (Abraham & Llewellyn-Jones, 2001; Ball & Ball, 1995; Cottee-Lane et al., 2004; Highet et al., 2005; MacDonald, 2000), and need help with their situation (Winn et al., 2004). Many parents wanted to be educated and learn about their child's eating disorder but found it hard to find advice about their role (Tierney, 2005; Keitel et al., 2010; Winn et al., 2004). This has been a factor that has encouraged parents to seek advice from a range of sources including, relevant media, professionals, friends, family and other parents, (Ball & Ball, 1995; Cottee-Lane et al., 2004; Honey & Halse, 2006b; McMaster et al., 2004; Sharkey-Orngero, 1999; Tierney, 2005).

It is probable that interventions to meet the needs of carers are not available or easily accessible to carers (Graap et al., 2008b; Winn et al., 2004). Specialists and services specific to eating disorders are usually limited to geographic areas which means they are few and far between (Gilbert et al., 2000; Winn et al., 2004). This means that many carers and parents had to resort to their own abilities and search for information about the eating disorder where many felt they were hitting brick walls constantly (McMaster et al., 2004).

McMaster and colleagues (2004) stress the huge amount of time and effort parents put in to find the help they require. Feeling unsupported and having the added pressure of trying to find information and resources while the child suffers a critical condition is highly distressing for any parent (Highet et al., 2005; McMaster et al., 2004).

Carers often try and turn to their family, friends and health professionals for support as they found it helpful to have someone listen to them (Honey & Halse, 2006b; Winn et al., 2004). But unfortunately, many people lack knowledge and understanding of eating disorders, so parents and carers cannot always turn to others within or outside the family for support (Highet et al., 2005; Hillege et al., 2006; Winn et al., 2004; Whitney et al., 2005). As a solution, many carers and parents of those with eating

disorders have found support groups to be invaluable (Cottee-Lane et al., 2004; Gilbert et al., 2000; McMaster et al., 2004; Poser, 2005; Winn et al., 2004), although support groups can be difficult to come by (Winn et al., 2004).

Support groups are important as they provide a forum for sharing experiences, discussing arising difficulties, and learning from others that have been in a similar situation (Abraham & Llewellyn-Jones, 2001; Cohn, 2005; Cottee-Lane et al., 2004; Poser, 2005; Winn et al., 2004). Such groups also provide a non-judgemental and safe environment where carers and parents that are going through similar experiences can share their feelings and support, as well as comfort and reassure one another (Abraham & Llewellyn-Jones, 2001; Cottee-Lane et al., 2004; Hight et al., 2005). Support groups are also a place parents can find information and resources regarding eating disorders (McMaster et al., 2004; Winn et al., 2004), and what to expect during the course of the eating disorder (Cottee-Lane et al., 2004; Winn et al., 2004).

Parent support groups are useful for parents, who are feeling demoralised and isolated (Lewis & MacGuire, 1985). Accessing a support group can reduce feelings of isolation (Winn et al., 2004), and increase self-esteem and hope through the sharing of experiences with others (Lewis & MacGuire, 1985). Parent support groups allow parents to discover that their reactions to the many stresses of an eating disorder are normal reactions under the circumstances (Lewis & MacGuire, 1985). Support groups assist with helping parents adjust to the fact that their child has an eating disorder (Lewis & MacGuire, 1985).

Parents clearly need the support and resources to care for a child with an eating disorder. New Zealand having a relatively small population spread over a large geographical space, suggests that the problem of having limited information, guidance and advice may be even greater for parents in New Zealand. Also, the small number of current support services available to the parents of children with eating disorders in New Zealand suggests help is difficult to find. It is likely for there to be many parents who feel distressed and unsupported. My research will provide an idea of the extent this occurs in New Zealand.

It seems that parents have a lot to say but little opportunity, my research provides an opportunity for parents to share their experiences and might allow parents to feel able

to speak about their situation (Ross & Handy, 2007; Winn et al., 2004). By exploring the experiences of parents, sufficient support and education could be developed and provided for parents to help with managing a child with an eating disorder (Ringwood, 2011). Furthermore, raised awareness and understanding could help reduce the stigmatisation of eating disorders by the public and, could lead to greater resources and support for parents in New Zealand. Programmes providing education to parents have been established in other countries and seem to be useful (Holtkamp, Herpertz-Dahlmann, Vloet, & Hagenah, 2005; Macdonald, Murray, Goddard, & Treasure, 2011).

Finally, research suggests that there are also positive factors that result from caring for an individual suffering an eating disorder. Primarily, sufferers of eating disorders and their parents believe the experience they go through strengthens their relationship (Kamerling & Smith, 2010; Perkins et al., 2004; Ross, & Handy, 2007; Tierney, 2005; Treasure et al., 2001). Many believe that the ways in which their relationship is strengthened would not have occurred without having had to manage an eating disorder (Ball & Ball, 1995; Treasure et al., 2001). For example, it is reported that mother and daughter often develop a unique kind of relationship from their experience with the eating disorder (Ball & Ball, 1995).

Some carers believed the situation improved family functioning and relationships within the family (Perkins et al., 2004; Ross & Handy, 2007). The family had to find their strengths, accept limitations and learn to express themselves in new ways which resulted in smoother functioning of the family (Ball & Ball, 1995; Ross & Handy, 2007). For instance, parents found communication and interactions with their child had to change over the duration of the eating disorder and were reported as having improved as time went by (Cohn, 2005). Family members learnt to be honest with each other when communicating, express themselves more and often developed better listening skills (Cohn, 2005). Some couples acknowledged that it strengthened closeness within their couple relationship in one way or another (Gilbert et al., 2000; Ross & Handy, 2007). On the whole, the family remained strong and family closeness endured despite the distress the family experienced (Hillege et al., 2006; Sim et al, 2009).

On a more individual level, some carers experienced positive change or personal growth and development (Kamerling & Smith, 2010). Improvements occurred in

perceptions, coping with emotions and, having a raised awareness and understanding of others (Cohn, 2005; Perkins et al., 2004). Parents felt they became more empathetic, compassionate (Perkins et al., 2004), honest and open minded (Cohn, 2005).

Some parents also believed their child developed personally and had a greater awareness and knowledge of self (Abraham & Llewellyn-Jones, 2001; Perkins et al., 2004). Parents sometimes reminded their child that they had overcome an eating disorder and this experience could be drawn upon whenever they were faced with difficult challenges in life (Tierney, 2005). Furthermore, it was thought that the personal experience and understanding of an eating disorder could help others in similar situations suffering an eating disorder (Ball & Ball, 1995).

In summary, previous research reports on various areas of caring for a child with an eating disorder, covering positive and negative outcomes. I chose to employ an exploratory, discovery-orientated approach due to the relatively limited amount of research in the field of eating disorders so far (Barker et al., 2002). Qualitative research of this kind aims towards understanding social phenomena in natural settings through the development of concepts (Pope & Mays, 1995). So the experiences, views and meanings of all participants are important to explore (Britten, 1995; Pope & Mays, 1995). Qualitative research is able to reach aspects of complex attitudes, behaviours and interactions (Pope & Mays, 1995), which is useful for, and valuable in, exploring the experiences of parents of children with eating disorders (Barker et al., 2002).

What I want to know, and the aim of my research is, what is the experience of parents caring for a child with anorexia really like in New Zealand. My objective was to provide the parents with an opportunity to voice their experiences in order to develop new understandings and knowledge of their experiences. A qualitative approach was employed to obtain in-depth data while exploring the experiences of parents who were caring for a child with an eating disorder.

Method

Participants

Parents of children diagnosed with an eating disorder were the target of this research. Their son or daughter had to be diagnosed with anorexia nervosa in childhood or adolescence. The child could be of any age and at any stage of the eating disorder or recovery. They could be living with their parents or in other care. Participation was voluntary, providing that parents met these criteria. Parents could be interviewed together or individually.

In total, twelve parents of nine daughters were interviewed, six fathers and six mothers. Two couples were interviewed together, one couple chose to be interviewed individually while the remaining six participants were also interviewed individually. Families varied in structure where some parents belonged to nuclear families while others came from blended families, solo parents also took part in this research. The occupations of parents also varied, some had business backgrounds, and some were in health care while others were stay at home parents. Demographic information was collected in wider and greater detail but will not be disclosed as it could reveal the identity of the parents and breach confidentiality. Given that New Zealand is a small country and anorexia a so-called 'rare' mental health issue, if too much was given away then the participants might be able to be identified by others. This research was approved by the Massey University Human Ethics Committee (MUHEC).

Procedure

Participants were initially difficult to recruit, which may have been due to eating disorders being an issue that is generally not talked about. Limited participant numbers therefore led to the use of the snowballing technique. This technique involved me, as the researcher, inviting a few individuals who met the criteria, to take part in this research and encourage appropriate others they knew to also participate (Barker et al., 2002; Robson, 2002). Snowballing seemed the most appropriate strategy for such a difficult to access population and specific research topic (Barker et al., 2002; Robson, 2002).

Once the population of interest was identified, information sheets (see appendix A for details) were distributed to potential participants to inform them about my research. Information sheets also informed potential participants of my current professional

involvement in the field of eating disorders and assured them of confidentiality as well as my ability to keep my professional and researcher roles separate.

Participants were asked if they knew of anyone else who met the research criteria and who may be interested in participating in this research (Barker et al., 2002). Potential participants were asked to contact me. Participants were assured again that theirs and others' identities would be kept confidential in this research. Parents were asked to discuss their intended participation with their child prior to providing their consent. This decision was in consideration of the child and preferable to commencing interviews in secret. Consent forms were completed by each parent prior to interviews.

In-depth interviews were carried out to discover the framework of meanings parents held about caring for a child with an eating disorder (Britten, 1995; Langdridge, 2007; Pope & Mays, 1995). As the interviewer, I explained that I was interested in what it was like for them as a parent, to care for a child with an eating disorder and asked them to share their experience. Open-ended questions were asked towards the end of the interview if required, in order to obtain more detail about various areas of the parent's experience (Britten, 1995; see appendix B for details).

Interviews ended when the parent had nothing more to say. Interviews were recorded on audiotape (Britten, 1995). Interviews ranged from 30-80 minutes in duration and were approximately 45 minutes on average. Sampling ceased once the point of saturation was reached, when there was little new information coming from the interviews (Barker et al., 2002; Robson, 2002). Saturation was established through the analysis and analysis occurred as each interview was completed (Langdridge, 2007; Pope, Ziebland, & Mays, 2006).

Data analysis

This research was based on phenomenological methodology where the methods were drawn from various phenomenological approaches including, descriptive phenomenology, interpretative phenomenology and hermeneutic phenomenology (Langdridge, 2007). The general focus of phenomenology is on understanding lived experience where the aim is to understand people's views of the world and what these perceptions mean to them (Crotty, 1998; Langdridge, 2007). The researcher must not be prejudiced in terms of preconceived ideas, but rather look at the world afresh (Crotty, 1998).

However, each phenomenological approach has a slightly different focus. Firstly, descriptive phenomenology is concerned with describing rather than explaining phenomena and was used in this research to provide a thorough description of the essence of the parents' experience, as society seem unaware of the experiences of parents (Langdrige, 2007). Interpretative phenomenology focuses more on the 'lifeworld' or lived experience and what the experience means to people (Langdrige, 2007), and was drawn on as it explains the experiences of parents and what their experiences' mean to them. Hermeneutic phenomenology contains a small group of methods and like interpretative phenomenology, also involves interpretive engagement but, to a larger degree (Langdrige, 2007). Hermeneutics attends to further details in the data for interpretation, to really understand the meaning of experiences (Langdrige, 2007). Hermeneutics was drawn on to dig that bit deeper and discover what the experiences of parents really meant to them and properly understand those experiences.

My approach to the method was based on the aim of my research which was to explore 'what it is like for a parent to care for a child with an eating disorder'. I felt the most accurate understanding of this topic would be captured by having this range of phenomenological approaches to draw methods from, rather than restricting analysis to one form of phenomenology or set of step-by-step rules (Crotty, 1998; Langdrige, 2007). My goal was to convey rich and in-depth understandings of what it is like to care for a child with an eating disorder.

Interviews were transcribed by me as they were completed; transcriptions included pauses, smiles or laughs and other notations in consideration of a hermeneutic approach (Barker et al., 2002; Langdrige, 2007). I listened to the audiotapes a number of times to ensure transcripts were entered correctly, and this also gave me the chance to become very familiar with my data (Barker et al., 2002). I then immersed myself in the data as I examined the transcripts repeatedly while trying to avoid any biased or preconceived ideas during the analysis (Barker et al., 2002; Crotty, 1998).

Relevant or significant sections or meaning units in the transcripts were attended to very closely on a case-by-case basis to discover overall meanings (Barker et al., 2002; Langdrige, 2007; Pope et al., 2006). Workable tables were produced following each interview so that the sections could be examined more rigorously (Barker et al., 2002; Langdrige, 2007). The visibility provided by the tables enabled me to identify

the point of saturation as mentioned previously (Barker et al., 2002; Pope et al., 2006; Robson, 2002).

An example of the table is unable to be displayed for reasons of confidentiality, as certain recordings and features within the tables could disclose the identities of the participants. But, the table had four columns and was based on the phenomenological approaches chosen for this research (Langdrige, 2007). The first column was for the page number of the transcript under examination to help find the original placing of the section for referring back to the context at large (Langdrige, 2007). The second was for each copied and pasted section or unit from the transcript that was under exploration (Langdrige, 2007). These were selected if thought potentially relevant or significant after repeated listening to the audiotapes and reading through the transcripts (Barker et al., 2002; Crotty, 1998; Langdrige, 2007; Pope et al., 2006). If unsure, sections were copied and pasted for further examination anyway as to avoid missing anything important (Pope et al., 2006). The third column was for notes of descriptions, meanings and interpretations in consideration of all phenomenological approaches and corresponded to the second column, these notes were changeable (Langdrige, 2007). The note-making process involved repeatedly reading through the copied and pasted sections of transcript and making notes of the descriptions, apparent or surface meanings and also the deeper, interpreted meanings with consideration of the context these were in (Langdrige, 2007). The fourth column was for potential patterns or themes (Langdrige, 2007). The meanings and interpretations in column three contributed or were linked to the patterns/themes, so each pattern/theme reflected those more detailed meanings or interpretations in column three (Langdrige, 2007).

Once reoccurring patterns/themes were identified they were labelled to include as much of the data as possible (Pope et al., 2006). The themes sometimes had to be restructured to become manageable, so some themes merged to form one theme where there was repetition or close similarity, and other themes had to be discarded if they did not fit well with the greater themes or, if they did not contribute significantly to the analysis (Langdrige, 2007; Pope et al., 2006). The entire process was fluid as it cycled backwards and forwards while the themes were checked and confirmed with the data (Barker et al., 2002; Langdrige, 2007; Pope et al., 2006). My knowledge in psychology had to be applied carefully throughout this process so as to remain close to the inherent meaning of the data and away from preconceived ideas, yet still delve deep enough to

get a thorough and rich understanding of what it is like to care for a child with an eating disorder (Barker et al., 2002; Crotty, 1998; Langdrige, 2007).

Each row in the workable table indicated a new or different topic under exploration. The length of each table depended on length and content of the interview under examination. Interviewing and data analysis occurred over a period of 8 months, resulting in a rich and in-depth understanding of what it is like for a parent to care for a child with an eating disorder.

The many themes from the individual tables or interviews were then transferred to a number of blank documents where if a theme could be grouped with different themes, it was placed on all of the relevant and separate documents. So each document contained a list of similar or related themes from each of the individual analyses. This way the themes from all of the interviews were made more visible and easier to work with. The themes over the documents were restructured following the same process as used for the themes of the individual tables or interviews, as described previously (Barker et al., 2002; Langdrige, 2007; Pope et al., 2006). It was from this that the larger themes emerged and the themes from the individuals merged together. The larger themes reflected all of the parents' experiences, or the general experience, of what it is like for a parent to care for a child with an eating disorder.

The findings of this research are set out in the following chapter, with a discussion chapter to follow the findings. To ensure confidentiality was maintained in this report, the findings contain summaries rather than quotes from parents. The summaries appear as quotes but have been reworded to conceal the participants' identities. The summaries contain carefully compiled sentences from the quotes of the parents from the interviews so that they still capture what was said without changing the meanings.

Findings

The purpose of my research was to explore what it is like for a parent to care for a child with an eating disorder. Although this seems like a straight forward question, the answer is rather complex. The experience of parents turns out to be a difficult battle and struggle for salvation. Through the analysis I discovered three main stages that parents go through, the 'insidious' stage, the 'tenacious' stage and the 'recovery' stage.

The insidious stage occurs during the onset and early days of the eating disorder. Anorexia manifests in the child in a gradual and sly way and has dangerous effects on the child. Once the parents are aware of the physical damage to their child and come to terms with their child suffering anorexia, the tenacious stage sets in. The tenacious stage is characterised by a lengthy duration where the parents continue in their attempts to rescue their child while the eating disorder persists in keeping the child in its firm grip. After a long struggle during the tenacious period the recovery stage eventually arises. By the recovery stage the parents have tried almost every option available to treat their child and the child has reached a point where they must recover what life they have.

The stages can overlap and things can regress or progress to any other stage at any time. Throughout the stages, the battle and struggle is ridden with uncertainty and contradiction and encompasses 'all' areas of the parent's lives, so emotions and coping are a huge part of the parent's experience.

Stage One: Insidious

The first stage is best captured by the term 'insidious' as the eating disorder tends to creep in and take over the child, and goes a considerable period of time without being recognised or detected by anyone due to being camouflaged by adolescence and foreign to most people. This means that by the time the parents realise their child is suffering an eating disorder, their child is entrapped and the damage is far-reaching. The child's health deteriorates further and further, relationships are affected more and more, while the child is seduced deeper and deeper into the eating disorder. In this initial stage the parents go through shock, blame, guilt, fear and anxiety. Parents coped by trying to develop a better understanding of their child's serious and life threatening condition.

Anorexia is seductive to the child and so the child is secretive about being subject to the eating disorder. This secrecy means the eating disorder remains hidden, and it is more difficult for the parent to recognise a mental health issue. Sometimes the parents

were tricked by the eating disorder and bought into the initial demands made by anorexia or unknowingly allowed eating disorder behaviours to occur which allows anorexia to slyly grow in severity.

My child had felt good about losing weight... She became an expert bluff and sneak at keeping her eating disorder under the covers... We encouraged a healthy diet... We shopped differently and cooked differently... My child restricted her intake further and further...

Alarm bells ring for some parents when the child shows more interest in dieting and fitness, and engages in weight loss behaviours such as restricting particular food groups and exercising more frequently. However, because anorexia typically manifests in childhood or adolescence, it is disguised by the time of onset as increased interest in diet and exercise is considered a common occurrence at some point in a child's school years. This leads many parents to believe that their child's behaviour is normal and that it is part of the adolescent stage and so the eating disorder remains unrecognised.

She became really interested in sports... I thought it was great as I shared the same interest... I thought being a vegetarian was just a phase she was going through... We noticed her change her diet but this is not abnormal for a teenager... It's a new thing; I went through something similar in my younger years...

The deterioration of the child's health remains hidden for some time and occurs at a rapid rate and so what initially seemed an innocent teenage phase suddenly turns out to be a serious and life threatening mental health issue. So after suspicion of an eating disorder parents took their child to a general practitioner. Parents often struggled to have the eating disorder recognised by a general practitioner and were sometimes undermined and their concerns downplayed. This left some parents feeling confused and frustrated, and meant delayed treatment for their child.

I hadn't really noticed anything then one day she collapsed at school... Anorexia was a possibility... The GP dismissed an eating disorder

and said there was nothing wrong... The doctor thought I was paranoid... It was so irritating and appalling... We went back to the GP again and yes she had anorexia... Then we had to wait days or weeks for the referral to be accepted...

At the same time, shock and disbelief were experienced by many parents.

I took her to another doctor who confirmed she had anorexia... Those early days were dreadful as parents... She would have the most bizarre behaviour sometimes... It was just overwhelming...

Parents also felt they were blamed by others for failing as a parent. Many parents took the blame on board and questioned their parenting skills and what might have contributed to their child's eating disorder, and this evoked guilt among many parents. Parents felt guilty for sometimes buying into the eating disorder and/or not detecting it sooner and acting earlier. So while the parents struggled to get help for their extremely ill child, they were made to feel the cause of their child's illness which triggered intense negative emotions. Parents had a battle beginning in their minds while they were also struggling to find treatment for their child with anorexia.

You feel to blame and that you've failed as a parent... When someone is diagnosed with cancer you wouldn't question the parents on their relationship with their child, you would be empathetic and supportive... I wondered if my past decisions and actions had influenced her when she was younger... You buy into the eating disorder in the beginning, thinking it's your child... I think we were a little slow to react but we were fairly early...

Furthermore, the serious and life threatening anorexia created intense fear and anxiety for many parents as they initially had little knowledge of eating disorders. The unknown was frightening for many parents.

We didn't realise how serious it would turn out to be... We became very concerned about her... We wondered how we would deal with the

situation... We were scared about doing the wrong thing and making things worse... I thought she might die...

Along with having to deal with such intense negative emotions, parents did what they could to cope when coming to terms with their child having an eating disorder. Anorexia was foreign to majority of the parents during its onset and early days. Many parents didn't have an awareness or deep understanding of eating disorders initially, yet they were determined to find help for their child. This was made more difficult for parents due to the lack of resources, knowledge and understanding for eating disorders in New Zealand.

It [the eating disorder] comes out of the blue for no rhyme or reason... I didn't really have any understanding of eating disorders prior... I read loads of books when it first reared its head... She was admitted to a general hospital and there was no specialist treatment... There isn't really any consensus among professionals...

So the child is drawn in by the sly but seductive eating disorder and remains undetected for some time due to being disguised by age of onset. The eating disorder grows in severity while the child's health deteriorates. Once discovered, the parents experienced shock and disbelief which were then followed by feeling guilty and to blame for their child's condition. Fear and anxiety set in for the parents as anorexia was an unknown illness that crept into and took over their child's life. The parents tried to understand and cope with this insidious illness.

Stage Two: Tenacious

Following diagnosis, the second stage emerged as one that was extremely 'tenacious' where the battle and struggle against the eating disorder was on-going and never ending for the parents. Anorexia continued persisting causing extensive damage and destruction, especially to the family and relationships, where the effects were worrying and scary. Parents often felt caught in the middle or stuck in a vicious cycle where it was near impossible to keep balance in their families and lives, or escape anorexia. In the struggle for the salvation of their child, parents battled at home, with the

medical system and society more indirectly, while they also battled their own cognitions caused by endless uncertainty and contradictions over the tenacious stage. Parents had to cope with the frightening possibility that their child could die, all the while they were feeling physically and emotionally, drained and exhausted.

What arose from my analysis was that the parents found their child to be oblivious or in denial of having an eating disorder. Their child seemed to be controlled by anorexia. Consequently, the child wasn't able to fight the eating disorder and so the parents often felt caught between their child and the eating disorder, fighting anorexia for their child. Parents fought many battles for their child suffering anorexia over the duration of the illness.

My child was blinded by the disease, completely oblivious of reality... She was unaware of there even being a problem... We had to fight anorexia because our daughter was incapable of fighting it... She used to fight us, and sit there and say there was nothing wrong when clearly there was... The parents do a lot of fighting the illness... We battled day in and day out, for the first twelve months... We agreed we were going to fight this thing together until it was gone...

Despite the child desperately needing treatment, health services generally acted as an ambulance at the bottom of the cliff. The child had to be medically unstable before they received sufficient attention or treatment. Parents found this contradictory as anorexia is a serious and life-threatening mental health issue yet severity was monitored in terms of physical health while the psychological health of their child was ignored. Parents had to wait until their child had physically deteriorated to a serious enough degree, and was sometimes bordering on death before intervention occurred.

It was like the medical system didn't want to intervene until the train had crashed... We took her back [to the medical professionals] a number of times to try and get an intervention... They [the medical team] said if she loses another kilo then we need to look at doing something more serious... It wasn't the trend to hospitalise, unless they [anorexia sufferers] weren't eating at all... The doctor decided that something did show wrong in the

blood results so finally admitted her to hospital... We had to watch her deteriorate then her body just shut down with everything... It's sad that we had to nearly lose her before something actually happened...

As a result, parents experienced intense fear, anxiety and helplessness.

We struggled for months at home on our own before she was admitted for treatment, and that was difficult... You give up on encouraging them to eat a range of foods as you struggle to get her to eat enough of one food type... All I could get her to have was that slightly flavoured water... She hadn't eaten anything for a couple of weeks and had started restricting water too... I was freaking out and wondered what was going to happen...

Once a hospital admission did occur, the contradictions continued as the child was treated for physical symptoms while psychological symptoms were neglected. However, at the same time parents knew that their child had no ability to rationalise and take anything in or see the benefits of weight gain while at such a low weight. This made it harder to get the child up to a weight so her brain could function and undergo psychological treatment. Parents wondered whether their child would make progress and had to cope with enduring stress. The duration and level of effectiveness of treatment remains unknown to everyone at the time which highlights how unpredictable and uncertain treatment for anorexia is and how anxiety-provoking and draining it is for the parents.

Our child was re-fed that was it, there was no psychological input... The emotional side of the brain outweighs the rational side when it comes to eating... There was no psychological leverage... They [the medical professionals] enforced her to eat through a nasogastric tube but she just couldn't do it, she kept pulling the tube out and refused to do it... She was put on medication to sedate her but that didn't work, she was still exercising through sedation... You start to run all sorts of scenarios through your mind as you wonder what will happen next and in the future... I just worried the whole time, it was horrific...

At home, the family had to make considerable adjustments to accommodate for the child with the eating disorder. The eating disorder became the centre of attention in the family as the child displayed challenging, disturbing and disinhibited behaviours which affected all other family members and caused much frustration. This put family members under great distress as everyday life became extremely difficult. So parents were not only caught between their child and the eating disorder, and feeling frustrated, but also had to try and keep a balance in their family and juggle things to meet each family member's needs.

The child's behaviour seemed self-centred and manipulative in favour of the eating disorder and its numerous demands. This and because the parents were often tricked and bought into the demands of the eating disorder, often left siblings feeling angry and resentful toward their parents and sibling suffering anorexia. Parents realised how much attention they had to give to their child suffering an eating disorder and that this did impact siblings. Parents worried about the impact on siblings and felt guilty about the situation while they struggled to keep balance within their families and attend to all their children's needs.

We threw a huge amount of attention at her [anorexia sufferer] and spent almost every waking hour with her... My other child has much less time with me... This created jealousy in her sister and set a bad example of how to get our attention... They [siblings] see her as getting away with things... They've [siblings] been angry, they've been sad... I didn't know whether to include them [siblings] in her matters or not... Sometimes her siblings miss out on social events because we have to manage whatever's going on with her... They just put up with it... I wondered how young children would cope with this and what the impact would be, because it's huge for the parents to deal with...

Meal times became a battle field. Family members sat through obsessive, ritualistic, disruptive and distressing behaviours while the parents struggled to convince their child to eat. Meanwhile the child usually displayed resistance and refused to eat which is extremely difficult for a parent to watch and tolerate. Parents went to extreme

lengths in trying to get their child to eat. As a result the parents would feel completely drained, frustrated and helpless while the eating disorder persisted.

She measured everything out and only ate with a teaspoon... We'd have all these different meals prepared in whatever way she said to try and get her to eat... She wouldn't have breakfast or lunch and I was struggling with getting her to have dinner... We would bargain with her, argue with her, or ignore her while she would get angry... Getting her to eat meant getting in the car and driving to her chosen destination... We would sit there for ages trying to get her to eat... You can't force somebody to eat...

Not surprisingly, relationships the child had with others were put under strain following the onset of the demanding and deceitful eating disorder. Parents were unable to trust their child which meant they had to watch their child very closely at all times and act accordingly. When the child perceived her parents as being unreasonable or mean, an argument or challenging behaviour would result. So when the parents fought the eating disorder the relationship was perceived and treated as 'bad' by the child, and 'good' when the parent meet the needs of the eating disorder. This left the parents feeling upset over their relationship with their child and confused as they were blamed by their child while they were doing the right thing.

We can't trust her, there's always that suspicion and vigilance... Lack of trust is really hard to live with, and a terrible way to be with your daughter... I could tell she was lying, well the eating disorder was... She kicked and screamed all the way to treatment, she tried to jump out of the moving car... She hated me for monitoring her and getting her the treatment she needed...

During the tenacious stage, parents discovered that the knowledge and understanding of eating disorders as well as treatment resources and facilities in New Zealand lacks hugely. There are few specialised facilities in the country and so children potentially have to receive treatment at a unit in Australia. Furthermore, parents believed that treatment programmes and options were not outlined clearly or at all by

health professionals in the services that were available, and this left parents feeling confused and ill-equipped. Parents wanted the treatment decisions more fully explained to them and more direction of what they were expected to do in their role as parents. However, parents were very appreciative of the majority of existing services and support, but believe more resources and facilities are in desperate need.

The medical system was appalling, the services provided were minimal... We had to go on a waiting list because there weren't enough beds... There's no financial support and minimal resources in New Zealand, the children have to go to Australia for treatment... Most of the things you have to do feel counter-intuitive, the outcome may have been different if we'd been given the reasoning behind what we had to do... No one really sat down and told use what the programme was about or how it would go... We need more facilities as well as expertise... But the support we have had has been great and we're really appreciative of that...

Some parents noticed a difference in treatment depending on the age of their child. Parents felt more excluded when their child was over 18 years of age and considered an adult. This was contradictory for parents as their child was in theory an adult but in reality, unable to look after herself due to her thinking being clouded or misdirected by anorexia. Parents believed they had more control over their daughter when she was a child as opposed to her being an 'adult'. Loss of control or not as much input in treatment was frightening for many parents as they worried about the well-being and future of their child.

You still have a degree control when they're a child because they still lean on you for advice and support... When she's 18 she's going to believe she has all this right but she doesn't have the strength or ability to deal with life... She's under a lot of control in treatment now but it concerns me what will happen once she turns 18... She was 18, she didn't want us involved anymore and so we weren't legally allowed to be included, we were excluded...

Through their experience, parents discovered how truly complex eating disorders are and that there are many levels of understanding which is usually based on one's involvement with an eating disorder. As the parents had little knowledge and understanding of eating disorders in the early stages, this encouraged parents to continue seeking out information and services to help them better understand their child's condition and what to do for their child. By this stage, parents became researchers and highly resourceful as a way of coping with their situation.

In the initial stages I had no idea about eating disorders... I probably thought like others, that girls into fashion and looks ended up with eating disorders – but it's not like that at all... Without any emotional involvement, an eating disorder would be very difficult to understand... I read constantly and am open to learning and understanding more... We bought books and tried to follow everything they said...

Parents also had various cognitive strategies to cope with the continuing blame, guilt and often regret, associated with their child having anorexia. Parents felt like they had failed as parents that it was their fault, and they sometimes wondered whether the decisions they'd made were the right ones. To cope with this, parents theorised about their child's situation, they searched for answers and tried to make sense of it all and develop a better understanding which did provide some reassurance and relief, but could also have a contradictory affect.

It [Anorexia] comes like a bolt out of the blue... She was always a fussy eater, right from birth... It has a genetic component and runs in our family... Teenage girls don't have a lot of resilience... She wanted to be popular with her friends and feel more accepted... She went back to school, things were getting back to normal, and it would be fine... You wonder why it happens but you will never know so you can't keep wondering...

Parents found their knowledge and understanding of anorexia to deepen with their experience but acknowledged that coming to a full understanding of this mental health issue is impossible for anyone. This idea is unsettling for many parents and sometimes

made coping strategies ineffective and reinforced their fear and anxiety. So along with the battle against the eating disorder, the battle in the minds of parents continued, increasing the size of the battle for the parents. Cognitions or thoughts ran wild as parents tried to make sense of their child's eating disorder.

Even after years of living with it, it's impossible to fully understand eating disorders... My understanding keeps changing... There are many theories but they can't all be right as some are opposed... One professional would give you a piece of advice and then another would tell you the complete opposite... Every strategy is so unclear and you don't know whether the strategy you've chosen is the right one... It was just so scary... And then in the back of your mind is the horrifying possibility that she might actually die...

Parents usually battled their fears and anxieties alone as they always knew that much of society does not understand anorexia and is even driven the opposite way by the media, toward preventing obesity by encouraging healthy dieting and exercise. This is frustrating for parents as this attitude can in some ways support anorexia, which I think shows society's ignorance. Parents often felt blamed by members of the public and such emotions were emphasised when others made inappropriate comments about the parents or their child. So the double battle continued as the parents had more to think about and dwell over in terms of what others thought as well as the impact of the eating disorder.

People just don't understand how much of an impact an eating disorder has on the family... Some tell you to just feed her, but it's not that simple... Society's focus is on losing weight and people make comments like you're lucky, I wish I could lose weight... People said we were lucky when we had a 'trip' to Australia for treatment... Society immediately assumes it's the fault of the parents... Someone asked if our daughter had forgiven me yet... You feel it as parents, that you're to blame... Parents have to deal with the ignorance of society as well as their child with anorexia and it's difficult...

I think the lack of understanding suggests anorexia is a mysterious mental health issue which is scary and unpredictable for many people, and so leads them to pass judgement and create stereotypes which causes stigma of anorexia for the sufferer and their families. Stigma then ends up causing the family to become isolated as outsiders are afraid of the mental health issue. Others do not know how to react or support the sufferer's family and so avoid the issue which means the parents have to manage and care for their family alone or with very minimal support.

Your family becomes labelled... Other parents tell their children to stay away from your children as they don't want their children suffering anorexia... Friends have good intentions but they don't really know how to react... Friends were great in the beginning, but support fades as they don't realise the eating disorder is a protracted illness... As soon as they hear it's a mental health issue, everyone runs a mile...

Parents battling their child's anorexia felt they should have received more support during the battle. Parents talked about the commonalities anorexia shares with cancer and the major difference being that anorexia is primarily a mental illness while cancer is a physiological illness. They are both persistent and life-threatening illnesses which evoke intense emotion for parents. However, cancer has a treatment path and prognosis which means the family have an idea of how treatment will progress and are warned when to prepare for the worst while they are guided how to do so. Conversely, anorexia has an unpredictable treatment plan and, prognosis remains unknown throughout the duration of anorexia, so the uncertainty is overwhelming. In comparison to cancer, parents are given minimal support, advice and guidance around the eating disorder due to anorexia being a mental health issue. Furthermore, anorexia is not only a psychological problem which parents found usually involved comorbid conditions such as depression and anxiety too but, anorexia also threatens physical health, so the sufferer has multiple issues in need of attention.

With cancer people are empathetic, they want to help you out and you're offered counselling, but with anorexia, everyone disappears, no one

offers to do anything for you and you're blamed for your child having an eating disorder... With cancer you have the choice to have the treatment or not, and it either works or it doesn't, those are the options, and then you can work through the outcome and get on with life... But with anorexia, you're watching your child slowly die as her body deteriorates due to the physical demands of anorexia... You've got the worst of both worlds, psychological and physiological problems... Usually you try to prevent someone from dying, but it's not that easy with anorexia...

It became clear from my research that parents found anorexia unpredictable. Parents concluded that there is just not enough understanding and/or expertise in eating disorders, or even mental health, among health professionals. As a result, health professionals did not know how to deal with a patient suffering anorexia. Their perception was sometimes that of the general population that the child is spoilt and just needs to eat. This form of stigmatisation effected the actions of health professionals towards the patient and family where they were treated in a negative or nasty manner. Receiving such feedback from society and health professionals helped instil frustration and anger in the parents.

I bet they only get five minutes on it [anorexia] at medical school... We had to take food to the hospital for her to eat because the food they served was disgusting and they didn't understand why this was a problem... A nurse tried to frighten my child to get her to eat, but frightening doesn't work... I had to help hold her down while they fed her... They never seemed to have the expertise... They'd exhausted all the treatment options and didn't know what more they could do...

Despite the contradiction of health professionals being unhelpful when the parents were desperate for help, the parents were able to identify positive experiences with health professionals and productive aspects of treatment. Negative experiences and contradictions activated parents coping mechanisms. Positivity was a coping strategy parents had to use frequently and it sometimes involved thinking of others in more difficult situations.

Some of the staff were empathetic while some of them were hostile and judgemental... The [eating disorder] team we had were really amazing... We were very grateful for the treatment in Australia... The therapist was lovely and went out of her way to help... We've had lots of issues but we're grateful for the support we've had to get where we are today... We've been really lucky...

When parents really struggled, they held on to hope and stayed strong and determined to rescue their child. Sometimes this meant being very assertive to ensure their child received the attention she needed. It gave them the strength to carry on battling their child's anorexia.

I hope that things will get better in time... If we weren't such strong and determined people we may not have got the help we needed... If we weren't as assertive as we are I don't know what would've happened... We just kept on their backs... You have to stay strong... We hope that we're near the end of the eating disorder... We live in hope...

Metaphors and analogies were strategies often adopted by parents as they helped parents better understand and explain their child's condition. Externalisation is an example of a frequently used strategy among parents and refers to the eating disorder as external to the child. Although parents felt that their child was external and separate to anorexia, practising externalisation was more difficult to actually do but became a useful strategy. Anorexia became something explicitly external to their child, a demon which inhabited and possessed their child. By making a conscious effort to separate the child from the eating disorder, parents were better able to manage their child's behaviour as well as their own reactions and emotions.

The best way I can describe it [parent's situation] is that your child has been inhabited by a demon... It's like 'The Exorcist'; she's possessed by the devil... It looks like your child but it's not and every now and then you'll see a glimpse of her... Anorexia is a demon within your child and your job

as a parent is to drive it out, so you get all the behaviours in your child because of that emotional pain... You're dealing with a monster and not your child...

As the demanding eating disorder endured and consumed most of the parent's time, parents had limited time to themselves. The parents pretty much had to give up their social lives and other leisure activities to be able to care for their child. Huge personal sacrifice and no time for self, contributed to the wearing down of parents to the point of exhaustion.

We stopped seeing friends, going out to dinners or having people around because it was too much for our daughter... That enthusiasm for cooking or entertaining others just gets destroyed... You lose all enjoyment around food... Anything that was once pleasurable no longer is, as someone else always attends - anorexia... We couldn't go away for the weekend or for a family holiday... I flagged finding a relationship... There's just no time for self...

Parents that worked had to juggle or cut back on their work hours, and many had to resign to make themselves available to care for their child on a daily basis. Restricting work hours was unavoidable for most parents as caring for their child was unbelievably demanding and was thought to definitely require the constant support from both parents. Parents who knew they were relatively strong and resourceful said they would not have been able to cope on their own over the duration of the draining eating disorder. As a consequence, most parents found the eating disorder not only to be physically and psychologically draining, but also found it to be financially draining. But, obviously parents were prepared to do what it took to save their child.

I don't know how these other mothers work as well, there's been days where I don't even know where the day has gone ... I had to reduce my hours at work so I could attend all the appointments and meetings... I eventually had to give up work to be there for my wife and family, there was just no other option... It's almost impossible for just one parent to manage a

child with an eating disorder... I couldn't work for 18 months... Treatment cost hundreds a week... The cost is just huge but you do it because you're talking about your daughter's life...

As caring for a child with an eating disorder ideally requires constant support from both parents, consistency and team work are essential. Parents were required to keep a tight couple relationship and boundaries for their child to contain or beat the eating disorder; otherwise the consequences could be devastating. This was highlighted by single-parent and blended families where a difficult situation typically became much more complex for families without both biological parents involved on a daily basis. Firm boundaries are much harder to hold in a blended family, as more than two parents are involved and living in different households which can mean different rules or boundaries in each household. Also, holding the boundaries alone can be difficult for a solo parent, especially when the parent is feeling completely drained and exhausted.

Consistency is the most important part of treatment... 95% consistency is worse than no consistency and creates a bigger issue... Both parents have to be on the same page... Inconsistency between parents can be very damaging to relationships... This thing [anorexia] puts so much stress and strain on marriages... I know of other couples that have separated... When you've got two different families wanting to go in different directions with treatment, it makes it very difficult and causes a lot of distress...

So it is obvious coping strategies were considered highly important and essential by parents. Conversely, seldom did parents have time to themselves to be able to use them. This wore parents down physically, emotionally and psychologically, where sleepless nights, anxiety and/or a low mood were commonly experienced. Parents found themselves stuck in a vicious cycle where they were struggling to care for their ill child.

Time out for yourself is so important... If you get the chance, you need to take yourself away and have a break otherwise it's just continuous... But there's just no time for self... I used to sit up late at night just watching

something mindless on television to escape... We'd lie awake at night worrying and not be able to get back to sleep... After a few sleepless nights I would end up crying... My wife became depressed from having to manage such challenging and disturbing behaviour all the time... I became a really anxious person... I had to start taking medication myself just to block off all the anxiety... I slept on the floor I was that exhausted...

Parents learnt a lot from their experiences and each found their own experience to be life changing in every domain. Generally parents had not realised how intense it would be to care for someone with an eating disorder. Parents discovered that blaming oneself and feeling guilty was not helpful for themselves or their child. Parents realised they just had to make the time to look after themselves as to effectively care for their child, this was important to cope. Having a child with anorexia meant the parents' lives changed forever.

It changes your life completely... Your social life changes, you lose friends... Family life changes, you're very conscious of your other children... I didn't realise how huge the impact would be on the family... It affects every area in your life, it encompasses absolutely everything... It is the most horrific and devastating experience, you wouldn't wish it upon your worst enemy... It's changed the way I view others and society... You wonder why this has happened but you can't feel guilty and blame yourself... You must put your energy into dealing with it rather than blaming yourself...

In short, the tenacious grip the eating disorder had on the child meant the parents spent most of their days battling the eating disorder and the many contradictions during this stage. The stress parents were put under was extensive and left them absolutely exhausted where some parents faced psychological challenges themselves. Parents felt they were living and breathing anorexia while they desperately wondered when the battle would end.

You're thrown into unavoidable conflict with your child every day which results in tears and hours of comforting them... I couldn't bear to begin another day because I knew it was just going to be the same old... You're just living and breathing, every bloody meal... It's on our mind when we wake up, it's on our mind when we go to bed, even when we're sleeping, it's all we talk about, it decides what we do... Our whole life is living and breathing anorexia... And you wonder when it's all going to end... It's just ghastly and absolutely devastating...

The tenacious stage is a long and enduring one where the parents must battle anorexia for their child who is in denial of having a problem. At home, the household must make many adjustments to accommodate the child with anorexia, and relationships are strained immensely. Parents worried about the impact of the eating disorder on their family and tried to better their understanding of their child's eating disorder. This was a difficult task for the parents given that New Zealand is limited in resources and expertise in eating disorders. Even when there were services available, their child would not be treated until they were medically unstable. Uncertainty regarding treatment and the eating disorder contributed to the parents' fear, anxiety and helplessness.

Furthermore, nationwide lack of awareness and understanding of eating disorders led to stigmatisation of the child, parents and family. Stigmatisation meant isolation and minimal support for the family, which frustrated many parents as it was clear to the parents that anorexia was as serious as other conditions, such as cancer. The effects of stigmatisation meant that parents had an additional battle to fight in their minds, with their own cognitions.

Not surprisingly, parents had to use their coping strategies frequently. Externalisation was a very helpful strategy for parents as it separated their child from the eating disorder and enabled parents to manage their own reactions. Unfortunately parents had little time to themselves, made many personal sacrifices and usually felt drained or exhausted. Anorexia meant that the parents' lives were changed forever. After living and breathing anorexia, the recovery stage could not come quickly enough for the parents.

Stage Three: Recovery

The end draws near but the battle never really ends, and this is captured in the third stage. This stage has two variations; the child may be considered 'recovered' from anorexia or, a 'chronic and enduring' sufferer of anorexia.

A child that has recovered from an eating disorder means that the parents have beaten the eating disorder in their battle for the salvation of their child. The term 'recovered' captures the general feeling of the parents and child conquering the first and second stages of anorexia. However, this is contradictory as the journey is not over, there is always chance of relapse and regression back to a previous stage.

When the child is categorised as a chronic and enduring sufferer of anorexia, she has chosen to live with anorexia and so no one will succeed in battling the eating disorder. By this stage, the eating disorder has become extremely severe and the symptoms too engrained for her to return to normal life. Treatment ceases and the child spends the rest of her life tiptoeing around death.

Although both paths lead to slightly different experiences of coping for the parents, the parents must accept their child has to live with a life-threatening condition. Each path still evokes intense emotions in parents where the aftermath is huge and requires parents to continue using their coping strategies for the rest of their lives.

In both cases there is always risk, but the type and degree of risk varies between paths and can be thought of as existing along a continuum. The child can move along the continuum throughout her life so this causes distress for the parents as sudden death is always a possibility. At the less severe or 'recovered' end, the common risk is relapse back into the grips of the eating disorder, where any stressor can turn out to be a major trigger.

You think things are going along fine and then she'll have a setback for whatever reason... Everyone holds their breath because anything might create stress... When she has a boyfriend you wonder what will happen, when she doesn't, you still wonder what will happen... University was a trigger and she deteriorated again... I was only away for five days and then she started restricting again and doing really weird things... Any slight hiccup in life can cause problems...

While at the more severe or 'chronic and enduring' end of the continuum, serious medical complications can lead to death as a consequence of the starvation and strain the body has been put through. The constant risk in both situations contributes to immense fear and anxiety experienced by the parents as they worry about their child and the future.

The hardest thing has been watching her nearly die, I don't know how many times... It's horrifying to see your child get so ill and to know that she could cardiac arrest at any time... You worry and wonder what her life will be like in the future... She's almost opted out of life really... She's got osteoporosis and her body won't heal itself... She has the body of an 80 year old... I would hate to think she is still battling anorexia when she's 40... Long term it's hideous...

Either way parents come to the realisation that they are left with no choice but to accept their child's reality. This involves eventually letting them go out into the world on their own despite their fears and anxieties, and their child's life-threatening condition. This is difficult for any parent but obviously more for a parent with a child with an eating disorder as the child struggles to cope with the stresses of daily life, hence manifestation of an eating disorder. The recovered child appears old enough and ready to leave the nest, yet is not capable and is rather dependent on her parents. The chronic and enduring sufferer seems far too ill to carry on with life without a higher level of support.

Sometimes we think maybe this is as good as it gets and she'll just have to live with it... Eventually you have to let them go, as with any child... We hope she will have enough support and awareness when she leaves home... They [the professionals] suggested we let her go flatting and she'll single swim... It's hard to imagine doing this in the next couple of years, and say to her this is your problem; you have to deal with it... But she just doesn't have the ability to deal with life...

In both cases, parents want their child to be happy, and to lead as normal life as possible while having a good quality of life. The contradicting thing for parents is that, unlike children without eating disorders, their child still requires very close monitoring in case the child slips back into a dangerous place despite being recommended a normal life by health professionals. Parents have to let their child go but remain vigilant, and intervene as they think necessary, and so the salvation continues. Constant vigilance and continuing salvation is extremely draining as parents are frequently thinking or worrying about their child.

We want her to lead a fairly normal life... She's been going well but you always have to check up... I didn't like living so far away because she's still vulnerable... I just want her to be healthy and happy but she's still not getting her period... We've been more hands off but it raises its head from time to time and so that awareness is always there...

Parents acknowledged the only thing that their family can do is to get on with their lives and live as normally as they can, despite being in a rather abnormal situation. Life appears fine or normal from the outside as the child continues on with life at school or university. However, things are very different and far from fine behind closed doors. Outsiders are often unintentionally ignorant as to what the parents are going through.

On the outside she looked like a normal child... People wondered what we were talking about... If you walked past her on the street you wouldn't think she was incredibly thin and so people don't think there's a problem... When her weight is okay she looks normal and leads a reasonably normal life... Behind closed doors, the shit that'll be going down, people just have no idea... The family just learns to live with it and get on with life... You just deal with it, you have to...

Unintentional ignorance from others in society, including family, friends and strangers, reinforces the lonely struggle and lack of support that parents have had all along. As their understanding of eating disorders developed, parents discovered a lot of empathy for their child and others in a similar situation to themselves.

Their [anorexia sufferers'] anxiety around food is so huge, they'll do anything to avoid it... She's dealing with enough mental issues without having to deal with the blame from the other kids... I'd love to be able to help them all [anorexia sufferers]... My heart goes out to any family in the midst of it, it's just stress, stress, stress... We can help other parents because we've been through it...

If they had not done so already, this led many parents to establish social networks with other parents, sometimes in search of support themselves but also to support, advise and help others. Although, initially when parents felt they were living and breathing anorexia, they did not wish to talk anymore about their situation due to feeling overwhelmed. But further down the track, parents found that opportunities to share their experiences and stories were generally helpful, reassuring and that it normalised their experience.

You don't really want to talk about it in the early days, it was just living it too much... The parent groups were great, really helpful, we learnt a lot... We were able to support each other... I could make sure he was looking after his relationship with his wife and empathise with him about other things... Nothing you said shocked anyone... There was always someone you could identify with... It's been useful to talk to others that have been through similar experiences...

Along with having support networks, coping strategies like externalisation as well as hope and optimism continue to be very useful. Externalisation continues to help the parents manage the eating disorder and manage their own reactions but also helps shift further blame that is cast upon parents by others. Hope and optimism feeds the motivation and determination of the parents and gives them strength to continue with salvation of their child.

Your heart bleeds for them, but it's not your child, it's the eating disorder...I just hope she has that awareness of when she's heading

*downwards so she can deal with it... Where there's life there's hope...
We've got there with her in the end, I hope, no we have...*

Obviously there are still many emotions to be managed during this stage. Parents grieved for their losses, they felt their child's life had been taken from them and it was years that they would never get back. At the same time, parents believed their child's development was put on hold and while the child became older, the child remained the same age mentally.

*She's been robbed of her teenage years... I grieve for what could have
been... Anorexia ruined things, she's lost years that she won't get back...
Her behaviour reduces to her younger sibling's level, I grieve for that... It's
hard to have a teenage daughter who's not there and you have to try and
mother her back to her actual age...*

Furthermore, the parents considered their child's siblings to have been robbed of their childhood years. Siblings had to mature very fast while parents cast much of their time and attention to their child suffering an eating disorder. Parents also grieved for the loss or under-development for their children's relationships with each other.

*They've [her siblings] missed out on childhood... They [her siblings]
had to grow up really fast and became independent... They [the children]
have a lot of relationships to rebuild... The chance of them [the children]
having a relationship with her when they're adults is pretty slim, it's very
sad...*

It is apparent that the aftermath of having a child with an eating disorder is just huge and extends through every aspect of the family. The general consensus among parents was that there was no good that came from their experience, some parents tried to think of positives but concluded that there was nothing positive that came out of their experiences. The devastation thrust upon the family and, the changes and adjustments the family must make to get on with their lives means coping strategies are absolutely essential.

Humour was used in conversation by many parents, although some parents seemed unaware of even using humour as strategy to downplay the frightfulness of the situation, or hide unpleasant emotions such as sadness. After such a lengthy battle against their child's eating disorder, parents had learnt to cope on an unconscious level. For instance, some parents would smile or laugh while joking about their distressing situation. This kind of response suggests just how consuming anorexia became of the parents' lives, as parents learnt how to just get on with life and coped on an unconscious level.

Hope and optimism regarding the child's situation, the parent's position, and the future of their family, also helps the parents cope with a tough reality. Parents were thankful and appreciative of the effective help that they did have and were able to think of worse situations they would not like to be in. This enabled parents to shift their focus away or recover from the ghastly situation they have been experiencing since the insidious stage, and move toward getting on with and living life to the full.

Whatever was happening at home, there was always someone having a more difficult time... Others have lived with it [anorexia] for years and nothing's changed, we're lucky... You can't remove the problem, you just have to get on with it and live life... Everyone has difficulties in their lives, problems in their family...

The recovery stage involves ongoing risk for both the 'recovered' and 'chronic and enduring' sufferers of anorexia. Whichever the recovery path, the parents must accept their child's reality and let her go to live her life as normally as possible. Emotions still run high during the recovery stage as the parents worry about and grieve for their child and so coping strategies remain essential. By this stage the parents realise just how devastating the aftermath of anorexia is. Many found support networks with other parents helpful and wanted to help others in similar situations. The recovery stage emphasises that the battle the parents have against their child's eating disorder is never-ending.

Findings summary

Caring for a child with an eating disorder involves three stages which are ridden with emotions, uncertainty and contradiction. The stages can overlap with one another and can reappear despite progression to another stage having already occurred. The insidious stage reflects the early days of the eating disorder where anorexia creeps in and takes hold of the child while it causes harmful effects. After realisation by the parents and a diagnosis, the tenacious stage begins. This stage has parents wondering when the eating disorder will end as it persists in progressively taking over more of their child's life. Parents experience high levels of distress as they witness the life being sucked out of their child while they struggle to save their child from anorexia. The lives' of the parents are changed forever. Eventually and with support from the parents, the child is able to recover what they can from life. The child recovers to a 'recovered' level or to a 'chronic and enduring' state, where both forms of recovery still involve risk. An eating disorder is a stigmatised mental health issue that requires ongoing monitoring by the parents. Parents have no choice but to learn to live with their child as a sufferer of anorexia, and so the search for salvation for their child continues.

Discussion

The value of this research within psychology

After initially struggling with finding participants for this research, the aim of my research was achieved. This qualitative research, gave parents in New Zealand the opportunity to share their experiences of what it is like to care for a child with an eating disorder. My findings revealed that parents' experiences have been unwarrantedly and extremely difficult as parents must battle a complex mental health issue with minimal resources and support, and all the while the eating disorder threatens their child's life and the parents are blamed for the situation. The rollercoaster of emotions and field of contradictions parents have to endure and work through while having minimal support, makes the experience of parents an exhausting nightmare.

My findings have been shown to some extent by other qualitative research (Cottee-Lane et al., 2004; Highet et al., 2005; Ross & Handy, 2007; Tierney, 2005). Some of this research has also found that parents go through certain stages throughout the time of their child having an eating disorder (Cottee-Lane et al., 2004; Highet et al., 2005; Tierney, 2005). There seem to be some similarities in the content of the stages with that of my research which will be outlined in the following. However, my research on the whole differs from other research as it covers a greater range of experiences compared to the majority of current research, and provides the New Zealand context for the findings. Furthermore, some of the existing research faces limitations which I took into account during the design of my research. For example, previous research has conducted focus groups which means participants are subject to group dynamics like conformity pressures during interviewing. Alternatively I employed individual interviews because individuals are more likely to express their personal thoughts and feelings regarding their experiences and go into more detail in their interviews (Barker et al., 2002; Robson, 2002).

A major finding of my research was that guilt and blame frequently manifested in parents over the duration of the battle against the eating disorder, and this is consistent with prior research (Ball & Ball, 1995; Highet et al., 2005; Hoste et al., 2011; MacDonald, 2000; Abraham & Llewellyn-Jones, 2001; Cottee-Lane et al., 2004; Sharkey-Orgero, 1999; Whitney et al., 2005). Parents were influenced by others to think that their child's suffering was their fault as others stereotyped anorexia and made judgements about parental ability. Parents had to avoid taking these perceptions of

others regarding their situation or, stigmatisation on board, as this could have a detrimental affect on their own mental health. My research demonstrated how this combination of findings contributed to an additional battle for the parents, a battle in the minds of parents.

Furthermore, the constant and high levels of uncertainty throughout the experiences of parents made the experience that much more distressing, creating much fear and anxiety. Parents were often worried or frightened about their child's well-being, future and ultimately, their child's life. Parents had to battle out the different scenarios playing in their minds while they were living and breathing anorexia and battling against their child's eating disorder. Sadly, many parents did end up developing anxiety and/or depressed mood over the duration of managing their child's eating disorder. This finding is supported by previous research (Kyriacou et al., 2008a; Martin et al., 2011; Zabala et al., 2009), which has also found that parents experience a high level of burden, and develop symptoms of anxiety and depression.

Furthermore, the immediate impact on the family was very significant and devastating (Ball & Ball, 1995; Cottee-Lane et al., 2004; Highet et al., 2005; Ross & Handy, 2007). The family had to deal with unreasonable and ongoing demands made by the child suffering the eating disorder as well as the extremely challenging behaviour associated with it. However, what has not been emphasised strongly enough by other research is that the aftermath is just devastating as every area of the parents' and children's lives are affected forever, involvement with an eating disorder is a life changing experience.

Unfortunately, stigmatisation of families due to misconceptions about eating disorders or mental health by those with no personal involvement led parents and their families to become isolated. Parents do not feel like they could talk to others due to all the judgement and lack of understanding (Ball & Ball, 1995). Stigmatisation and isolation has been found in previous research and means that the battle against the eating disorder is a long and lonely struggle for the parents (Highet et al., 2005; Hillege et al., 2006). Sadly parents and families are not provided with a great deal of support. Talking with other parents or being part of support networks benefited most parents. This finding is consistent with other research (Cottee-Lane et al., 2004; Highet, et al., 2005), which also found that support and understanding were often hard to find, while

opportunities to share experiences with other parents or support groups were considered highly valuable.

Overall my findings emphasise the need to educate society about eating disorders. People need to understand that anorexia is a complex mental health issue that is not caused by the parents, is not easily treated, and is definitely not as simple as telling someone to, 'just eat'. Anorexia often involves comorbid conditions, usually anxiety and depression; this means that multiple psychological issues as well as physiological complications must be dealt with. Nationwide mental health education regarding eating disorders would raise awareness of the complexity of eating disorders and their extensive impact, minimise stigmatisation and increase support networks which could ultimately lead to better outcomes for anorexia sufferers, their parents and their families.

However, another complexity for parents in New Zealand was that the medical system has been lacking in resources and expertise. Barriers to resources and expertise seem to be the case in other parts of the world as well (Highet et al., 2005; MacDonald, 2000; Tierney, 2005). For instance, parents found that much of the time, psychological problems were left untreated and physiological symptoms took priority in treatment. This seemed strange to parents as anorexia is primarily a mental health issue yet much of the focus was on the physiology of the child, which was needed, but mental health seemed to be neglected. This lack of knowledge, understanding, resources and expertise needs to be addressed so that the treatment of eating disorders and the parents' experience can be improved. This way parents would feel more supported and levels of distress would be likely to decrease, as other research also points out (Whitney et al., 2007; Whitney et al., 2005).

Sadly parents became used to coping alone. Coping was difficult for parents and sometimes parent were not even aware that they were using their coping mechanisms, like in the case of using humour. Humour was used frequently in conversation to help downplay distressing situations or hide unpleasant emotions. This emphasises just how consuming an eating disorder can be of the parents' lives because many parents had learned to cope habitually where they did not even realise they were coping.

Externalisation is a coping strategy that was consciously used by parents and was found to be rather effective in this research, but with the exception of a very small number of studies like that by Ross and Handy (2007), externalisation has not come across as such a strong and useful strategy. Parents actually found externalisation to be

extremely helpful in managing their emotional reactions triggered by the foreign eating disorder. This example supports the point that parents' wider experiences have not been deeply explored by a lot of previous research.

Another finding less emphasised by prior research is the numerous contradictions faced by parents throughout the battle against their child's eating disorder. Firstly, the eating disorder is difficult to identify due to it being disguised by the age of onset, generally during teenage years. Behaviours similar to eating disorder symptoms are thought to occur often at this stage in life anyway. This difficulty in recognising an eating disorder has been pointed out by other research (Ball & Ball, 1995; Cottee-Lane et al., 2004; Highet et al., 2005; Sharkey-Orgnero, 1999), and means that parents are left wondering what normal behaviour is and what it is abnormal. Parents initially sided with normal teenage behaviour when really it was eating disorder behaviour their child was displaying. But just how insidious anorexia is does not seem to be really captured by many researchers.

Parents also found their role to be contradictory and this needs to be emphasised. Parents discovered that much of what they were required to do was counter to what they thought was right. They wanted to be given more reasoning and direction from health professionals regarding their role as the parent. As a result parents often felt like they were floundering around in contradiction and confusion which is distressing in itself.

It did not help that the medical system lacked resources and expertise and acted as an ambulance at the bottom of the cliff. Only those that were already in need of life-saving help were attended to, rather than trying to prevent anorexia in the early stages and before the 'tenacious' eating disorder really set in. More focus on prevention could decrease the number of serious and chronic sufferers of anorexia and make parents' experiences less distressing, draining and exhausting. This suggests there is much room for improvement in the treatment of eating disorders in New Zealand.

Anorexia needs to be treated as other persisting and life-threatening illnesses are, with empathy and support. For example, many parents compared and contrasted anorexia to cancer as both are serious illnesses that persist and have the potential to take lives. However, due to stigmatisation of mental health issues as previously mentioned, and to eating disorders being considered as relatively rare, resources and facilities to treat anorexia within New Zealand are in very short supply. With the benefits from nationwide education, more resources and facilities, including expertise, anorexia would

be up to par with other serious and life-threatening illnesses like cancer. This would make parents' experiences much more supported and manageable, where they may even feel more comfortable with sharing their experiences for research purposes with the aim to educate others and improve services or treatment for in the future.

The 'recovery' stage was also highly contradictory as the child is never really recovered as the term suggests. Life is assumed to be back to normal but it never really gets back to normal, because the serious and life-threatening risk remains, and remains hidden to others in society. The child is given back their sense of control when she is far from being capable of controlling her life, and in fact the parents remain constantly vigilant in the salvation of their child. Not surprisingly, grief and sadness for missed years of life and lost relationships were commonly experienced among parents, consistent with other research (Hight et al., 2005; MacDonald, 2000; Treasure et al., 2001; Whitney et al., 2007).

Unlike previous research (Perkins et al., 2004; Ross, & Handy, 2007), in this research the parents struggled to find the positives that came out of their experience, and instead concluded that there was nothing very positive about having a child with an eating disorder. This supports the notion of how difficult it really is for a parent to care for a child with an eating disorder, and that their experience has been overwhelmingly negative.

However, despite the negatives, developing their understandings further enabled parents to cope with this mysterious mental health issue, as well as with all the uncertainty and unpredictability that came with it. However, it was clear that understandings deepen throughout experience and involvement but that things never made complete sense. So the many remaining uncertainties created an unsettling feeling for parents and made them feel they are caught in a vicious cycle where they have to learn to attempt to keep balance in their families and lives while living with such a destructive mental health issue. So the battle against the demon anorexia continues; it never really ends.

With now having a deeper understanding of parents' experiences, it is much clearer to me as to why I initially had such difficulty in finding participants that felt comfortable with sharing their experiences with me. As there is such a wide lack of understanding and knowledge in eating disorders by many people in New Zealand, it is not surprising that parents prefer to keep their stories from all the unjustified scrutiny

and judgement. The stigmatisation of mental health issues, such as anorexia is just appalling and is something I think needs to be addressed nationwide. Fortunately, I was able to explore the experiences of parents and hear about all these issues, while parents were able to offload their thoughts and emotions in the process.

In reflecting back over the research process and from keeping a research diary, I noticed that my initial understandings or expectations of what it would be like for a parent to care for a child with an eating disorder changed. My ability to set aside my own preconceived ideas allowed me to realise how incredibly difficult it is for the parents to care for a child with an eating disorder. I had not been aware of how extensive the impact on the parents and family was, and how caring for a child with an eating disorder is so constant and ongoing for a parent.

As the researcher I was aware that the participants initially thought I only wanted to hear about certain aspects of their experience, and so wanted to provide me with that information only (Langdrige, 2007; Mays & Pope, 2006; Yardley, 2008). However, once I explained what an in-depth and open-ended interview was, participants were able to speak freely about their experiences while covering a range of aspects in detail. It did often take parents a few minutes to feel more relaxed and comfortable in the interviews, but once they did, their stories began flowing.

This research involved a desirable number of participants which increases the likelihood of developing a relatively accurate understanding of the parents' experience. Participants had to meet specific criteria to ensure they were right and relevant for the purpose of this research (Yardley, 2008). A fewer number of participants would not have captured the experiences of parents as thoroughly. More participants could have contributed to a more detailed description, although the point of saturation was reached so it is unlikely that more participants would have made a considerable difference on the overall findings of this research (Barker et al., 2002; Robson, 2002).

Although there were some similarities with other research, not all of my findings were consistent, different and inconsistent findings emerged from my research also. For example, a couple of the families seemed to have slightly different experiences from others but once these cases were explored further, I discovered that the difference could be accounted for by the family structure or stage of the eating disorder. So instead, these cases simply emphasised the findings in my research, as the experiences were occurring at a greater intensity. This divergence between my initial and later understandings or

expectations, and convergence with other research findings contributes to the validity of my research (Mays & Pope, 2006; Yardley, 2008).

A limitation of this research is that I was only able to obtain participants that currently lived within the Auckland region. My analysis may have led to different findings if parents from locations outside the Auckland region had participated in my research. I am confident, since having a child with anorexia is such a difficult situation, that parents' experiences in other locations in New Zealand would be very similar, and that the findings obtained here are more widely applicable to parents in this situation beyond the Auckland region.

Another consideration to be aware of is related to the snowballing technique (Barker et al., 2002). The potential issue with this technique is that the initial respondents could have referred other like-minded people who share the same views as them, to participate in this research (Barker et al., 2002). Furthermore, all the parents who were interviewed had daughters suffering anorexia; none of the parents had sons with anorexia. However, a higher number of females suffering anorexia is typical of the population under exploration (APA, 2000). Furthermore, the strength of using snowballing for this research topic is that the population under exploration was difficult to access and the snowballing technique enabled increased participant numbers. A lower number of participants would have meant fewer experiences would be researched or explored which would mean that an in-depth understanding would be less likely (Barker et al., 2002).

Something else which could be considered for future research is bulimia. As other research suggests, bulimia seems to be much more common than anorexia, while also remains typically hidden as cases are likely to remain undiagnosed (Clarke & Polimeni-Walker, 2004; Hoek & van Hoeken, 2003; Wakeling, 1996). There are likely to be many similarities between bulimia and anorexia in terms of the parent experience, stigmatisation and the impact of bulimia. There will also be differences so, future research on bulimia could further inform nationwide education and provide a fuller picture of eating disorders. More extensive research on eating disorders has the potential to improve treatment and services for eating disorders in the long run and would help solidify a foundation for further research in eating disorders in New Zealand.

The experience of parents of what it is like to care for a child with an eating disorder has rarely been qualitatively researched in New Zealand. Although I have

provided a well-researched account of what it is like for a parent to care for a child with an eating disorder, it would be interesting and helpful to compare this with the accounts of other researchers. For instance, additional accounts could suggest whether improvements in services or treatment have occurred, or what needs to be addressed in the field of eating disorders and to what extent. This would help build on the good foundation that this research has established.

Concluding comment

Ultimately, the parents found themselves in a battle against a demon for the salvation of their child; this demon known as anorexia was insidious, tenacious and sometimes unstoppable. The eating disorder took a psychological, emotional and physical toll on all of the parents where the contradictions and uncertainty were overwhelming. The lives of parents were changed forever. Fortunately many of the parents found that after sharing their experiences with me, they had felt a release of built up thought and emotion. This goes to show that it is useful for parents to talk to others about their experiences, and it is concerning that stigmatisation discourages them from doing so. This is why society needs to be informed and to become more aware and understanding of eating disorders, as well as the fact that anorexia has the ability to creep up and take hold of anyone!

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Appendix A

*Caring for a child with an eating disorder***Information Sheet**

My name is Ashley Bellingham and I am part the way through a Master of Arts (MA) in Psychology, which I am doing part time at Massey University. I am conducting a research project under the supervision of Professor Kerry Chamberlain as part of my degree requirements. I think there are gaps in the research concerning eating disorders within New Zealand and my interest is in the parents of children with eating disorders. The aim of my research is to explore how parents experience their child while their child has an eating disorder (Anorexia Nervosa).

Something else I would like you to know about me is that I am also employed as a XXXXX at XXXXX. I consider my employment separate from my research project. However, my employment still means there is potential that your child may be accessing the service while I am carrying out my research project. I want to assure you that I work professionally, that I will adhere to the confidentiality arrangements made with you and, to the Massey University Human Ethics Committee guidelines and, most importantly, know that your participation or non-participation in this project will NOT affect the service delivered to your child. XXXXX is aware of my research project including what I have just described, and remain supportive of my university studies.

Who can take part?

I would like to interview you if you are willing to share your experience regarding you and your child and their eating disorder. You and your child may be male or female and your child diagnosed with anorexia nervosa. Both parents may interview individually if

they wish as both perspectives are likely to differ. Your child can be of any age, at any stage of the eating disorder or recovery, and may or may not be living with you.

I recognise that caring for someone with an eating disorder is highly distressing and that talking about your experiences may not be easy so I will do everything I can to ensure that this is a safe, respectful and interesting experience for you. You may even find it helpful.

What will be required of me if I wish to participate?

As your child may be accessing XXXXX, I request that you inform your child of your participation before consenting to participate, as the interviews will be based on your involvement with your child. I would rather your child is aware of the interview.

You will need to take part in one individual interview with me that will last between 45-120 minutes. The interviews will be recorded on audiotape and then transcribed by me. If you do want to participate, contact me and we can negotiate an interview time, I am pretty flexible. In terms of an interview location, I thought that it would be most convenient and more comfortable for you if the interview took place in your home however, other arrangements can be made if this is not desired. Just so you know, during the interview you do not need to answer anything you do not want to and can have the tape recorder turned off at any time. If you become really uncomfortable about the research, you have the option of withdrawing your participation up to 1 week after the interview.

How will your information be used?

Information you provide will be treated confidentially, all names and identifying features from the interview will be removed. Only my supervisor and I will have access to the transcripts of our conversations. Audiotapes from the interview and your consent

form will be stored separately and securely in my home and, then will be destroyed at the end of my research. Transcripts will be stored safely for 5 years by my supervisor before being disposed of, as required by research protocols.

You are given the option on your consent form of whether or not you wish to have a summary of the research findings sent to you. If you would like the summary sent to you, please provide your details in the space provided on the consent form.

Please feel free to contact myself or my supervisor if you have any questions about this research project, we will be happy to answer them anytime.

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This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application 11/021. If you have any concerns about the conduct of this research, please contact Dr Ralph Bathurst, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 9570, email humanethicsnorth@massey.ac.nz.

Appendix B

Interview Topics

Demographic information:

- Ethnicity
- Living arrangement of child with the eating disorder
- Parental situation e.g. partner versus single parent
- Ages and genders of other members (siblings) in the household
- Eating disorder diagnosis
 - Gender
 - Age of onset
 - Duration
 - Number of previous hospitalisations
 - Current stage/situation of eating disorder e.g. receiving treatment versus recovered

Topic areas for interviewing:

- What do you think about eating disorders?
 - What is your understanding of an eating disorder?
 - How do others perceive eating disorders?
 - How do members in your household perceive eating disorders?

- How do you view treatment for eating disorders?
 - What is your experience of treatment?

- What is your experience of having a child with an eating disorder?
 - Can you talk about how your experience has been?
 - What has your role as a parent been like?

- How has this changed overtime? i.e. before, during, ?after
- Can you talk about any experiences differing over various contexts? E.g. home, school, community..

- What has your experience of support been like?
 - What has been the most important source of support to you and how has this helped?

- How has an eating disorder affected your family?
 - How are the relationships between household members?
 - How do you think other members have found being involved?
 - What sorts of activities do your family do together?

- In what ways has your child having an eating disorder impacted on you?
 - Knowledge?
 - Opinions or values?
 - Feelings?

- What has been the most difficult thing you have experienced in your situation?
 - How do you cope?
 - What coping skills do you have?

- What has been the most positive outcome of your situation?