

PARENTAL GRIEF WHEN A CHILD IS DIAGNOSED WITH A
LIFE-THREATENING CHRONIC-ILLNESS:
THE IMPACT OF GENDER, PERCEPTIONS AND COPING STRATEGIES.

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My Family

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Abstract

The grief experienced by mothers and fathers when their child is diagnosed with a life threatening chronic-illness was investigated in order to validate the presence of grief in these parents and look at the factors that influence it. More specifically, I was interested in whether the grief experience differed for mothers and fathers and the impact that perceptions and coping have on both these gender differences in grief and on grief in general. The particular population investigated in this study were parents of children with Cystic Fibrosis. Participants were recruited through questionnaires randomly sent out by the National Cystic Fibrosis Association. In all, 37 mothers and 15 fathers took part. Results not only confirmed presence of grief in these parents but also indicated that this grief differs for mothers and fathers, with mothers reporting significantly higher levels of physical distress. In line with the literature no gender differences were found in regards to perception of impact parents felt their child's chronic-illness had had on their lives. Contrary to what was expected, however, no differences were found amongst the coping strategies used by mothers and fathers. In regards to the question of which factors have the greatest impact on the grief experienced by mothers and fathers combined, the coping strategy of self-blame was found to be the most important, followed closely by negative perceptions. The significance of these findings and their implications for parents and the people who work with them was discussed.

1. Introduction

Loss is an experience familiar to all individuals. Whether it be the loss of a job, skill, relationship, health, finances, self-esteem, trust, freedom or ideals, it is something men and women encounter countless times throughout their life-span. In recent years, interest in the area of “loss” in psychology has grown rapidly. Encouraging this interest is the growing belief that the most severe events in life are loss events (Hobfoll, Freedy, Green, & Solomon, 1996).

Losses occur in any number of situations, and come in various shapes and sizes. They may range from something as small as the loss of one’s first tooth, to something as big as the loss of a loved one. Furthermore, with any single loss multiple losses may occur. For example, in losing a spouse, one does not just lose a partner, but also a companion, cook, breadwinner and parent for one’s children (Lendrum & Syme, 1992). Having noted this, it is important to keep in mind that loss affects everyone differently. Some people struggle, while others take it in their stride.

Saunders (1989) commented that grief is a normal reaction to a significant loss. Typically individuals think of grief as occurring only in the context of bereavement, the loss of a loved one through death. Losses by death, however, are not the only losses that need to be grieved (Lake, 1984). A growing number of researchers have acknowledged this idea by conducting studies on the effects of other types of loss (Parkes, 2001). Their results reveal that people grieve many things. That is, whether it is something such as their sight, hearing, or a limb, people grieve for what they have lost.

The area of loss that is the focus of this present study is that experienced by parents who are informed that their child has a life-threatening chronic-illness. This type of loss is of interest because it involves grieving the loss of an ‘ideal’, not a tangible object. In this case the ideal lost is that of ‘the healthy child.’ When a woman is pregnant she is aware there are risks and that problems may arise. Generally, however, these thoughts are put aside and it is expected that she will give birth to a healthy child. During pregnancy it is also common for expectant parents to develop images and expectations of what their child will look like and be like. When the child

arrives and the parents are informed that he/she has a life-threatening chronic-illness this image is shattered (Collins-Moore, 1984, cited in Worthington, 1989). In turn, rather than feeling the joy they had anticipated, mothers and fathers are left in a state of shock and disbelief (Bright, 1986; Young, 1977).

The loss parents of chronically-ill children experience is also of interest because although death has not occurred, the prospect of one's own mortality is brought to mind. This is important as death is a frightening and painful aspect of life that many would rather not think about (Kübler-Ross, 1997). The main reasons for this are that death creates anxiety as individuals imagine being separated from loved ones. It threatens plans for the future, and instils fear as one thinks about the horrors involved in the actual death (DeSpelder & Strickland, 1999). However, although men and women like to behave as if they will live forever, it cannot be denied that for everyone living today death is inevitable (McNamara, 2001). Parents of chronically-ill children know this reality all too well. Death for them is a more immediate concern, as they have to work to keep their children well, and in some cases live with the knowledge that their child's lifespan will be shorter than most. Living with such awareness is important as it changes the outlook of these parents, causing them to change their priorities, be more appreciative of each day, more aware of how precious life is, and therefore more likely to live life to the full in order to make the most of the time they have with their child.

Past studies have looked at both parents of children suffering chronic-illness and those suffering life-threatening chronic-illnesses. In general, these studies have tended to focus on the stress the illness puts on the family unit and the burden of illness-related tasks, rather than the loss experienced (for an example see, Melnyk, Feinstein, Mouldenhouer, & Small, 2001). In recent years, however, the loss these parents experience has been increasingly recognised, with Davis and Schultz (1998), for example, concluding that underlying the daily stress involved in the case of caring for a child with schizophrenia was a pervasive theme of loss and grief.

In explaining the rationale behind their 1998 study, Davis and Schultz talked at length about the idea of 'chronic sorrow,' a term used to describe a prolonged grief-like state. The theory

of chronic sorrow was proposed by Olshansky in 1962. In studying the parents of mentally defective children, Olshansky (1962) not only identified the presence of grief, he concluded that this grief was ongoing. It was believed that the reason this grief remained unresolved was not due to the inability of mothers and fathers to accept the reality of their child's disability, but rather that it was simply a normal, understandable reaction to a continued loss. That is, the loss experienced by these parents evolved and redefined itself over time, with the loss of the "perfect child" becoming the loss of the "healthy young adult." This process repeatedly reminded parents of what they had lost, which in turn complicated and prolonged grieving by making it difficult for them to assimilate the totality of the loss, a task that is considered an essential part of grief work (Davis & Schultz, 1998).

Amongst this, however, it should be noted that the presence of chronic sorrow did not mean that parents of chronically-ill children would not receive joy and satisfaction from their child, and live in a state of constant sadness (Young, 1977). This is because the intensity of grief felt with chronic sorrow varies over the lifespan, resulting in periods of stability and instability for parents (Worthington, 1989). More specifically, sorrow tends to appear when the child is unwell, and fades into the background when the child is in good health. Furthermore, it should also be noted that chronic sorrow was not considered abnormal. Rather it was believed it would be the absence of such sorrow that should provoke professional concern (Ferguson, 2002).

Grief is an important part of loss, allowing men and women to come to terms with the loss and resulting changes in their lives. Although grieving a loss is never easy, in this situation it is made more difficult by the fact the loss suffered does not involve a tangible object. Parents of chronically-ill children still have a child, but they will never know their children as they might have been. What they have lost is hopes, dreams and expectations. Adding to this difficulty, parents of chronically-ill children may find there is little time to grieve, because the child needs specialized care and attention, requiring parents to learn about medicine and therapy treatments.

The importance of looking into this area is highlighted when one considers that it is likely that whether or not parents grieve will have implications for their future emotional well-being.

Acknowledging the experience of grief will also have implications for individuals working with mothers and fathers whose child has just received the diagnosis of a life-threatening chronic-illness. It puts these individuals in a position to validate the loss experience, help parents recognise what it is they have lost, and gives them permission to grieve this loss. This is important as many parents may not realise what they are feeling is grief. Clarifying this not only puts a name to the feelings they are experiencing, it also places them in a better position to understand what is happening, and gives them an idea of what is to come.

Furthermore, assisting parents who are struggling with the news of their child's diagnosis becomes even more important in the light of research which suggests a link between the health of the child and family functioning. Patterson, Budd, Goetz and Warwick (1993), for example, noted that the functioning of the family, as evidenced by its ability to flow through with treatment regimes, had been identified as critical factor in preventing lung deterioration and promoting health and well-being in children with cystic fibrosis.

Grief is an important topic to study with there being several misconceptions widely accepted by the general public that can hamper the grieving process. Although grief is an emotion that is universal, it is an emotion many are afraid to feel. One of the main reasons for this is the fear that if men and women let it in, it will consume them indefinitely. While it is not true, this belief is engrained in social norms that discourage the open expression of emotion. As a result, men and women hide public displays of emotion and are expected to control their feelings. In general, most comply with these norms as violating them not only causes the individual to feel embarrassed, shameful, out of control and weak, but it also results in discomfort for others who may be present (Saunders, 1989; Stinson, Lasker, Lohmann & Toedter, 1992). To give an example of such norms at work, when talking about someone who is crying it is often said that they 'broke down' in tears. Talking in such a manner implies that the person is weak. In reality, however, tears are important as they enable the necessary release of intense feelings. In all, to overcome such misconceptions people need to be educated, to help them realise grief does not

need to be feared, and that even though it may seem impossible they can overcome grief, heal and even grow from the experience (Tatelbaum, 1980).

In looking at the grieving process questions such as “why are some better at coping with grief than others?” and “what determines a positive outcome?” emerge. The answers to such questions lie in the fact that grief is a complex phenomenon, the effects of which are mediated by a wide range of variables (Toedter, Lasker & Alhadeff, 1988). In the following study, three of these variables will be assessed in order to see how they impact upon the grief process. These variables are gender, perceptions of the impact the child’s chronic-illness has had on one’s life, and coping strategies.

Although it was acknowledged that chronic-illness has an impact on the whole family, research has traditionally focused on mothers and their reactions to having a chronically-ill child. As a result, the differential impact of chronically-ill children on both mothers and fathers has remained a largely unexplored area (Katz, 2002a). This focus on mothers was due to the fact that they were generally easier to contact, and as the primary caregiver they tended to be the ones who attended hospital appointments with their child (Levers & Drotar, 1996). Furthermore, it was assumed by researchers that fathers would perceive, react, and cope in the same manner as mothers (Katz, 2002b). In the past, it was not uncommon for fathers to be largely absent in the lives of their children, with social norms suggesting that it was a fathers role to provide for his family, while it was the mothers role to look after the household. Today, however, these roles have changed, with fathers becoming more involved in the care of their children. It has also been acknowledged today that men and women do differ in their grief reactions. For these reasons there is an increasing urgency to investigate the needs, perceptions, and coping styles of fathers and to look at how they compare to mothers (Katz, 2002b).

Knowledge of how mothers and fathers differ in their grief has important implications for couples and the individuals working with them. For example, it could assist professionals in helping couples open the lines of communication, in order that each partner may better understand how the other is responding to the situation. This is important as it gives couples an

insight into what each may be going through, and sheds some understanding on why their partner may be behaving as he/she is. Knowing that one's partner may be grieving differently and on a different schedule may in turn help prevent differences in experiences from driving a wedge between couples, and assist in preserving the relationship during a time of intense stress (Hunfeld, Mourik, Passchier, & Tibboel, 1996; Saunders, 1989). This is particularly important with a strong relationship believed to form an important source of support for parents (Friedrich, 1979 and Friedrich, Wilturner, & Cohen, 1985, cited in Bruce, Schultz & Smyrnios, 1996).

Furthermore, I feel it is important to look at parents' perceptions of the effect they feel having a child with a chronic-illness has had on their lives, and the impact that this then has on the grief experience. Perceptions explain why different people react to the same event in very different ways. They colour individuals' thoughts and therefore, influence their attitudes, what they say to themselves, how they answer questions such as 'why me?' and whether they decide to focus more on life or death. For these reasons, it is likely that parents' perceptions about their child's diagnosis will have a significant impact on the grieving process.

Lastly, I am interested in looking at whether coping has an impact on the degree of grief experienced by parents of chronically-ill children. Snyder, Ford, and Harris (1987) defined coping as an attempt to lessen the physical and psychological pain associated with negative life events. Van Heck and De Ridder (2001) added to this noting that it is also used to regulate emotion and reduce the threat of loss. In all, coping refers to the way one manages different situations. If effective it should reduce pain and result in a more positive outcome for the individual (Stroebe, Hansson, Stroebe, & Schut, 2001). With this in mind it is likely that coping does have an impact, some strategies being more influential than others. I intend to look at whether there are any gender differences in coping strategies used by parents. Being aware of any differences here is important because just as differences in grief could put strain on a relationship, so too could differences in coping.

For the purposes of this study, grief is defined as an emotional (affective) reaction to a significant loss. This reaction incorporates both diverse psychological (cognitive, social,

behavioural) and physical (physiological, somatic) manifestations (Stroebe, Hanson, Stroebe, & Schut, 2001). No distinction will be drawn between normal and pathological grief. There are two reasons for this. The first is that the main focus of this study is to look at the experience of these parents, the emotions they feel, and what they go through, not to say what is normal, and what is not. The second is that it is difficult to draw distinctions between normal and pathological grief. Keeping in mind the fact that everyone experiences grief differently, the task of setting a cut-off point can be dubious. Adding to this, it is sometimes difficult to differentiate pathological grief from related disorders such as depression, anxiety or post-traumatic stress (Stroebe, Hansson, Stroebe, & Schut, 2001).

The work of Olshansky (1962) suggests that the grief felt by parents of chronically-ill children will be ongoing. As children grow, the demands of their illness vary. These changes, along with changes in the child's health impact upon the grief experienced. For this reason, I have decided to focus on a specific phase of illness. The period chosen to examine is the time of diagnosis and following year. This phase was chosen because the period following diagnosis has long been considered one of the most difficult for families. Not only do parents have to cope with their perceptions of loss, they must also learn new medical routines, and reorganise family roles in the face of terrible uncertainty (Quittner, Di Girolamo, Michel & Eigen, 1992). Furthermore, the decision to look no further than one year post diagnosis was made based on studies such as that by Ventures (1981, cited in Hymovich & Baker, 1985) who noted that amongst families of children diagnosed with cystic fibrosis, life by the end of the first year became less stressful, strained family relations eased, initial disruption had been minimised by new routines, and some agreement among family members about future goals and aspirations had occurred.

It was also decided to focus on a specific chronic-illness rather than generalise across different types of chronic-illnesses. The chronic-illness which will be the focus of this study is cystic fibrosis (CF). At present there are over 300 individuals in New Zealand who have CF, with an incidence rate here of one in every 3000-3500 live births (Cystic Fibrosis Association of New Zealand, 2006). Across the world cystic fibrosis is the most common life-threatening genetic

condition among Caucasian children. It is a disorder of the exocrine glands that predominantly affects the respiratory and digestive organs (Jones, Campbell, Mulhern, Marrett, Patterson & Jennings, 1998a). More specifically, the exocrine glands in individuals with CF produce a thick, sticky mucus that clogs their lungs, which in turn causes respiratory problems and makes them prone to chest infections. This thick mucus also blocks ducts in the pancreas, preventing digestive enzymes reaching the intestines which they need to do to help properly digest food (Anderson, 2006). As a result these individuals do not absorb the nutrients from food as they should. To combat these problems daily physiotherapy is required to clear mucus from the lungs, and enzymes must be taken with everything one eats to ensure that food is absorbed into the body. Courses of antibiotics are also often taken in order to treat chest infections. In all, this treatment is purely palliative, with there as yet being no cure for CF. As children grow the disease gradually progresses and more complications arise.

There are several reasons behind my decision to study this particular condition. The first is that CF is diagnosed soon after birth. This is important in terms of this study as it means that what is lost was the 'ideal' of the 'healthy' child parents expected not the 'healthy' child they once knew.

Secondly, CF children look no different from other children. In fact the only way you would know a child has CF is if you were told. This in turn means that I can be sure that what is being grieved is the lost health of the child, not any obvious physical manifestation of a disability.

The third reason is the fact that unless one already has a child or close relative with CF the diagnosis will come as a complete shock. This is because CF is a genetic disorder requiring two recessive genes, one from the mother and one from the father. Thus, for a child to have CF both parents must carry one CF gene each. If this is the case, then for each child this couple has the probability it will be born with CF is 1 in 4. Approximately 1 in 25 individuals are carriers of the CF gene (Cystic Fibrosis Association of New Zealand, 2006). Most of these individuals are unaware of their carrier status, and will remain so until a child with CF emerges. Furthermore, unlike other chronic-illnesses such as Down's Syndrome, CF is not automatically picked up while

the baby is in the womb, which in turn means that parents are given no time to prepare themselves for what is to come.

Fourthly, advances in medical research and treatment are improving the life expectancy of children with CF. Before the advent of antibiotics more than half of those with CF died by age two, and more than three quarters died by age 10 (Dushenko, 1981). This increased to 15-17 years in 1981 (Dushenko, 1981), and in 1990 it was reported as 27.6 years (Patterson et al., 1993). Today individuals with CF are living into their 30s and 40s. Furthermore, changes in treatment and medications over the last decade have improved the quality of sufferers' medical conditions, delaying the onset of physical symptoms and reducing the incidence of hospitalisation (Dushenko, 1981). This in turn has enabled individuals with CF to live relatively "normal" lives. Thus, not only are many now reaching adulthood, they are also joining the workforce, and some are even having families of their own. As a result of these developments, there has been a change in focus from living with the very real threat of death in childhood, to managing a chronic condition (Levers & Drotar, 1996). In this light, it is important to help the parents of these children grieve their loss and accept this diagnosis so that they can in turn recover, reorganise and move on to enjoy the time they have with their child.

Although the life expectancy of individuals with CF is good today, mothers and fathers live knowing that eventually they will lose their child, as the illness is terminal, and the life expectancy limited. With this in mind, the grief experienced by the parents of CF children will likely vary over the course of the illness. The reason I wish to examine the initial stages of the grieving process of these parents is because I believe the manner in which they begin grieving will likely affect the course of any subsequent changes in grieving as the disease progresses.

My overall aim in this research is to find out what the grief process looks like in parents whose child has been diagnosed with a life-threatening chronic-illness and to discover how this grief is influenced by an individual's perceptions and coping strategies. I also wish to investigate any gender differences that occur by asking the questions: Do men and women differ in the grief they experience, in the impact they feel the chronic-illness has on their lives, and the coping

strategies they use? Lastly, I am interested in finding out whether the grief experienced at the time of diagnosis relates to the current distress mothers and fathers feel when thinking back to that time.

Advances in medicine and the ability to keep sick babies alive have meant that today there are an increasing number of children living with chronic-illnesses (Worthington, 1989). Looking at the grief experience of the parents of these children is important, because effective care of the child relies on their effective parenting (Hauenstein, 1990). Helping parents recognise their loss not only enables them to be there for their child, it also helps them to better understand their pain, move through their grief and get back up on their feet. Furthermore, in assessing the impact coping and perceptions have on grieving, and the gender differences that occur in grieving, it is hoped that the understanding of individual reactions to loss and the process of grief will be furthered.

Implications for this research arise in the area of counselling that aims to help couples strengthen their relationship with each other by shedding understanding as to what each individual is feeling. As family is one of our most valuable resources, strengthening this bond is important (McCubbin & Figley, 1983). It is thought that this research will be able to identify areas in which one can better assist individuals as they cope with the news that their child has a life-threatening chronic-illness. Furthermore, in bringing this loss to the attention of parents, doctors and nursing staff alike, it is hoped that one will be able to prevent another tragedy happening like that that occurred in Nelson in 2004, where a father in his grief killed his five month old daughter who had just been diagnosed with lissencephaly, a rare condition that had caused her brain to stop developing at the age of a 13 week-old foetus.

2. Literature Review

2.1 Major Theories on Grief

The notion that men and women grieve losses other than death was mentioned as early as 1917 in a paper by Freud entitled 'Mourning and Melancholia.' In this paper Freud wrote that grief follows upon every loss, whether it be the death of a loved one, a material possession, or an ideal such as a particular philosophy, religious conviction or patriotic dream (Saunders, 1989).

It is important to mention Freud's writing from the outset when talking about theories of grief as it contains a number of important features that have influenced later descriptions and assumptions about the nature of this subject (Archer, 1999). Freud believed the one thing certain regarding grief was that the individual was affected by the experience. On saying this he noted that the symptoms of grief vary among individuals and that the outcomes of grief could be either positive or negative (Saunders, 1989).

Freud viewed grief as an active process. One that involved a struggle to give up the emotional attachment one has to an object (Archer, 1999). Initially it was thought that recovery from bereavement was achieved when one reached a final detachment. After the death of his daughter, however, Freud acknowledged that "although we know that after such a loss the acute state of mourning will subside, we also know we shall remain inconsolable and will never find a substitute. No matter what may fill the gap, even if it be filled completely, it never the less remains something else" (written in a letter to Bainswagner 1929, cited in Rubin & Malkinson, 2001, p.233).

Although Freud wrote about grief and loss in 1917, it was not until the 1940s that the empirical study of grief and its consequences gained momentum (Stroebe, Hansson, Stroebe, & Schut, 2001). One of the earliest and most well known studies of grief conducted at this time was Lindemann's 1944 'Symptomatology and Management of Acute Grief.' In this study Lindemann (1944) evaluated the anecdotal accounts of acute grief reactions in relatives of individuals lost in

Boston's Coconut Grove nightclub fire, as well as relatives of individuals killed in World War II and patients who had experienced the death of a relative. In line with Freud's earlier writing, Lindemann (1944) worked from a psychoanalytic point of view. Like Freud (1917) he too described grieving as an active process. The term coined to refer to this process was 'grief work'. A name which reflected the fact grieving took time and energy, and involved a number of tasks that need to be completed. These tasks were thought to be: dealing with the pain of grief, releasing and readjusting to the world without the lost object, and forming a new identity with new relationships and roles (Saunders, 1989).

From his observations Lindemann concluded that grief consisted of a syndrome of five components: somatic distress, preoccupation with image of deceased, guilt, hostility and disorganised behaviour (Cleiren, 1993). Not stopping at this, Lindemann went on to describe the grief experience in more detail. Reporting, for example, the physical symptoms one may feel such as tightness in the throat, or an empty feeling in the abdomen. He also noted a desire to withdraw from others, a tendency towards heightened irritability and anger, and an intense subjective distress (Saunders, 1989). Lastly, he noted that many attempt to avoid the pain connected with grief by a flight into activity that helped one to keep their mind off what had happened. Today Lindemann's writing is still considered accurate, and one of the best accounts of the grief syndrome. It has had a strong influence on subsequent research and led to the first studies looking at grief for other losses (Archer, 1999). There is, however, one thing letting down Lindemann's 1944 study. This is the absence of qualitative data to show the frequency and intensity of symptoms (Saunders, Mauger & Strong, 1975).

Glick, Weiss and Parkes' 1974 study of widows and widowers in Boston overcame these problems by using a structured interview technique that allowed for the quantification of results, and thus produced more reliable and objective data than had been obtained before. Adding to this they also made use of a control group with which to compare their findings. This group was matched case for case with bereaved participants. Developments such as these were important,

because as methodological sophistication increased, a multi-dimensional picture of bereavement emerged (Saunders et al., 1975).

Parkes (1970, cited in Lendrum & Syme, 1992) went on to outline four stages of grief: numbness involving shock and disbelief, yearning and searching, disorganisation and despair, and reorganisation. These stages were based on the work of Bowlby (1980) who noted three phases small children move through when separated from their mothers: protest, despair and detachment (Parkes, Relf & Couldrick, 1996). Parkes modified these stages to apply to bereavement in adult life.

As well as his stage model, Parkes' (1972) work is often noted for what he called 'pangs of grief.' These pangs refer to episodes of relentless anger, severe anxiety, and psychological pain brought on by reminders of the loss. Relating this back to the work of Bowlby (1980), these pangs are thought to resemble the separation anxiety experienced by young children when their mothers are absent (Saunders, 1989). In the case of parents of chronically-ill children, it is likely such pangs are experienced each time the child's health declines or a developmental milestone is not met. Furthermore, in terms of recovering from bereavement, Parkes stressed the importance of cognitive restructuring. A process which involved bringing the pain of loss to consciousness and expressing the feelings connected with it. This was thought to be important with suppression of this pain believed to only prolong the grief process (Cleiren, 1993).

The last chapter in Parkes' 1972 book is titled "Reactions to other types of loss." In this chapter Parkes (1972) looked at how grief at death resembled reactions to other types of loss. In doing so he referred to a group of 46 amputees interviewed at one and thirteen months post loss. Parkes (1972) noted that on face of it, the loss these individuals suffered did not bear much resemblance to the loss of a loved one. For example, you don't love your leg in same way, and society does not expect you to mourn such a loss. Despite this, however, he noted that those who studied the psychological reactions to such a loss repeatedly mentioned the grief individuals experienced, with the same components of grief present. Similar findings were reported by Fried (1962, cited in Parkes, 1972) who studied Boston slum dwellers grieving for the loss of their

homes after they were forced to move. These individuals were interviewed before the move and again two years later. In concluding his study Fried wrote:

While there are wide variations in the success of post relocation adjustment and considerable variability in the depth and quality of the loss experience, it seems quite precise to refer to the reactions of the majority as grief. These are manifest in the feelings of painful loss, the continued longing, the general depressive tone, frequent symptoms of psychological or somatic distress, the active work in adapting to the required altered situation, the sense of helplessness, the occasional expressions of both direct and displaced anger, and tendencies to idealize the lost place. (1962, p.190, cited in Parkes, 1972)

Elizabeth Kübler-Ross and her work with terminally ill patients brought attention to the field of death and dying. In her early work Kübler-Ross (1969) outlined what she considered to be the five stages a dying patient passed through before their death. During a period of volunteer work at Chicago's Light House for the blind, however, Kübler-Ross (1997), like Parkes (1972), came to realise that her stages could also be applied to the way men and women deal with other types of loss. This conclusion was reached through observations in which she noted that many of the parents of children who were blind went through the same reactions as her dying patients. That is, they experienced shock and denial, anger and rage, grief and pain. They bargained with God, questioned "why me?" and withdrew into themselves for a while. In terms of the loss they were grieving Kübler-Ross wrote "they associated the birth of a blind child with loss - the loss of the normal and healthy child they expected..." (1997, p.162). In terms of recovering from bereavement Kübler-Ross (1997) believed that if an individual was allowed to get his/her feelings out by expressing their anger, crying, grieving, articulating their fears and working through her stages, they would reach acceptance. It should be noted that acceptance here did not mean that an individual was happy with the situation, nor that they would no longer experience and feel various emotions, but that some resolution had taken place, and that they were no longer angry or depressed (Kübler-Ross, 1997). In all, Kübler-Ross (1997) believed that those who were able to express themselves and reach acceptance would find they are better able to manage their lives, while those unable to externalise their feelings, frustrations, and guilts would remain in them.

Horowitz (1990) focused less on the symptoms of grief, and more its inner workings. In line with Bowlby (1980) and Parkes (1988), Horowitz believed that a large part of grief work

involved the revision of inner models, schemas, and assumptions held about the world that had become redundant after a major change (1990, cited in Bruce et al., 1996). The idea here was that every individual has a model in their mind that they have created of how the world should be. When men and women encounter a situation that does not fit this model they are motivated to process this information until change occurs either in the situation itself or in their inner schemas. This drive is called completion tendency, and continues until the new reality and one's inner models of reality reach accord (Bruce et al., 1996). For parents of a child with a chronic-illness this task is constant, and lies at the heart of a continual source of grief as it requires them to rework their expectations of what might have been throughout the life course of their child (Bruce et al., 1996). Theorists have suggested that it is these inevitable discrepancies between reality and prior models of the world that explain much of the pain accompanying the grieving process (Horowitz, 1990, cited in Bruce, Schultz, Smyrniotis, & Schultz, 1994). These discrepancies are difficult to escape with expectations of normal development firmly entrenched in one's mind. In regards to CF, for example, one thing parents have to adjust to is the realization that they will most likely outlive their child. This fact is challenging in that it is contrary to what one would consider the natural order of things, with children thought to represent and carry on the future of the family line. Furthermore, it is also a fact that cannot be forgotten, with parents reminded of this particular discrepancy each time their child falls ill.

If men and women cannot change the stressor, they need to relinquish their firmly held assumptions so that they can then form new assumptions that accord with reality (Davis & Schultz, 1998). Intrusion and avoidance play a large role in forming new world models, with there being a give and take relationship between cognitively processing aspects of a loss and controlling amounts of distressing information. As an individual thinks about a particular loss its enormity is gradually unveiled. Whenever the awareness of a loss begins to overwhelm the individual avoidance is activated to regulate the flow of information, and dampen distressing information (Davis & Schultz, 1998). It should be noted, however, that if avoidant processes dominate the experience of grief, the necessary processing of loss is prevented and schema

incongruent with external reality will continue to influence an individuals' thinking, emotions and behaviour (Davis & Schultz, 1998).

When the processing of information results in adequate revision of the inner models, intrusive and avoidant mental processes reduce and emotions related to these processes abate. As this is the case, the presence of these two variables indicates that the individual is still in the process actively dealing with the loss (Davis & Schultz, 1998).

Lastly, it should be noted that not all theories of loss organise the experience of grief into stages. Stroebe and Schut (1995, 1999, cited in Riches, 2002), for example, put forward the idea of what they called a Dual-Process Model. This model involves two states. The first of these is a 'loss-oriented' focus, in which the individuals focus is on the loss. The second is a 'restoration-oriented' focus, in which their attention is on restoring life. It is believed that individuals suffering a loss oscillate between these two states. Sometimes their focus is on the loss, while other times it is on getting on with life. It is thought that it is the social context, and the nature of the loss that determine whether an individual primarily swings toward one or the other. It is also thought that one's social role determines where they spend more time. That is, if your identity is based around being the primary carer, your style of coping is likely to be more loss-oriented. On the other hand, if work is a major part of your identity it is likely that your style of coping will be more restoration-oriented. As this is the case it will therefore be likely that the coping style of women is more loss-oriented while for men it is more restoration-oriented. Both orientations, however, are important and should be used, with exclusive use of one leading to complicated unresolved grief.

2.2 Controversies Concerning Theories of Grief

Amongst the many theories of grief noted above there are some areas that are debated, with different researchers holding differing points of view. Noting these contrasting views, and keeping them in mind is important in that it not only increases one's understanding of grief, but it also reminds one just how complex the grief experience is.

2.2.1 Grief work

For most of the 20th century many researchers assumed that grief work was central to the resolution of grief. That is, the notion men and women have to confront their grief in order to come to terms with the loss and avoid its negative consequences. This belief originated from psychoanalytic theory in which theorists such as Freud implied that grieving was a job individuals neglected at their peril (Parkes, 2001). Similarly, Cobb and Lindemann (1943, cited in Archer, 1999) commented that “it seems the grieving person can delay his grieving for a period but not avoid it” (p. 819). In recent years, however, this assumption has been under scrutiny. There are a number of reasons for this, the most important being that it is difficult to define exactly what grief work is and what it involves (Archer, 1999). For example, Stroebe (1992, cited in Stroebe & Schut, 2001) noted the definition lacks clarity in that it does not differentiate between negatively associated rumination and more positively associated aspects of working through the loss. Furthermore, actively confronting a loss does not always predict a more effective resolution, with there being some cultures where there is apparent adaptation without the confrontation of working through grief (Stroebe, 1992, cited in Stroebe & Schut, 2001).

In all, these mixed findings would suggest there are alternative routes to recovery from grief (Archer, 1999). With this in mind, however, the notion of grief work should not be discarded, as it remains a powerful tool for understanding the way people adapt, and captures a large part of the essence of coming to terms with loss (Stroebe & Schut, 2001).

2.2.2 Resolution

Controversy also surrounds questions about resolution. From a Darwinian perspective, grief is resolved when there is a return to normal functioning in everyday tasks, distress and intrusive thoughts are absent, and one has mentally accommodated to the changed reality. In research such resolution is generally measured by the absence of distress and or depression (Archer, 1999). Loss, however, is something men and women adapt to rather than get over. Thus, although some refer to resolution in terms of recovery, it is more accurate to say adjustment. This is because

recovery implies that an individual returns to where they were before the loss, whereas adjustment acknowledges that things can never be the same (Archer, 1999). The importance of this distinction is clearly noted when one is looking at the loss experienced by parents of children with CF. As the illness is not going to go away, life for these parents can never return to how it was before the diagnosis. In recovering, therefore, what these parents do is adapt to their new reality.

2.2.3 Stages

The view that grief consists of a series of stages is important in that it attempts to capture the dynamic nature of grief and organise it in a way that acknowledges things are not independent but linked. This aside, however, questions have arisen as to whether or not a stage view best describes the process of grief. Problems with this view include the fact that it does not address the principle of what may be underlying the reactions to different stages. Evidence also now indicates that stages overlap considerably with one another, and that the time courses of specific reactions differ. Furthermore, some argue that a stage view is misleading with individual differences and changing contexts meaning that grief does not fall into a simple pattern. Instead, they believe evidence is more compatible with the idea that grief consists of several intermingling reactions, which although broadly changing over time do not show a smooth progression (Archer, 1999).

Although the current study is focusing on grief experienced by parents in the year following their child's diagnosis, it should be noted that in regards to the bigger picture it is debated as to whether a stage view of grief best describes the grief experienced by parents of chronically-ill children. It has already been noted that grief in parents of chronically-ill children is thought to be ongoing (Olshansky, 1962). With this in mind, Worthington (1994) argued that a linear/stage view (such as that proposed by Kübler-Ross) in which grief moves from a start point to an end point does not fit. Rather, in this situation Worthington (1989, 1994) believed that a more cyclical view, in which the different elements of grief move in continuous circles, would be more appropriate. The reason for this is that this view supports the idea that there is no end to

grieving, and allows for the fact that one will experience periods of stability and instability in which they fluctuate between being in control, feeling depressed, and feeling angry. In all, further research looking into this area is needed, with the question of which model best fits this situation still needing to be answered.

2.2.4 Categorising individuals

One needs to be careful in categorising and judging people according to their grief reactions alone. An example of why this is the case was illustrated in a study by Singh and Raphael (1981) that looked at the relatives of individuals killed in a rail disaster in Australia. In conducting their study Singh and Raphael (1981) noted that some of the bereaved relatives were difficult to categorise due to the fact that they had either not appeared to go through the stages of grief, had inhibited or suppressed grief, or had got involved with a new partner clearly as replacement for the old. While it was thought that these individuals may later suffer the consequences of not having resolved their grief, eighteen months after the disaster no sign of this was present, with all individuals doing well. Alternatively, Singh and Raphael (1981) suggested it may be that there are certain men and women who may not grieve in a way one might expect or consider adequate and yet suffer no adverse consequences for doing so. In practice, differences such as these need to be respected, with there being a danger that complications will arise if an individual is made to feel that he/she is grieving in the wrong way.

2.3 Summary on Views of Grief

In all, there are many different theories on grief, all of which have implications for how grief should be approached and considered. Amongst these theories run several common threads. One of these being that theories typically stress the challenges individuals face when bereaved and the tasks they must address in grieving (Attig, 1996). Most commonly mentioned is that individuals must accept the reality of their loss, and work through the pain of grief.

Another is that grief is a multi-dimensional phenomenon, involving more than just sadness and depression. In this light, it is thought that grief consists of a series of distinct periods that can be identified and described by particular features. Although, there is some variation in what these are, those typically mentioned are shock and disbelief, followed by somatic distress and acceptance where one sees a reduction in the intensity of emotion, and a reestablishment of social contacts (Attig, 1996). In terms of these different stages, Parkes and Kübler-Ross note they are not fixed and may overlap. Thus, an individual does not necessarily move in an orderly progression from Stage 1 to 5. Rather they can move back and forth, they may experience more than one stage at a time, and they may miss a particular stage all together (Attig, 1996; Berk, 2001). Supporting this, Peppers and Knapp (1980, cited in Toedter et al. 1988) noted there are various routes one may take when grieving. This in turn means that although individuals may ultimately have the same grief scores, the way they reached these scores may be very different.

A third common thread is the acknowledgement that everyone grieves differently. It could be expected that everyone grieves the same, especially if they have suffered the same loss. This, however, is not the case, with there being a great amount of individual variation when it comes to grieving. As individuals, men and women place different levels of importance on different losses. The loss of a pet, for example, may mean more to one individual than another. Men and women are also influenced by different social and cultural norms that dictate different ways of dealing with death. This realisation highlights the importance of context. Although the theories and their stages are valuable, they tend to remove individuals thoughts and feelings from the context that grants them meaning (Berk, 2001). Grief researchers need to keep this in mind, in order to ensure that they do take context into account.

In all, noting these different theories about the grief process is important in that it creates a greater understanding as to the sorts of feelings parents of chronically-ill children experience, and in turn assists in providing a solid foundation and guidance for further research in this area.

2.4 Evidence of Grief in Parents of Chronically-ill Children

It is generally accepted that the death of a child (regardless of age) is the most devastating of all bereavements, and one of the most difficult losses an individual will experience (Cleiren, 1993; Sprang & McNeil, 1995). The reason for this is that children are seen as an extension of their parent and as such represent the future of their family line (Sprang & McNeil, 1995). In this light, it follows that the birth of a chronically-ill child may result in a similarly strong feeling of grief for parents. This grief originates from the loss of the 'healthy' child expected. It is then added to by the grief that accompanies the realisation of the constant care the child requires, and the impact that the illness will have on normal family functioning. Lastly it is fuelled by the uncertainty surrounding their child's quality of life and life expectancy (Worthington, 1989).

2.4.1 Parents of children with cystic fibrosis

Children with cystic fibrosis do not appear physically different from other children, nor do they suffer any serious developmental delays. For these reasons it is thought that it may be difficult for parents to grieve this diagnosis, as from the outside their children appear to be healthy. Studies, however, reveal that these parents do in fact experience grief.

Bluebond-Langer (1996) noted that one of the biggest issues parents have to deal with when their child is diagnosed with CF is the prognosis. After interviewing many parents she wrote that for much of the first year parents see their child as dying. One parent, for example, commented "I think about it, the dying, all the time" (p. 147). Another mentioned that it took her about a year to get over, while it took her husband only a couple of months. It was on this parent's mind constantly. She felt numb, questioned why this had happened, why she had not known about it, and worried about the medication she was required to give her child. In summing up she noted that it was not until she saw her child up and walking, that she began to feel better (Bluebond-Langer, 1996). As a result of feelings such as these Bluebond-Langer (1996) noted that in the first year parents are reluctant to get too attached to their child.

In further accounts of first hand experiences one mother commented that when told of the diagnosis she found it very difficult to think of her child as having anything approximating normal life. She also noted that instead of rejoicing with her new baby at home she had to cope with the reality of a serious illness, and the fear of what it held not only for the child but for whole family (Jones et al., 1998a). In this a sense of disbelief was also acknowledged, especially if one had already had a healthy child.

Early accounts of children with CF and their families tended to report they experienced significant (sometimes psychopathological) degrees of depression, anxiety, and family disruption. For example, Lawler, Nakielny, and Wright (1966, cited in Dushenko, 1981) reported emotional distress and clinical depression in eight out of eleven mothers of CF children interviewed. Although this study had methodological problems it is interesting to note its conclusion that most parents of children with CF could be classified as psychiatrically ill.

More recent research, which has employed greater methodological control, tends to find that parents do not experience significantly greater amounts of psychological distress, evidence more problem behaviours or manifest more family dysfunction as compared to families who do not have a child who is chronically-ill. Levers and Drotar (1996), for example, reviewed 31 articles that described the functioning of both families and parents of children with CF. In doing so they noted that parents of children with CF experienced greater stress and burdens than parents of healthy children. The most common concerns parents had were the difficulty of the treatment regime, the terminal nature of the illness and the disruption of intra-family relationships. Despite this stress, however, they concluded that parenting behaviour and family functioning (cohesion and adaptability) were similar in both CF and healthy control groups (Lewis & Khaw 1982, cited in Levers & Drotar, 1996).

Jedlicka-Köhler, Götz and Eichler (1996) aimed to study the emotional and cognitive reaction of parents to the diagnosis of cystic fibrosis in their child. They found that the most frequent stressing feelings parents felt when informed of their child's diagnosis were fear and

despair. Disappointment, guilt, resignation, and anger were also reported but to a lesser degree. Furthermore, when asked, just over half reported they experienced an initial shock-like reaction.

In their study Jedlicka-Köhler et al., (1996) went on to look at the impact such emotions have on information recall. Interestingly, they found a significant decrease in understanding and recall of information in those individuals who had a greater emotional response. Similarly parents who had reported an initial reaction of shock were found to have understood less and retained less than those who had not. Doctors may assume that after an extensive discussion with a specialist parents will have a clear understanding of CF, as they have been able to ask questions and talk at length with someone who knows a great deal about their child's illness. These last results, however, highlight the negative effect emotional distress has on optimal learning. As impairment of this sort is unavoidable in this situation Jedlicka-Köhler et al. (1996) suggested that repeated interviews and written material should be mandatory. Furthermore, doctors should also be aware that while parents have the opportunity to ask questions when being informed of their child's diagnosis, they may not know what questions to ask.

According to Jedlicka-Köhler et al. (1996) the most threatening information perceived by parents was the news of a shortened life expectancy and incurability of the condition. In regards to their emotional and behavioural responses during the days after the diagnosis, 87% talked with friends and relatives about disease, while 78% had desire to talk with the physician again because of upcoming questions. Finally, they concluded by noting that although valid statistical analysis was not possible it did seem that the intense emotional reactions parents had experienced during the informing interviews lessened during the days following the diagnosis.

In a similar study looking at mothers and fathers of infants and toddlers recently diagnosed with CF, Quittner et al. (1992) reported that compared to a normative sample of non-CF parents, CF parents experienced higher levels of both situation specific and global measures of parenting stress, strains in the performance of family roles, and elevated levels of depression. Within this gender differences were noted with mothers experiencing significantly greater strain in managing their caregiving role and higher levels of depression than fathers. For mothers there

was a strong association between role strain related to CF and depression, while for fathers stressors related specifically to parenting child with CF were strongly related to depression (Quittner et al., 1992).

Lastly, in relation to CF, Berslau (1982, cited in Nagy & Ungerer, 1990) noted that it is a consistent finding that mothers of CF children suffer more psychological distress than mothers of healthy children. Furthermore, Dushenko (1981) noted that parents usually adopt a predictable sequential pattern in coping with the situation. Starting with fear and anxiety, progressing through disbelief to anger and hostility, and, if counselling is successful, end with acceptance of the disease and its uncertain course. It is interesting to note this pattern as it appears very similar to the process of grief outlined in the theories cited above.

2.4.2 Parents of children with other chronic-illnesses and disabilities

Evidence of grief reactions have also been identified in parents of children diagnosed with other chronic-illnesses and disabilities. Research in this area has tended to focus on children with either an intellectual disability or schizophrenia.

Studies by Bruce et al. (1994) and Bruce et al. (1996) confirmed the presence of grief in parents of children with an intellectual disability. In 1994 Bruce and her colleagues used a single point design, while for her 1996 study she interviewed parents annually over a three year period. Both studies yielded similar results, supporting the proposition that children with an intellectual disability represent a source of loss and grief for parents that is ongoing (Bruce et al., 1996).

Similarly Davis and Schultz (1998) aimed to validate the presence of grief in parents of children with schizophrenia. Although schizophrenia differs from cystic fibrosis and intellectual disability by not being diagnosed soon after birth, it is still of interest, as its diagnosis represents the loss of an ideal. Davis and Schultz (1998) believed that underlying parenting such a child is a pervasive theme of loss and grief. This grief starts with the onset of the disease when parents lose the child they once knew, and continues as they grieve the hopes and dreams they had for their child. Their study supported these beliefs, finding that parents were grieving their child's illness.

Further supporting the notion of grief, Melnyk et al. (2001) noted that parents' responses to the diagnosis of their child's chronic-illness commonly included shock, disbelief, denial, and anger. Additional responses included despair, depression, frustration, confusion, feelings of guilt, decreased self-worth, and a lack of confidence. All of these responses have been identified as characteristics of grief.

In all, the studies cited above in relation to parents of children with CF and other chronic-illnesses are important in that they suggest parents are grieving for the loss they have experienced. The importance of studying this loss and the grief experienced is in turn realised when one becomes aware of just how long lasting this grief can be. Bright (1986) highlighted just this when he noted that elderly patients arriving in hospitals and nursing homes were still grieving the fact they had given birth to a disabled child some 50 years earlier. Although this grief had likely been reactivated by the fact these individuals were no longer able to care for their disabled children, Bright (1986) observed that the memory of the shock they felt when told of their child's diagnosis was never lost.

Possible Factors Impacting on Grief in Parents of Chronically-ill Children

Although there is considerable evidence that parents of chronically-ill children experience grief, the literature also indicates that not everyone experiences grief in the same way. Therefore, in order to answer questions such as 'why do some individuals manage better than others?' it becomes important to look at the factors that impact upon one's grief experience and contribute to individual difference. There is considerable agreement that certain moderator variables such as age, socioeconomic status, and religion may have an effect on bereavement outcome (Saunders, 1989). Three such factors looked at in the present study are gender differences, perceptions, and coping. I have decided to look at gender due to the fact that there is a need for more studies to look at and compare the grief experience of both mothers and fathers. Perceptions and coping on the other hand were selected as not only are they factors that appear to impact grief, but they are also factors that appear amenable to intervention.

2.6 Gender Differences in Parental Grieving

It is conceivable that the distress caused by loss will vary according to the gender of an individual (Jacobs, Kasl, Ostfeld, Berkman, & Charpentier, 1986). Most studies investigating gender differences have tended to look at widows and widowers. More recently, however, gender differences in parents who have lost a child, or have a child who is chronically-ill have become a focus. Both sorts of studies confirm the existence of gender differences in grieving (Davis & Schultz, 1998).

The focus of the present study is on grief felt at the time of diagnosis and the year following. Few studies looking at gender differences in relation to grief have focused on this particular period, with most deciding instead to focus solely on mothers. Because of this, research referring to the experience of parents of chronically-ill children in general (not just at the time of diagnosis), and studies looking at parents who have lost their children, will be mentioned.

Studies investigating mothers and fathers responses to their child's illness generally conclude that women respond more emotionally, grieve more openly and intensely and experience greater levels of sadness, anger, depression and guilt (Hunfeld et al., 1996). Men on the other hand are thought to be less emotional in their responses, to grieve in a more stoic manner and to be less affected by the experience (Mastroyannopoulou, Stallard, Lewis & Lenton, 1997; Davis & Schultz, 1998; Stinson et al., 1992). Men generally tally lower grief scores than women following the death of a child (Benfield, Lieb & Vollman, 1978, cited in Dyregrov & Matthiesen, 1987) and report fewer symptoms of depression (Wilson, Fenton, Stevens & Soule, 1982, cited in Dyregrov & Matthiesen, 1987). Furthermore, it is suggested that they have a shorter grief period, with men desiring to move on with their lives while their partners remain depressed (Clyman, Green, Rowe, Mikkelsen, & Ataide, 1980, cited in Dyregrov & Matthiesen, 1987).

A study by Benfield (1976) looked at 101 couples whose critically ill newborns survived after referral to neonatal unit for intensive care. These parents were found to experience similar grief reactions to couples who infants did not survive. More specifically, the grief scores of

mothers were significantly higher than those of fathers, with mothers reporting greater levels of guilt, anger, feelings of sadness and a loss of appetite. They also were more likely to admit to feelings of disbelief, praying, depression and crying. No differences were found in terms of irritability, preoccupation, difficulty sleeping and wanting to be left alone. In concluding Benfield (1976) noted that these results may be an underestimation of the actual grief experience, as when participants filled in their questionnaires they were nearly home and therefore knew that their child was going to be alright.

In a study by Hunfeld et al. (1996) 13 couples who had lost an infant due to a major congenital anomaly were assessed six months after their loss on the prenatal grief scale. Contrary to previous findings of less intense grief in men, the couples in this study did not differ significantly in regards to the overall intensity of their grief scores. When looking at the pattern of association between the scores of mothers and fathers, however, no strong relationship was found. Hunfeld et al. (1996) thus concluded that although the intensity of their grief was the same, how mothers and fathers grieved was different. Although Hunfeld et al.'s (1996) small sample size prevents one from drawing conclusions here, it is interesting to note these results because they suggest that while grief may be experienced in different ways by mothers and fathers, its overall intensity can be felt the same.

Contrary to the literature and what was expected, Davis and Schultz' (1998) study that looked at parents of children with schizophrenia found no gender differences in grieving, suggesting that fathers were not any less affected by the loss, and grieved similar to mothers. Using the same measure, however, Bruce et al. (1994) and Bruce et al. (1996) found mothers experienced a more intense grief reaction to their child's intellectual disability, scoring higher than fathers on measures of intrusive thoughts, active efforts to avoid distress, and emotional distress related to recall of time of diagnosis. Although the persistence of these differences has not been established, Bruce et al. (1996) found they remained over the studies three year period and occurred irrespective of the similarities between mothers and fathers in both the intensity of

wishing for what might have been for their child and the reduction of this tendency over time (Bruce et al., 1996).

A study by Beutel, Willner, Deckardt, Von Rad, and Wiener (1996) looked at couples shortly after miscarriage and 6 and 12 months later. This group makes an interesting comparison with parents of children who are chronically-ill with a major source of their grieving coming from the fact that they have to give up the expectation, hopes, and fantasies they held for their unborn child. Fathers in this study were found to grieve less enduringly and intensely than mothers. More specifically, men did not react with an increased depressive reaction. They cried less, felt less need to talk about their loss, and scored lower on measures of bodily complaints, anxiety, and sadness. Furthermore, two thirds reported they tried to distract themselves by burying themselves in their work. This was especially true for men who felt concerned and burdened by the grief their partners experienced. Lastly, men were reluctant to seek help. If they did so, it was for their partners sake, or as a couple (Beutel et al., 1996).

A study by Dyregrov and Matthiesen (1987) reported on the grief reactions of 55 couples who had lost an infant to neonatal death, stillbirth and sudden infant death syndrome (SIDS) one to four years prior. It was found that mothers scored higher than fathers on scales looking at general wellbeing, depression, anxiety, intrusive thoughts, and bodily symptoms. In terms of specifics, Dyregrov and Matthiesen (1987) reported significant differences with women experiencing more anxiety, self-blame, sadness, intrusive thoughts and sleep difficulties. No significant differences were found in the amount of amount anger, restlessness and work involvement. Lastly mothers felt they had recovered less from the loss and had more lasting emotional and body problems, thus confirming the idea mothers experience more intense and longer lasting grief reactions. Furthermore, it was noted that there was a relationship between couples with a high score in one spouse correlating with a high score in the other and vice versa. This is interesting as it suggests there may be some relationship between couples in regards to the grief they experience.

In coming to such conclusions one needs to be careful not to be too rigid, keeping in mind that the differences that occur within genders are larger than the differences that occur between genders. As an example of this, Kennel, Slyter & Klaus (1970, cited in Dyregrov & Matthiesen, 1987) reported that while two denied having grieved, several fathers appeared to grieve as long as or longer than their partners. This was particularly true for men involved in transportation and care of their baby to the hospital centre.

2.7 Possible Reasons for Gender Differences in Parental Grieving

Having established that gender differences do occur in grieving, attention will now be turned towards the causes of these differences.

2.7.1 Bias in tests

It should be noted that there is a suggestion the gender differences found in grieving are due to a well-established bias in grief inventories. This bias being that the female grief reaction has been treated as the yard stick against which the male response has been compared. As a result, in comparing men to a female standard of grief, the male grief response is thought to have been inadequately measured, leaving gender differences far from clear. In the past it has been assumed that because they express less emotional distress than females men are either less affected or not affected at all. Just because females are more expressive, however, does not mean they feel more grief (Davis & Schultz, 1998; Stinson et al., 1992). Researchers today are aware of this bias and have taken it into account in their inventories. Importantly, the new instruments developed with this in mind continue to find gender differences in grieving.

2.7.2 Social expectations

Social norms and cultural expectations have a powerful influence on how individuals react to loss. These expectations differ for men and women, and therefore, are likely to play a significant role in explaining differences in grieving.

It is generally accepted that women are more emotional than men. As a result they are given permission to cry and openly express their feelings (Stinson et al., 1992) which in turn encourages them to be more communicative about their loss (Staudacher, 1991). Social norms for men on the other hand emphasise the importance of appearing competent, independent, in control and unemotional (Jacobs et al., 1986). Unlike women, men rarely discuss personal matters. Doing so may be taken as a sign of weakness, leaving them vulnerable to others (Fasteau 1974, cited in Stinson et al., 1992). Men are expected to be the strong one in a relationship, and as such often cast themselves in the role of the protector (Peppers & Knapp 1980, cited in Stinson et al., 1992). In this role men are expected to hold the fort, keep their emotions in check and deal with various decisions and arrangements at a time when their partner is likely to be physically and emotionally incapacitated (Stinson et al., 1992; Staudacher, 1987). Thus, while men do grieve, cultural norms that advocate male inexpressiveness and responsibility cause them to deny their grief and internalise their feelings of loss (Stinson et al., 1992). For example, McKeever (1981, cited in Hauenstein, 1990) found that fathers reported extreme distress when learning their child was ill, but were reluctant to express this because they perceived their pressing role to be that of supporting their partners.

2.7.3 Gender roles

Differences in gender roles may also account for contrasting differences in mothers' and fathers' experiences of grief. Firstly, mothers tend to be the primary caregivers, and take on most of the responsibility for their child's medical care. Supporting this, Quittner et al. (1992) noted an unequal divide of caretaking responsibility with mothers of children with CF indicating that their spouses rarely assisted with medical routines, were frequently absent in the evenings and were not very helpful in managing the child's illness (Quittner et al., 1992).

Secondly, fathers tend to be the primary breadwinner. In Quittner et al's (1992) study 100 percent of fathers, compared to only thirty percent of mothers, worked outside the home. This is important because several studies indicate that women who occupy multiple roles report greater

emotional and physical well-being than those who occupy fewer roles. Consistent with this, mothers in Quittner et al's (1992) study who were employed outside the home showed significantly lower levels of role strain and depression than those who were unemployed. The reason employment is thought to have this effect is that it offers stimulation, self-esteem and relief from caretaking responsibilities.

Despite changes in labour force participation and gender roles children are still a more central component of women's roles than men's (Stinson et al., 1992). This in turn impacts upon expectations when a loss involves a child, with the belief that because children are more central emotionally and physically to the mother, the mother is more affected (Stinson et al., 1992). Gender roles, however, may address this imbalance with Rando (1995, cited in Berk, 2001) noting that because they express their feelings, seek social support more readily and are more willing to ask for help, women are better prepared to deal with grief.

2.7.4 Attachment

Differences in attachment to the child at birth may lead to differences in grieving. The idea here is that as mothers carry the baby they develop an early bond with their child, while attachment for fathers comes later, after the birth (Theut, Pedersen, Zaslow, Cain, Rabinovich & Morihisa, 1989; Peppers & Knapp 1980, cited in Stinson et al., 1992). It is therefore thought that loss that comes soon after birth will be felt more strongly by mothers. Later on, however, when the investment is more even differences between couples in the loss experienced will be smaller (Archer, 1999). In support of this notion Fish (1986, cited in Saunders, 1989) found that for younger children fathers grieved less than mothers. When the child was older mothers continued to report higher levels of grief, but the disparity grew smaller.

2.7.5 Time spent with child

Bruce et al. (1996) suggested that the amount of time spent with one's disabled child may influence grieving. This is thought to be due to the fact that as mothers are more involved in their

child's direct care, they are confronted more regularly with reminders of their loss, while fathers are more likely to be at work and therefore shielded from emotionally distressing triggers and have less time for ruminating on them (Bruce et al., 1996). Work thus, may represent a welcome escape for fathers. Supporting this, Cook (1988, cited in Bruce et al., 1996) noted that fathers repeatedly mentioned work as a place where they could forget about their child and his/her illness. Although men may be shielded from distressing triggers Bruce et al. (1996) suggested such shielding may be harmful in that it restricts the opportunity for fathers to work through their feelings. As evidence of this they noted that in contrast to mothers, fathers' distress related to recalling the time they were told of their child's diagnosis did not reduce over time. Further research to confirm such thinking is needed, with Davis and Schultz (1998) concluding that with the exception of intrusive thoughts, the number of hours one spent with their child was not an intervening variable for mothers and fathers grieving the diagnosis of schizophrenia.

In all, the literature on grieving that is cited above is important to the current study in that not only does it suggest that mothers and fathers of chronically-ill children grieve differently, but it also puts forward some suggestions as to why this may be the case.

2.8 Perceptions

Having noted the effect gender has on grief, attention will now turn to perceptions, another factor that is thought to impact the grief one experiences.

When it comes to stressful situations, just as important as the situation itself is the matter of how one perceives it. As individuals people control how they see things; whether they interpret them as positive or negative, a challenge or an enemy. Highlighting the importance of such views Worthington (1989) noted that the way one coped with illness and the duration and extent of one's grief depended on the way one perceived it.

Perceptions are shaped by an individual's knowledge, capabilities, life experiences and social-cultural background (Katz, 2002b). As well as differences in thresholds for tolerance, and

opinions of what is and is not a crisis. Such differences are important with it being the way men and women experience, think of and feel about events that make them crisis situations (Murgatroyd & Wolfe, 1982).

Evidence of the importance of perceptions and the impact they have on grief can be found in the literature. Copeland and Clements (1993), for example, found that parents who coped and adapted less successfully to their child's chronic-illness tended to have a more negative and fatalistic attitude of their child's illness (Katz, 2002b). Similarly, Wallander, Varni, Babani, Tweedle Banis, & Wilcox (1989, cited in Katz 2002b) reported mothers' perceptions and beliefs regarding the severity of their child's illness correlated with positive coping and adaptation. Katz (2002b) commented that parents who perceived their child's chronic-illness as more or less severe than it objectively was may find it difficult to come to terms with and adapt to the diagnosis, while Schaefer and Moos (2001) noted a close relationship between appraisal, wellbeing, and successful adaptation to life's crises, with those who viewed new tasks and roles as a challenge thought to be able to cope more actively with their losses and subsequently be more transformed by them.

Katz (2002b) found a significant difference in perceptions between parents of children with life-threatening and non life-threatening illnesses, with parents of children with life-threatening illnesses perceiving the illness as both more negative and more positive. This finding is important as it highlights the fact that although the illness has a negative impact, it can also have a positive impact. For example, those who felt that their child's illness had caused their lives to stop also felt it had brought their family closer together (Katz, 2002b). Thus despite the severity of the illness, it is still possible to find something positive. A study by Katz (1984, cited in Katz 2002b) which looked at the perceptions of mothers of infants with a congenital heart disease supports this point. These mothers perceived their children as less problematic than mothers of healthy infants on variables such as eating, sleeping and maintaining a routine. Katz (2002b) concluded that it appeared mothers of critically-ill infants tended to deemphasise the severity of their child's illness and the impact it had on their lives.

The importance of positive perceptions was noted by Folkman (2001) in a study of AIDS caregivers she and her colleagues conducted between 1990 and 1997. At the end of their survey caregivers were asked to report what they had learned, gained and how they felt different. Despite the situation they were in, almost all of the responses to this question were positive. Folkman (2001) explained this by noting that positive reappraisal can help one redefine and focus on the positive remaining. This in turn can help motivate them to reengage in efforts to cope with an ongoing stressor. Furthermore, it was also suggested that positive emotions may provide an important “time out” when distress is intense. In concluding Folkman (2001) noted she and her colleagues were so amazed at the level of positive psychological states they found among caregivers in their study, that they revised their coping model to highlight the importance of positive affect.

Supporting this, there is increasing recognition and growing research that suggests a significant number of parents actually report numerous benefits and positive outcomes for their families associated with raising a child with a disability. These include coping skills (adaptability), family harmony (cohesiveness), spiritual growth or shared values, shared parenting roles and communication (Ferguson, 2002).

This is not to say that having a child with a disability is not a stressful event. In regards to overall perceptions Katz (2002b) found that parents of children with life-threatening illnesses (as compared to those with non life-threatening illnesses) still perceived the illness as more catastrophic. This is likely due to the uncertainty that surrounds the future, more frequent and lengthy hospitalizations, and the threat of death (Sloper 2000, cited in Katz, 2002b).

2.8.1 Gender differences in perceptions

The idea that parents cope as a unified team, perceiving and responding identically to critical times cannot be assumed (Copeland & Clements, 1993). In terms of perceptions, however, those studies that have been done tend to support the notion that mothers and fathers do not differ significantly in their perceptions. A study by Copeland and Clements (1993), for example,

compared mothers and fathers' perceptions of their child's chronic condition with a sample of 19 couples. They concluded that while couples responses to the situation and the strategies they used to support themselves were not the same, their perceptions were (Copeland & Clements, 1993). More specifically, 58% agreed with regard to their perceptions concerning the severity of their child's condition, 63% agreed on what they noted as the most difficult time they had experienced since they noticed something was wrong with their child, 68% responded identically when describing the stability of their family, and 79% agreed that there were positive aspects in their situation such as a greater appreciation of their child and family (Copeland, 1993). Although Copeland and Clements' (1993) small sample size means that one needs to be careful in generalising these results, they have been supported by other studies. Hymovich and Baker (1985) found no significant differences between mothers and fathers in terms of their perceptions of the impact of CF, while Katz (2002b) found no significant differences when she looked at the perception of the impact of the child's illness in 80 mothers and 80 fathers (Katz, 2002b). Despite this non-significant finding, however, Katz (2002b) did note that mothers perceived the impact as both more positive and negative, and overall as more catastrophic.

In regards to the current study the literature cited above is important in that although it suggests perceptions will not help in explaining the difference between mothers and fathers in relation to grief, it does indicate that perceptions will impact the grief individuals' experience. Furthermore, the effect of perceptions does not stop here, with the way an individual perceives a particular situation likely to also impact the coping strategies they decide to use. It is to coping that my attention will now turn.

2.9 Coping

Coping is thought to be another important factor affecting the grief experience, with the way men and women cope likely to influence the intensity of their grief, as well as their overall adjustment. In regards to the current study, coping is defined as specific strategies (both cognitive and behavioural) that people use to master, reduce, or minimise the external and internal demands of a

particular stressful situation (Carver, Scheier, & Weintraub, 1989; Folkman, 2001; Stroebe & Schut, 2001).

Several general characteristics regarding coping are noted in the literature. First, is the fact that coping is contextual and thus influenced by appraised characteristics of the person, environment relationship (Folkman, 2001). This in turn means that a strategy that works in one situation may not work in another. Similarly what works for one individual may not work for another. Second, coping is a process that changes as a situation unfolds, (Folkman, 2001) with strategies varying over the course of a particular situation, just as just as they do between situations (Carver et al., 1989).

There are many ways one can think about coping in regards to explaining individual differences. One is that individuals possess a preferred set of coping styles that they bring with them to each situation they face. Folkman and Lazarus (1980, 1985, 1986, cited in Carver et al., 1989), however, shy away from this kind of thinking, arguing that coping should be thought of as a dynamic process that shifts in nature from one situation to another. They believed that having a specific style was counter productive as it locked one into a particular way of responding, thereby removing the freedom and flexibility to change responses with changing circumstances. Taking this into account, another way to think of individual differences is that personality characteristics predispose one to be attracted to certain strategies when confronting adversity (Carver et al., 1989). Furthermore, it should be noted that as well as personality factors, the decision to use a particular coping strategy is affected by external factors. These include things such as skills the individual holds, their socioeconomic status, and the social support they have available.

In terms of models of coping, Lazarus and Folkman's (1984) Stress Coping Model is well known. The basic assumption of this model is that when confronted with a stressor the first thing men and women do is evaluate it; looking at its meaning (is it positive or negative), then at what they can do about it. Both appraisals are important as they in turn determine how one chooses to cope (Maes, Leventhal & De Ridder, 1996).

Coping responses have been defined in terms of active and avoidant strategies. Active referring to behavioural responses designed to change either the nature of the stressor or how men and women think about it, while avoidant keep them from directly addressing the event (Taylor, 1998). Active coping is generally seen as the better of the two, with avoidant coping considered by some to be a marker for adverse responses (Taylor, 1998). The reason for this is that active problem focused coping is thought to provide the individual with a sense of control in an illness context that usually makes one feel helpless, by allowing them to feel mastery, at least for a moment (Folkman, 2001). In all, this is important as it helps the individual realise they do have some control in that they have the power to make choices about what they do. In regards to parents of children with CF, for example, while they cannot change the fact their child has CF, they do have control over their child's treatment, and can choose to be active when it comes to things such as physiotherapy and medications which help improve their child's health and assist in holding back the progression of the disease.

Coping responses have also been defined in terms of problem solving and emotion focused responses. Problem solving relates to doing something to elevate the source of stress, while emotion focused is based on regulating the emotional consequence of events. While in any situation both are used, it is thought that the predominance of one over the other is determined by personal style and the type of event. For example, if the event is controllable problem focused coping is likely to be more prominent. If it is uncontrollable then emotion focused coping is more likely to be used (Carver et al., 1989).

Lastly, Family Stress and Resiliency theories view coping as an active process, one that involves the use of existing strategies but also the development of new ones (McCubbin, Thompson & McCubbin, 1996). Sometimes one cannot use strategies they have used in the past. For example, concentration may be poor which in turn makes reading difficult. The ability to develop new strategies, or adapt old ones in this situation is therefore necessary (Jordache, 2005; McCubbin et al., 1996; Monat & Lazarus, 1985).

These descriptions and theories of how coping strategies are categorised are important in that they lay the ground work for how researchers think about coping and the work that has been done on coping. Attention will now turn to look at what coping strategies parents of chronically-ill children use the most and the effect they have on one's well-being.

2.9.1 Coping strategies used by parents of chronically-ill children

Patterson, McCubbin, and Warwick (1990, cited in Katz 2002b) noted that parents experiencing stressful events such as a child's chronic-illness tended to use more coping behaviours than parents experiencing less stressful events. Furthermore, Katz (2002b) noted the severity of the child's illness appears to have a differential impact on coping, with parents of children who have life-threatening conditions evidencing a larger repertoire of coping behaviours than parents whose children had non life-threatening conditions.

In regards to the use of specific strategies, Katz (2002b) found that those most used by mothers and fathers to help them cope and adapt to their child's chronic illness were family problem solving coping behaviours. These included maintaining and promoting the cohesiveness of the family unit, sharing time and experiences together, and sharing the daily chores. In concluding Katz (2002b) noted that these findings were in turn supported by the research literature that noted the importance of integration and cohesiveness in enhancing adaptation to a chronic-illness.

After interviewing 100 families of children with CF Venters (1980, cited in McCubbin, McCubbin, Patterson, Cauble, Wilson & Warwick, 1983) concluded that there were two major coping strategies that appeared to promote a high level family functioning. These were coping by sharing the burdens of illness (both among family members and with someone outside the family unit), and coping by using an existing philosophy about life held by the family to endow the illness with meaning and make sense of what had happened. The importance of this last strategy is supported by Saunders (1989) who suggested that one of the most difficult yet important tasks for those who are bereaved is to find some meaning in the situation. Furthermore, Macintosh,

Silver, and Wortman (1993, cited in Schaefer & Moos 2001) found greater participation in religious activities and social support enabled parents who had lost a child to SIDS to find meaning in their child's death. This in turn enhanced their well-being.

Social support is another strategy that appears to be crucial for successful adaptation with parents experiencing stress as a result of their child's chronic-illness having described the need for informational, emotional, and practical support (Katz, 2002b). Interestingly, within this it would appear that informational support (parent to parent) is more important than formal social support (e.g. a professionally-led support group). Supporting this Hymovich and Baker (1985) noted that while only 19% of their sample belonged to an organised group, when needing help with their child's development, care, and condition 63% of parents talked to other parents.

Information seeking also seems an important coping strategy for mothers and fathers with Levers and Drotar (1996) noting that studies have identified parents desire more information about CF. Interestingly the information parents were after here was not just that concerning various aspects of the disease such progression, diet, physical care, and physical development, but also information about how to raise CF children in general, the emotional and social development of these children, managing behaviour, what to do when they become ill, raising siblings, and how to explain CF to others (Hymovich & Baker, 1985). Within this, Levers and Drotar (1996) also noted that in receiving information parents wanted a positive hopeful emphasis from their health care provider.

In terms of coping styles that can hamper grieving it is thought that rumination (focusing on distressing aspects in a repetitive, passive manner) may worsen the impact of a loss. The reason for this being that it enhances the effects of depressive mood on thinking by reducing an individual's motivation to act that would normally give them a sense of control and lift mood, and by encouraging them to think negatively about themselves and their lives (Stroebe & Schut, 2001). Denial is also thought to have a negative impact on coping in that it prevents one from dealing with the situation. Although such thinking may be true, it seems more likely that it is excessive amounts of such strategies that are harmful rather than the strategies themselves. That

is, while large amounts of denial may be detrimental, small amounts may be beneficial in helping to protect an individual when they receive unexpected bad news.

The impact that coping well can have, and the importance of this, was noted by Patterson (1985, cited in Patterson et al., 1993) who found that families who were more expressive and emphasized family integration were better able to comply with home treatment regimes. This compliance in turn helps to explain one way in which coping can affect health. Highlighting this point, Patterson et al. (1993) found that when the coping of both mothers and fathers of children with CF emphasised family integration, support for self, and medical consultation, their child's lung function trend was better. Importantly coping here needed to be balanced across these three areas. As well as highlighting the effects of coping well on health, this finding is important as it shows that having a child with CF is not an either or proposition for the family. Either caring for the child totally, or caring for one's self totally. Rather it is a combination of the two (Patterson et al., 1993).

In all, the findings cited above suggest that parents of children who are chronically-ill will make use of a wide range of coping strategies. In particular, those that seem most beneficial are those that focus on integration, cohesiveness, finding meaning in their situation, gathering information, and enlisting social support. These findings aside, one needs to be aware that there is variation, with what works for one individual not necessarily working for another. With this in mind attention will now turn to what is known about gender differences in coping.

2.9.2 Gender differences in coping strategies used by parents of chronically-ill children

Although the evidence for gender differences in coping following bereavement is limited, it is generally thought that women tend to confront a loss, while men use more practical, less emotional styles of coping (Archer, 1999). Women are thought to be more expressive in their coping by letting their feelings out. They are also thought to make greater use of the social supports available in talking with others about their loss. Several studies have acknowledged this thinking in finding that men tend to rely on their partners as their main source of social support,

whereas in addition to their spouses, women make use of other formal and informal sources of support (Katz, 2002b). Differences such as these between mothers and fathers are in turn reinforced by social expectations with Cook (1988) noting that while the fathers in her study indicated that they had not sought out people to confide in, they felt deprived of support from others because they were men. Similarly, Stinson et al. (1992) noted that it is difficult for men to receive support from others in a crisis situation because they are expected to be strong and in control.

Compared to women, men are thought to be both more active and silent in their coping. Cook (1988) identified four strategies fathers used to cope with their grief both during and after the death of their child to cancer. These strategies were: thinking about something else, reason/reflection, doing something else, and solitary expressiveness. Interestingly, all of these strategies involved handling upsetting feelings without disclosing them to others, and the use of either cognitive or active ways of dealing with grief.

Furthermore, Cook (1988) commented on men's ability to control their thoughts and feelings, and the way they use this ability to deal with distressing situations. For example, she noted that fathers allowed themselves to express grief by crying, but only when no one else was present. In all, Cook (1988) believed the need to remain in control was vital to men's coping, concluding that they exerted considerable effort in managing their feelings, and worked hard at grief despite appearing to be less affected by loss.

Another strategy Cook (1988) noted was that the fathers in her study repeatedly mentioned that they thought a great deal about what had happened and the details of the illness. They searched themselves for something they could have done differently, and tried to seek some meaning in what had transpired. The aim of such thinking was to accept the illness and interpret it in a positive manner. Although this method was not always comforting, it continued to be used, and was thought to be important with Cook (1988) noting that it was a strategy not often mentioned in studies regarding female bereavement. In light of these findings it can be concluded

that coping in men appears to involve dealing with loss in a manner that makes their grief less obvious.

When men do express grief it is thought to be done through energy consuming activities such as building, making major repairs to the house or car, working longer hours, or taking more business trips. Alternatively, men may also choose to become more involved in the charity that raises awareness about their child's illness.

A study by Mastroyannopoulou et al. (1997) identified coping differences in parents of children with varying life-threatening illnesses. The most commonly used strategies by fathers at diagnosis were to cope practically or emotionally withdraw, whereas for mothers coping focused more around emotional release. Mothers were also more likely to desire emotional support at diagnosis, and reported higher levels of expressiveness. Mastroyannopoulou et al. (1997) concluded the coping style used by women put them at risk for poor mental health and adjustment. Interestingly, the parents themselves did not always see their styles of coping as effective with only half of them feeling that they had coped well (Mastroyannopoulou et al., 1997).

Differences in the coping styles used by mothers and fathers have also been noted by Turner-Henson, Holaday and Swan (1992, cited in Katz, 2002b) who reported that mothers tend to have a wider range of coping behaviours than men. These included cognitive and interpersonal coping styles directed at family duties and commitments of care. Lillie (1993, cited in Katz 2002 b) on the other hand noted fathers tend to use mainly cognitive, behavioural styles involving work and family responsibilities.

Furthermore, a study by McCubbin et al. (1983) noted that whether a particular coping strategy was used by a man or woman resulted in different implications for a child's health. That is, in a sample of parents of children with CF, they found that for mothers, maintaining family integration, cooperation, and an optimistic definition of the situation was associated with positive gains in their child's height and weight, while maintaining social support, self-esteem and psychological stability was associated with change in lung function. For fathers on the other

hand, maintaining social support, self-esteem, and psychological stability alone was associated with positive gains in height, weight and lung function (McCubbin et al., 1983).

Interestingly although individuals are bound to be aware that people vary in regards to the way they cope, a study by Copeland and Clements (1993) noted that mothers and fathers were not able to identify support strategies used by each other. This finding, in turn, has important implications for marital harmony in that it indicates that partners are not aware of the strategies each other use in order to deal with distressing events. Therefore, tension, for example, may arise with one spouse interpreting his/her partner's longer hours at work as an indication of a lack of support and interest, rather than a way of coping with the emotions they are feeling. Supporting this Saunders (1989, cited in Archer, 1999) claimed 75-90% of couples have serious problems following the death of a child, and this is a direct result of incongruent coping styles. If these parents had had a better understanding of how each other was coping it might be that such problems would be less likely to arise.

In regards to the current study these findings are important in that they suggest men and women do differ in the coping strategies they decide to use. It is likely therefore that these differences will in turn account for some of the gender differences that occur in grieving. Furthermore, although coping is but one of many factors that influence grief, it is important in that it is one of the few factors amenable to brief interventions (Folkman, 2001). In intervening one has to be careful with McCubbin et al. (1983) noting that "only selectively should we intervene in their coping efforts, when requested, and most often in an advisory capacity" (p.228). The reason for this is that everyone has their own support systems and coping strategies that they should be encouraged to use (McCubbin & Figley, 1983). Intervention, however, has proved helpful with Melnyk et al. (2001) noting that teaching parents the five steps of problem solving (identifying problems, determining options, evaluating options and choosing the best one, acting, and seeing if it works) resulted in enhanced problem solving skills and better coping outcomes.

2.10 Hypotheses

The aim of the following study is to examine the grief experienced by parents who have a child with cystic fibrosis. My first priority here is to validate the presence of grief in these mothers and fathers in the year following their child's diagnosis. As CF is a chronic life-threatening condition, it is believed that while mothers and fathers have not lost their child, they have lost the ideal they held of the 'healthy child' and it is this ideal that needs to be grieved.

My next priority is to look at the area of gender differences and what causes them. In light of the above literature it is predicted that mothers and fathers will differ in the grief they experience when informed of their child's diagnosis, with mothers experiencing significantly greater level of grief than fathers. In regards to what causes this gender difference, the two characteristics of perceptions and coping will be investigated. I expect to find that mothers and fathers will not differ in terms of their perceptions relating to the impact that their child's illness has had on their life. I do, however, expect to find that they will differ in regards to the coping strategies they use.

The impact that coping, and perceptions have on grief in general will also be investigated. Here, I expect to find that each of these factors will be related in some way to an individual's overall grief score.

Lastly, the experience of grief then as it is related to grief now will be looked at, with it predicted that grieving at the time of diagnosis will be related to the current distress one feels when recalling the stress experienced during this time.

3. Method

3.1 Participants

Thirty-seven mothers and 15 fathers of children with cystic fibrosis participated in this study. The mean age (and standard deviation) of mothers and fathers was 40.7(8.42) and 46.1 (8.04) years, respectively.

Participants were randomly recruited with the help of the National Cystic Fibrosis Association who sent out a letter explaining the study and the questionnaire to be filled in to 180 of its members. These two items can be found in Appendix A and B respectively.

Participation for each individual took approximately 20 to 25 minutes, and was completely voluntary. An incentive of the chance to go into a draw to win one of two \$50 grocery vouchers was offered. Mothers and fathers who had more than one child with CF were asked to please respond in regards to their first child only.

Sixty-three questionnaires were returned, giving a return rate of 35%. Replies came from all over New Zealand; as far south as Invercargill, and as far north as Whangarei. Of those returned six were discarded due to the fact that they had either been sent to an address that was no longer valid, or to individuals who belonged to the association but did not have a child with CF.

3.2 Materials and Procedure

Parents first read the covering letter which introduced the study, highlighted the aims, and invited individuals to participate. If they decided to take part they then filled in the enclosed questionnaire and returned it in the stamped self addressed envelope. If they wished to go in the draw to win a grocery voucher, they wrote their name and address on a piece of paper and put it into the small unmarked white envelope provided. They then sealed this envelope and posted back with their questionnaire. This step was taken to ensure all responses remained anonymous. Upon arrival questionnaires were checked to ensure they were completed, and the white

envelopes taken and put in a separate location to await the draw. Only two of these envelopes were ever opened, these being those of the two individuals who won the draw.

“The Anonymous Grief Questionnaire” contained an information sheet explaining why the study was being done, what was involved, and indicated that consent was given by filling in and returning the questionnaire. In all, the “The Anonymous Grief Questionnaire” contained six individual questionnaires that had been compiled into one place to make it easier for participants to complete.

The first of these questionnaires asked for demographic information such as age, gender and occupation of the primary earner in the household. The birth order of the child with CF, the age he/she was when diagnosed and the child’s current age were also sought.

The remaining five questionnaires were all established measures. Details of these measures are mentioned below.

Revised Grief Experience Inventory (Lev, Munro & McCorkle, 1993b)

The Revised Grief Experience Inventory (RGEI) is a 22 item self report measure that assesses the experience of grief and bereavement. This scale was chosen because it is both a concise and valid measure that is sensitive to the grief experience.

The RGEI was developed for use with adults, and contains four sub-scales. As grief is a multidimensional process a questionnaire that outlined the different aspects of grief in its sub-scales was important because it ensured one was measuring more than just depression. It also allowed more of an insight into how people grieve and enabled one to be more accurate in identifying where help may be needed. For example, an individual may only be having difficulty with one particular area of grief.

The revised version of the Grief Experience Inventory was chosen because it is a much briefer measure than the 135 item original, and therefore, less burdensome to fill in. This characteristic is important, especially when one is answering items about negative feelings such

as grief (Tomita & Kitamura, 2002). It was also chosen as its rating scale allowed for more varied responses, in comparison to the original in which participants responded with yes/no answers.

The RGEI was revised using Parkes' (1972) theory of grief. Its 22 items were chosen because they had corrected item total correlations of .35 or above, and its four sub-scales are based on a principal components factor rotation which yielded a four factor solution. The four sub-scales in this inventory are; existential concerns, depression, tension and guilt and physical distress. Responses are scored on 6 point scale ranging from slight disagreement (1) to strong agreement (6). Each answer is recoded, and then summed to get a score for each sub-scale. The sub-scale scores are then summed to get a total score. Overall higher scores indicate higher levels of grief.

In regards to norms, the mean total score and standard deviation for the questionnaire was 75.5(25.7). For each of the sub-scales the mean and standard deviations were; existential concerns 20.1(8.5), depression 22(7), tension 8(4.6), and physical distress 22.5(9.3) (Nezu, Ronan, Meadows & McClure, 2000). The reliability for the total scale was established as 0.93. While for the sub-scales the coefficient alphas were; existential concerns 0.87, depression 0.80 tension and guilt 0.72 and physical distress 0.83 (Nezu et al., 2000).

A factor analysis of this measure supported the theoretical conceptualizations of grief as detailed by Lev et al., thus supporting its construct validity (1993, cited in Nezu et al., 2000). Furthermore, Nezu et al. (2000) noted it has clinical validity in that it is easy to administer and score, and can be used as a quick check for level and type of grief (Nezu et al., 2000).

Brief COPE (Carver, 1997)

The Brief Cope is an abbreviated version of the original sixty item COPE inventory of Carver Scheier and Weintraub (1989). As with the RGEI the briefer version was chosen as it is shorter (only 28 items) and therefore takes less time to complete.

There are too many ways to deal with adversity to be able to measure them all in one inventory. The Brief COPE, however, does a good job with its 14 sub-scales covering a wide

range of coping strategies. It should be noted that in this two sub-scales from the original 60 item measure were omitted when creating the Brief COPE because they had not proven useful in previous work. These were restraint coping and suppression of competing activities. Furthermore, three scales that had been problematic were slightly refocused. Positive reinterpretation and growth became positive reframing. Focusing on venting of emotions became venting, and mental disengagement became self distraction. Lastly, self-blame was added due to evidence of its emergence in studies as an important response. Having accounted for these changes, the 14 sub-scales that make up the Brief COPE are: self distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning items, acceptance, humour, religion and self-blame. For the present study the sub-scale of humour was dropped. The items included in this scale were; 'I've been making jokes about it' and 'I've been making fun of the situation.' It was thought that these items were not appropriate, and may be seen as offensive in the context of talking about the diagnosis of a life-threatening chronic-illness in one's child.

The two items for each sub-scale are summed to get a total score for that particular coping strategy. There is no such thing as overall coping score here, the idea being that one looks at each sub-scale separately to see what its relation is to other variables.

This scale was developed from a theoretical basis, and can be reworded to refer to the way an individual copes in general or the way they cope in a particular situation. For this study it was worded to apply to a specific situation. Data concerning reliability and validity of the Brief COPE come from a sample of individuals who had experienced Hurricane Andrew and were participating in a study of responses to natural disaster. Despite fact that each scale on the Brief COPE only contains two items their reliabilities all met or exceeded the value of 0.5 that is regarded as minimally acceptable. In fact, all but venting, denial and acceptance exceeded 0.60, thus indicating that the scale has adequate internal reliability (Carver, 1997).

CHIP (McCubbin, McCubbin, Nevin and Cauble, 1981)

The Coping Health Inventory for Parents was developed to assess parents' appraisal of the coping behaviours they are currently using to manage family life when they have a child who is seriously or chronically ill (McCubbin et al., 1996). It contains three sub-scales, each of which represents a particular coping strategy. These are: 1) maintaining family integration, cooperation and an optimistic definition of the situation, 2) maintaining social support, self esteem and psychological stability, and 3) understanding the medical situation through communication with other parents and consultation with the medical staff (Katz, 2002b). Parents are asked to record how helpful each behaviour is in their particular family situation on a scale ranging from 'very helpful' (3) to 'not helpful' (0). If a coping behaviour was not used they are asked to record why by checking either; 'I don't cope this way because I choose not to use it' or 'coping behaviour is not possible in our family/not applicable to us.' It should be noted that coping here is defined as "personal or collective (with other individuals/programmes) efforts to manage the hardships associated with health problems in the family" (McCubbin et al., 1981, p.444).

In the present study only one of these sub-scales was used. This was the one looking at the use of the medical team. It was decided to include this scale because it is considered an important aspect relevant to the coping of parents of chronically-ill children, but one that is not accounted for in the Brief COPE. The scale consists of eight items looking at behaviours associated with communication with the health care team and other parents of children with chronic-illnesses, as well as attempts to master illness related home care issues and medical regimes (McCubbin et al., 1996).

The norms given for this questionnaire are based on data from a sample of 308 mothers and fathers who have a chronically-ill child. Responses in each sub-scale are summed to yield a total score for that sub-scale. For the third sub-scale the mean score and standard deviation for mothers and fathers were 15(7) and 12(8) respectively (McCubbin et al., 1996). Analysis of these data revealed good reliability with a Chronbach alpha of 0.71 (McCubbin et al., 1983).

Perceptions of the Impact of the Child's Chronic-illness on the Parent Questionnaire (Katz 1994)

This questionnaire assesses parents' perception of the degree of catastrophe caused by their child's chronic-illness. It contains ten items that have been divided into two factors containing five items each. The first of these factors contains items looking at the positive outcomes and impact of the child's illness on the parent, while the second looks at the negative outcomes and impact of the child's illness. Responses to each question are rated on a five point likert scale, from 'completely agree' (5) to 'completely disagree' (1). A final score for each factor is calculated by summing the respective items. Depending on which factor one is looking at, higher scores indicate a greater impact of either negative or positive aspects of the illness on ones' life.

This scale is based on Bristol and DeVilliers (1980) Definition Scale that was developed to evaluate the degree of catastrophe perceived on having a handicapped child. Its face validity was determined by three judges, and its construct validity demonstrated by factor analysis (Katz 1994, cited in Katz 2002b). In terms of internal reliability the Chronbach alpha for the positive impact scale is 0.64, while for the negative impact scale it is 0.66 (Katz, 2002a).

Experience of Stress Scale (Horowitz, Krupnick, Kaltreider, Wilner, Leong, Marmar, 1981)

The Experience of Stress Scale is a self report measure that asks participants to rate their upset and adjustment in relation to a particular event. It consists of three separate thermometer scales ranging from 1 to 100. Each scale asks one question. These are: the level of upset when the event occurred, the current level of upset about the event and the current level adjustment.

The present study only used one of these scales. Parents were asked to rate their current level of upset when thinking about the time they were informed of their child's diagnosis. This scale was chosen because the presence of distress is thought to be an indication that one is still in the process of grieving (Davis & Schultz, 1998). This is important in this study, as I am interested in looking at whether grief felt at the time of diagnosis relates to the amount of grief felt now. The validity of this scale has been reported with significant differences found between clinical and non-clinical populations following parental bereavement (Bruce et al., 1996).

4. Results

Descriptive information regarding my sample is presented in Table 1. These data represent the age and socioeconomic level of mothers and fathers, the age their child was diagnosed, the age their child is now, and the birth order of their child. A series of *t* tests were run in order to determine whether mothers and fathers differed on any of these characteristics. Only one significant difference was found. This was that the fathers in this sample are older than the mothers, $t(46) = 2.01, p < .05$. In line with this, it should also be noted that a difference of marginal significance was also found between mothers and fathers in terms of the current age of the child, with children of the men in this study being slightly older than those of the women, $t(50) = 1.80, p < .08$.

Table 1

Characteristics of mothers and fathers of children with cystic fibrosis, age of child at diagnosis, current age of child, and birth order of child

| Characteristic | Mothers (N = 37) | Fathers (N = 15) | <i>t</i> | <i>p</i> |
|-----------------------------------|------------------|------------------|----------|----------|
| Age | 40.7 (8.41) | 46.1(8.04) | 2.0* | .05 |
| SES Level ^a | 3.0 (1.46) | 3.1 (1.67) | .08 | .93 |
| Age child diagnosed (months) | 1.7 (1.68) | 1.7 (1.22) | .01 | 1.00 |
| Current age of child (years) | 10.3 (7.31) | 14.4(7.47) | 1.8 | .08 |
| Birth order of child ^b | 2.0 (1.14) | 1.8 (.86) | -.7 | .49 |

^a The SES level for mothers and fathers was rank ordered from 1 (highest pay) to 6 (lowest pay). For both mothers and fathers SES level ranged from 1 to 6.

^b For mothers the birth order of their child with CF ranged from their first to their fifth born. For fathers the birth order of their child with CF ranged from their first to their third born.

* $p < .05$

Before data analysis began four questionnaires were removed due to the fact the children involved were more than a year old when diagnosed. Another was removed because comments written on the front indicated the participant's responses were likely to be biased towards a particular direction.

This study has a between groups design. Its independent variable is gender, while its dependent variables consist of the sub-scales of the grief, perception and coping questionnaires.

The first step taken in this analysis was to calculate the descriptive statistics for each questionnaire. These statistics are reported in Tables 2 through 5. Except where noted, numbers cited represent the mean responses participants gave to each question in a particular sub-scale. At the same time a *t* test for independent means was conducted in order to determine whether or not any differences noted between the scores of mothers and fathers were significant. The results of these analyses are also presented in Tables 2 through 5.

Table 2 reports the descriptive statistics and *t* test results for the four sub-scales and overall score that make up the Revised Grief Experience Inventory (RGEI). The data here support the hypothesis that mothers and fathers grieve the loss of the 'healthy' child they expected with their total RGEI scores indicating slight levels of grief. While as hypothesised mothers responses in each of the sub-scales are higher than those of fathers, only one of these differences was found to be significant. That being, mothers scored higher than fathers on measures of physical distress, $t(50) = 2.25, p < .05$. In regards to the total score, my hypothesis that mothers would score higher was partially supported with marginal significance found, $t(50) = 1.80, p < .08$.

Table 2
Mean, standard deviation, and t-test results of mothers' and fathers' scores on the Revised Grief Experience Inventory

| Scale | Mothers | Fathers | <i>t</i> | <i>p</i> |
|----------------------|-------------|-------------|----------|----------|
| Existential Concerns | 3.5 (1.61) | 2.8 (1.19) | -1.5 | .15 |
| Depression | 4.3 (1.25) | 3.7 (1.35) | -1.5 | .14 |
| Guilt | 3.9 (2.22) | 3.3 (1.31) | -1.7 | .10 |
| Physical Distress | 3.6 (1.31) | 2.7 (1.19) | -2.2* | .03 |
| Total Score | 15.3 (5.39) | 12.6 (4.91) | -1.8 | .08 |

Note. This was a six point scale, with responses ranging from 'strong agreement' (6) to 'strong disagreement' (1). Also note that the total score consists of the sum of the four sub-scales. Thus the highest possible value that could be reached was 24.

* $p < .05$

As hypothesised no significant differences were found among mothers' and fathers' scores on the questionnaire looking at parents' perceptions of the impact of their child's chronic-illness.

Instead, in looking at Table 3 one can see that mothers' and fathers' responses were almost identical, with only .01 of a difference between parents in terms of positive perceptions, and .19 in terms of their negative perceptions. Furthermore, the low standard deviations reported here indicate that all participants responded in a similar manner.

Table 3

Mean, standard deviation, and t-test results of mothers' and fathers' scores on the Perception of the Impact of the Child's Chronic-illness on the Parent Questionnaire

| Perceptions | Mothers | Fathers | <i>t</i> | <i>p</i> |
|----------------------|-----------|-----------|----------|----------|
| Positive Perceptions | 1.9 (.63) | 1.9 (.48) | .04 | .97 |
| Negative Perceptions | 2.8 (.76) | 2.9 (.56) | .89 | .38 |

Note: This was a 5 point scale. With responses ranging from (1) 'totally agree' to (5) 'totally disagree.'

Participants' scores on the Brief COPE are presented in Table 4. Contrary to what was hypothesised results revealed no significant differences between mothers and fathers in terms of coping strategies used.

Table 4

Mean, standard deviation, and t-test results of mothers' and fathers' scores on the Brief COPE

| Coping Strategy | Mothers | Fathers | <i>t</i> | <i>p</i> |
|-----------------------------|------------|------------|----------|----------|
| Self-Distraction | 1.8 (.72) | 2.0 (1.05) | .6 | .52 |
| Active Coping | 2.9 (.83) | 2.7 (.82) | -.6 | .53 |
| Denial | 1.6 (.81) | 1.3 (.52) | -1.3 | .19 |
| Substance Use | 1.3 (.51) | 1.3 (.84) | .2 | .82 |
| Use of Emotional Support | 2.5 (.84) | 2.4 (.84) | -.4 | .70 |
| Use of Instrumental Support | 2.3 (.80) | 2.0 (.87) | -1.3 | .20 |
| Behavioural Disengagement | 1.4 (.70) | 1.2 (.36) | -1.0 | .37 |
| Venting | 1.6 (.60) | 1.7 (.82) | .7 | .46 |
| Positive Reframing | 2.5 (.98) | 2.6 (.81) | .3 | .75 |
| Planning | 2.6 (.86) | 2.2 (.94) | -1.3 | .21 |
| Acceptance | 3.3 (.87) | 3.2 (.70) | -.1 | .89 |
| Religion | 1.9 (1.08) | 1.9 (1.27) | .1 | .91 |
| Self-Blame | 2.0 (1.05) | 1.8 (.96) | -.9 | .39 |

Note: Responses here were rated on a four point scale from (1) 'I have not been doing this at all' to (4) 'I have been doing this a lot.'

Table 5 contains the statistics for two separate scales. While no statistical differences were found in regards to parents' responses on the first of these questionnaires, they were found on the second. That is, contrary to my hypothesis mothers and fathers do not appear to differ in terms of their use of medical services, $t(50) = -.24$, ns. As hypothesised, however, when it came to the current distress parents felt when thinking back to the time their child was diagnosed, mothers scored significantly higher than fathers, $t(50) = 2.18$, $p < .05$.

Table 5

Mean, standard deviation, and t-test results of mothers' and fathers' scores on the CHIP and ESS questionnaires^a

| Questionnaire | Mothers | Fathers | <i>t</i> | <i>p</i> |
|--------------------------------|--------------|--------------|----------|----------|
| Use of Medical Services (CHIP) | 2.2 (.55) | 2.2 (.46) | -.2 | .82 |
| Current Distress (ESS) | 71.3 (30.45) | 50.1 (34.66) | -2.2* | .03 |

Note: The CHIP was a 4 point scale, with responses ranging from (0) 'not helpful' to (4) 'extremely helpful.' The ESS on the other hand was a one off thermometer scale ranging from (1) 'not distressed' to (100) 'extremely distressed.'

^a CHIP = Child Health Inventory for Parents; ESS = Experience of Stress Scale

* $p < .05$

In regards to the use of medical services, 5.8% of the total responses given by fathers on this scale indicated that a particular coping strategy had not been used. Of these, 85.7% were due to the fact an individual had chosen not to cope that way, while 14.3% were due to the fact that that particular strategy was not possible in their situation. For mothers on the other hand, 6.8% of the total responses given indicated that a particular strategy had not been used. Seventy-five percent of the responses here were due to the fact they had chosen not to use a particular strategy, while 25% were due to the fact the strategy was not possible.

In the next step of data analysis a series of correlation analyses were run in order to determine the patterns of association between mothers and fathers. The correlations for mothers are reported in Table 6, while the correlations for fathers are reported in Table 7. For the sake of clarity only those relationships that were significant at either the 0.05 or 0.01 level are reported. Looking at Table 6 it is clear that self-blame, use of medical services, and negative perceptions all have a

strong association with various aspects of grief for mothers. Table 7 reveals that as well as self-blame and negative perceptions, venting, the use of emotional support, and the age their child was when diagnosed all have a strong association with grief in fathers.

Tables 6 and 7 also note several strong patterns of association between perceptions and various coping strategies. For mothers, denial, instrumental support and positive reframing are negatively associated with positive perceptions. Self-blame is negatively associated with negative perceptions, and behavioural disengagement positively associated with negative perceptions. For fathers, on the other hand, positive reframing and religion are negatively associated with positive perceptions, while denial, venting and self-blame are all negatively associated with negative perceptions.

In regards to the current distress felt when thinking back to the time of diagnosis, Tables 6 and 7 reveal that contrary to my hypothesis there is no significant pattern of association for mothers or fathers between it and grief felt at the time.

Lastly, a series of step-wise regression analyses were performed in order to determine which factors, if any, impact most upon an individual's overall grief score. The dependent variable for this analysis was the total RGEI score, while the independent variables consisted of the sub-scales from all of the other questionnaires used in this study.

Table 8 reveals that when this regression was run separately for mothers, self-blame appeared as a significant predictor, accounting for 31.7% of their total grief score, $F(1,33) = 15.33, p < .05$. As can be seen by looking at Table 9, self-blame also appeared as a significant predictor for fathers, accounting for 50.7% of the variance in their grief scores, $F(1,11) = 11.31, p < .05$.

Table 8

Stepwise regression analysis of mothers' grief scores on demographic information, perceptions, and coping strategies^a

| Model | Variables entered | β | R ² | df | F | p |
|-------|-------------------|---------|----------------|------|--------|------|
| 1 | Self-Blame | .563 | .317 | 1,33 | 15.33* | .000 |

Note: only those variables that were shown to be included in the stepwise regression are shown in the table.

^a Dependent variable = total RGEI score

* $p < .05$

Table 9

Stepwise regression analysis of fathers' grief scores on demographic information, perceptions, and coping strategies^a

| Model | Variables entered | β | R ² | df | F | p |
|-------|-------------------|---------|----------------|------|--------|------|
| 1 | Self-Blame | .712 | .507 | 1,11 | 11.31* | .006 |

Note: only those variables that were shown to be included in the stepwise regression are shown in the table.

^a Dependent variable = total RGEI score

* $p < .05$

Table 10 reveals that when the scores of mothers and fathers were combined self-blame again appeared as the most important factor, accounting for 34.6 % of the variance in grief scores. This time, however, negative perceptions also appeared as a significant factor. Together both accounted for 41.4% of the variance in parents' overall grief scores, $F(2,45) = 15.89, p < .05$.

Table 10

Stepwise regression analysis of mothers' and fathers' grief scores on demographic information, perceptions, and coping strategies^a

| Model | Variables entered | β | R ² | R ² change | df | F | p |
|-------|------------------------------------|---------------|----------------|-----------------------|------|--------|------|
| 1 | Self-Blame | .588 | .346 | | 1,46 | 24.30* | .000 |
| 2 | Self-Blame Negative Perceptions | .477 -.284 | .346 .414 | .068 | 2,45 | 15.89* | .000 |

Note: only those variables that were shown to be included in the stepwise regression are shown in the table.

^a Dependent variable = total RGEI score

* $p < .05$

5. Discussion

The results of this study have confirmed the presence of grief in parents of children with cystic fibrosis in the year following their child's diagnosis. Although the intensity of grief identified was only slight, finding that it does exist in and of itself was important in that it indicates parents do grieve the loss of the 'healthy' child they expected. As hypothesised, it was also found that the grief experienced during this time differed for mothers and fathers, with mothers reporting significantly greater levels of physical distress, and a total grief score that was marginally higher than that of fathers.

These findings are in agreement with prior studies such as that by Quittner et al. (1992) who identified the presence of grief in parents of children recently diagnosed with CF. Furthermore, they also confirm the work of Lev et al. (1993a) and Beutel et al. (1996) who found significantly greater levels of physical distress amongst the women in their studies as compared to the men.

As well as physical distress, it was expected that mothers and fathers would differ significantly on existential concerns, depression, and guilt. Although significance for these three factors was not found, it should be noted that mothers' responses to these areas were greater than those of fathers. This accounts for the partial significance between mothers and fathers overall grief scores, which in turn suggests that had I had a larger sample these differences would likely have been significant.

In all, these findings have important implications for parents, researchers and health care professionals. Validating the presence of grief in parents and acknowledging that this grief is a natural response to such a diagnosis would appear to be important, in that it would put mothers and fathers in a better position to understand and address their feelings. It may also assist in enhancing the predictability of ones' behaviour which would in turn help in reducing any fears that one will lose control. Similarly, ensuring that medical practitioners are aware of this loss and its impact would also appear important, in that, not only would give them a greater understanding of what parents experience, it would encourage greater empathy. This, in turn, would put them in

a better position to provide the support and help needed. Such thinking is supported in the literature with Worthington (1989) suggesting that caring may be closest the medical team can come to curing in regards to many of the difficulties associated with chronic-illness. That is, when a condition cannot be cured, one's ability to help mothers and fathers through the difficult times is the type of healing that may be most helpful, with there being a great deal that can be done to improve the psychological and social consequences of a condition that will, in turn, assist parents as they continue to live and work through the more difficult stages of reoccurring grief (Worthington, 1989).

Implications also arise in the area of simply acknowledging this loss, with Kennedy (1970, cited in Fortier & Wanlass, 1984) noting that although an individual may be aware of their grief, they may hide their feelings due to the lack of understanding they feel from the environment. Studies such as this one, which highlight the presence of loss, would therefore seem important in helping to increase understanding in society which could in turn make it easier for individuals to feel their pain rather than feeling that they have to hide it.

Furthermore, the finding that mothers and fathers differ in the grief they experience raises implications in and of itself in regards to both the marital relationship and help offered to individuals. Although there is debate as to the effect this type of loss has on the marital relationship, in either bringing a couple closer together or drawing them further apart, one thing that is certain is that a strong relationship has consistently been shown to form an important source of support in weathering this parenting experience (Friedrich Wilturner and Cohen 1985, cited in Bruce et al., 1996). In light of this Stinson et al., (1992) commented that where there are large differences in grieving between couples there is the potential for marital conflict. Ensuring parents are aware of the fact that they will grieve differently, and helping them to understand their partner's unique response to loss would therefore seem important in helping to reduce misunderstanding and tension. In regards to providing support on the other hand, making sure that individuals who deal with these parents are aware that mothers and fathers are likely to respond

differently is important in ensuring that although men's grief may appear less than that of their partners, it still acknowledged and their needs met.

Having identified that mothers and fathers grieve differently following a diagnosis of CF in their child, the next question to answer was that of what causes these differences. Ones' perceptions were thought to play an important role in terms of impacting upon an individual's overall grief score. In regards to accounting for differences in grief between mothers and fathers, however, it was not thought to be a factor, with previous studies reporting that parents tend to be very similar in their perceptions of the impact that their child's chronic-illness has had on their lives (Katz, 2002b). The present study confirmed this finding with no significant differences found between parents in either positive or negative perceptions.

With this in mind, the factor thought to be at the heart of differences in grief between mothers and fathers was coping. Contrary to my hypothesis, however, statistical analysis failed to yield any significant differences between mothers and fathers in relation to coping strategies used. This absence of differences is not supported by the literature. It is possible that the lack of differences identified here is due to the fact that in this particular situation the coping strategies used by parents are more similar than different. Alternatively, it is also possible that this lack of difference is again due to my small sample size. Supporting this suggestion it should be noted that variation did emerge when looking at the patterns of association between grief and coping in mothers and fathers. For mothers these patterns suggest that assessing medical services as helpful, less use of self-blame, and negative perceptions are associated with more grief. For fathers on the other hand, lower levels of self-blame and negative perceptions, increased use of venting, emotional support, and age of child at diagnosis were associated with greater levels of grief.

The fact that the age of the child when diagnosed and venting appear to be associated with grief in fathers is supported by research that suggests that grief in fathers increases as the child grows and differences in parental investment and attachment even out (Archer, 1999), while in terms of gender stereotyping, venting is an acceptable way for men to show their grief. The association of medical support and grief in mothers is also supported by the literature with Katz

(2002b) noting that mothers made greater use of this strategy than did fathers. The association between greater emotional support and increased grief in fathers on the other hand is more difficult to explain in that it appears contrary to what both common sense and the literature would suggest. In terms of this study one needs to be careful in generalising these associations as they are simply correlations. Further research is thus needed here in order to look at these associations with greater depth and statistical precision.

To investigate further what causes mothers and fathers to differ in their grief a stepwise regression analysis was performed to determine the specific factors that contribute most to the participants' overall grief score. Interestingly, the factor that accounted for most of the variance in grief scores was the same for mothers and fathers. This factor was self-blame. The importance of self-blame is noted in the literature with studies such as that by Rodrigue, Morgan, and Geffken (1990) finding it to be a strategy used more frequently by mothers of children with autism and Down's syndrome as compared to mothers of developmentally normal children. Carver (1997) also noted its importance, commenting that self-blame had been found in research to be a predictor of poor adjustment under stress, and that because of this he had decided to add it to his coping inventory. Further research is needed to confirm both the importance of self-blame and the manner in which it affects grief.

Due to my small sample size a regression analysis was also performed with mothers' and fathers' scores combined, to determine whether there were more factors that accounted for individual variance in the experience of grief. In conducting this study it was expected that in some form or another differences in perceptions, and coping would affect the grief experienced. This thinking was confirmed in this last analysis that found the coping strategy of self-blame to account for most of the variance in grief, followed closely by negative perceptions. The fact that negative perceptions has emerged here as an additional factor to self-blame is important in that it confirms just how influential ones perceptions are. The power of perceptions is clearly highlighted in the literature with Sarason, Shearin, Pierce and Sarason (1987, cited in Cleiren, 1993), for example, finding that it was the perception of support rather than actual receipt of

support that was most indicative for good adjustment. Similarly, Singh and Raphael (1981) noted that the bereaved in their study who perceived intervention as unhelpful did as badly as those who received no intervention.

Knowledge of the impact of factors such as these is crucial for those working closely with these parents in that it gives them a greater understanding as to what characteristics may put individuals at risk. Important implications, in turn, arise here from a practical point of view with self-blame and negative perceptions both appearing to be characteristics that can be changed through intervention. That is, time could be spent ensuring parents understand that there was nothing they could have done to prevent their child being born with CF. Cystic Fibrosis is genetic and therefore embedded in the child's DNA from the moment of conception. Although it is understandable that parents may feel guilty, the reality is that it is something they had no control over with CF unfortunately being one of those things individuals remain unaware of until it emerges in their family line. Individuals can be tested to determine if they carry the gene, and babies can be tested for CF in the womb. However, in order to be tested one first needs to be aware that they are at risk. Generally the only people aware of the risk are those who already have a child or a sibling with CF.

As well as this, individuals working with these parents could try and dampen their negative perceptions. Altering ones' perceptions to be more positive is vital in this situation with perceptions influencing how one sees the world and therefore impacting upon how they cope and react. Medical practitioners may be of assistance here by providing parents with relevant information and making themselves available to parents if they have any questions they would like to ask. Speaking with other parents who have children who are older may also be helpful, in that it would enable one to see that although the diagnosis is not good these children can live relatively normal and full lives. Importantly, in attempting to alter ones' negative perceptions and views regarding self-blame it needs to be kept in mind that no one strategy satisfies all. Therefore, the more options for coping/assistance offered in this regard the more opportunity there will be for one to fit each individual.

Lastly, this study also asked parents about the current levels of distress they felt when thinking back to the time they were informed of their child's diagnosis. As expected, a significant difference was found with mothers scoring higher than fathers, thus suggesting that mothers more so than fathers are still in the process of working through the implications of their loss. This finding is in line with past studies that have also yielded similar results (Bruce et al., 1994; Bruce et al., 1996). Furthermore, it was thought that this current distress would be related to the grief one felt at the time of diagnosis. This, however, does not appear to be the case with no relationship between these two factors appearing in regards to the patterns of association or regression analysis.

In all, the findings of this study are important in that they give a general picture of grief and the factors that impact upon it. Within this, however, one needs to remember that there is much individual variation, both within and between the genders. In this light both researchers and those individuals who come into contact with these parents need to be careful not to stereotype them, but instead look out for and be sensitive to the needs of each individual. With reality being that grief cannot be packaged into a neat little box.

A criticism of past research has been that many studies looking at parents of chronically-ill children have relied on single site measures. As a result an effort was made in this study to recruit participants from several geographical areas. Doing so has in turn increased the generalizability of these findings.

Knowledge in relation to a specific illness is important in identifying characteristics relevant to that group. Just as important, however, is developing knowledge that can be generalised to apply to a body of groups (Quittner et al., 1992). In the case of this study, as well as being applied to the general population of parents of children with CF in New Zealand, it is thought that these results could also be generalised to parents of children with other health concerns. One does need to be careful in generalising with different illnesses containing different variables, such as the degree functioning is impaired, which, in turn, are likely to impact upon the grief felt. This being said, however, the focus in this study has been on the specific area of how

parents felt when they were informed of their child's illness, and the loss experienced in regards to the 'ideal' of the healthy child. Regardless of illness this is an event and loss all parents will have experienced. Future research could look to confirm such thinking by looking to identify self-blame, gender, and negative perceptions as factors that impact on the grief experience in parents of children with chronic-illnesses other than CF.

In light of these findings this study does contain several limitations that need to be acknowledged. First, the sample of participants was self selected, in that they had to volunteer to participate. This, in turn, raises the possibility that those who volunteer may be coping better with their loss than those who do not (Davis & Schultz, 1998). Furthermore, all participants are members of the National Cystic Fibrosis Association which suggests they are perhaps being more active in their efforts to cope than those parents who are not members. These two factors would suggest participants are managing better than non participants. Keeping this in mind, however, such factors highlight the strength of the grief reaction amongst these parents, with it likely that the estimates of grief reported in this study are lower than its true prevalence among parents in the general population.

Furthermore, the retrospective nature of several of my questionnaires may have resulted in confounding variables such as the fact that if an individual is doing well now they may recall the experience then as being more pleasant than it actually was. Although this may be true, Jedlicka-Köhler et al. (1996) noted that men and women remember things of high personal relevance, with the intense emotions experienced at the time of such events accounting for better recall later. In regards to this study, it was decided that a retrospective design was best due to the fact that talking about grief and loss is a sensitive topic, and as such one it was thought best to approach when the emotions surrounding the event were not so raw. Future research, however, could look at actually interviewing parents in the year following the diagnosis.

Lastly, there is the possibility of further confounding variables such as other life events that might have affected the measure of grief specific to this loss. Future studies could combat

this by getting participants to indicate if any other significant life events occurred around the time of diagnosis.

These limitations aside, the results of this study are thought to represent a valid account of the grief experienced by mothers and fathers of children with CF. It has been shown that mothers and fathers differ in the grief they experience. What causes this difference, however, remains unclear, with no significant differences found between parents in terms of coping strategies and perceptions. This lack of differences may very well have been due to this study's small sample. Future research with a larger sample would therefore appear important.

These findings also suggest that other factors need to be looked at in order to better explain what causes gender differences in grieving. As grief is largely defined by the social environment, it would be interesting investigate the impact of social norms in regards to the degree they are felt by the individual. Furthermore, as women tend to be the primary caregiver it would be interesting to look into the role of work and the impact those greater hours of contact with the child have on the grief one experiences.

As much of what is currently known about gender differences in grieving is based on studies looking at widows and widowers, research such as that conducted here needs to continue. The reason for this being that not only is it helping to identify similarities and differences in the grief felt by parents of chronically-ill children, but it is also adding to the overall understanding of gender differences and grief in general.

6. Conclusion

I set out in this study with a desire to discover more about the experience of grief and the factors that influence it. In particular I was interested in the grief men and women experience for losses other than death. Such grief is important to investigate with losses both big and small engrained into the fabric of everyday life. It would seem therefore, that learning to manage and adapt to loss is vital if one is to overcome it and continue making the most of life.

The loss experience at the centre of the current study was that of the loss that occurs when parents are informed their child has a life-threatening chronic-illness. Although men and women may not always spell out what they hope for in life, as individuals they do tend to have unspoken and perhaps even unacknowledged expectations for the future (Bright, 1986). For expectant parents these expectations centre around the fact that their child will be healthy and live a life that will exceed theirs. Understandably, the loss of such expectations is devastating, as not only have parents lost the ideal they had of a 'healthy' child, they have also lost their hopes and dreams for that child and their future.

I decided to focus on the grief parents experience in the year following the diagnosis, because I believe that how mothers and fathers grieved then would be related to how they are managing now. Furthermore, I was encouraged by Olshansky (1962) who noted that as well as receiving the facts of the illness, parents need the opportunity to ventilate, clarify and receive support for the legitimacy of feelings they experience.

The life-threatening chronic-illness looked at in this study was cystic fibrosis, a condition that requires daily medical treatment, physiotherapy, three monthly hospital visits, and at best cuts one's life expectancy in half. It was thought that to grieve a loss such as this would be difficult due to the fact that what has been lost was an ideal, not a tangible object. Despite this concern, however, evidence of grief was found in both the mothers and the fathers participating in this study. Importantly, it was also found that this grief differs for mothers and fathers. Although this study was unable to determine what causes this difference between parents, knowing that this difference occurs in and of itself is important in that it reminds one that while fathers may not

express their grief in the same manner as their partner, they are still hurting and feel the pain of the loss.

In the past there was a tendency to stereotype grief responses, forcing people into a general pattern. Grief that fell outside this pattern either by being too long or intense, or too short and painless was considered pathological (Saunders, 1989). It is thinking such as this that has made research on grief all the more important. In conducting this study and reading the research I have come to realise that there should be no set expectation for how people grieve. Because the reality is that everyone grieves differently. In this light, while theories such as those of Kübler-Ross (1969) and Parkes (1972) are important in that they increase one's understanding of the grief process, they need to be viewed as guidelines rather than set rules regarding where an individual ought to be at a particular point. The reason for this is that individual differences create great variability in regards to the duration and expression of grief. Recent research has acknowledged this, noting that there is much overlap and passing backwards and forwards between the different stages proposed by the likes of Parkes (1972) and Kübler-Ross (1969), with grief felt in many areas at once. Furthermore, problems may arise if individuals fear that they are not experiencing grief correctly (Toedter et al., 1988). Saunders (1989), for example, cautioned that ignoring individual differences by putting time limits on grief was likely to only cause problems, with individuals becoming frustrated when grief went beyond the period expected. This in turn was thought to be dangerous in that it may lead to feelings of hopelessness and helplessness.

It was found that when looking at mothers and fathers together, the factors that most account for the variance in individuals' grief scores were self-blame and negative perceptions. These findings are important in that they remind us that grief is a complex, multidimensional phenomenon, one that is influenced by many moderator variables. Furthermore, they are also important in that both factors are amenable to change.

In doing this study I have come to believe that perceptions in particular are crucial in determining whether an outcome will be positive or negative for the individual. Perceptions

impact on most areas of life, they colour the way one sees the world and in turn influence how a situation is defined. As a result, they form an integral part of coping with the strategies an individual chooses to use largely determined by their appraisal of a given situation. Furthermore, perceptions themselves are influenced by emotion. This in turn suggests that not only do they have an impact on the grief experience, but the grief experience is likely to impact on them.

I started out wanting to discover more about how one could help parents who were struggling with the news that their child had a life-threatening chronic-illness. I think that as human beings when someone is in pain all one instinctively wants to do is take that pain away. Having come to the end of this research, however, I can now see that one's focus should not be on removing the pain, but rather on giving an individual the tools they need to manage and get on with the situation. This is because although unpleasant, the pain that accompanies a crisis is not something that can be taken away. Rather it is something everyone must experience and work through themselves.

Although most individuals will manage to make it through such times without too much trouble, one does need to be aware of those who struggle. In regards to providing support, given the variability that occurs in individual differences Bruce et al. (1994) noted that the wider the range and flexibility of supportive services and the programmes that can be made available the better. In terms of helping, the only thing I would caution is that one needs to be careful that they do not take over for the parent, with the aim needing to be to help them help themselves. Furthermore, one also needs to ensure they do not exclude the individual's family, making them feel as if they are extra, and thus discouraging their support. In some situations all that may be required in terms of help is a listening ear and an acknowledgement of their loss. In others assistance may be needed to provide individuals with the tools they need to get on and tap into the coping strategies, resources and support systems that surround them.

In still other cases Davis and Schultz (1998) suggested that counselling in which one looks at the implications of their loss may be helpful. If counselling is offered pairing it with something else that seems more important at the time may be helpful. The reason I suggest this is

that Singh and Raphael (1981) noted that individuals whose loved ones had died in a rail disaster made better use of counselling when it came from police who escorted them to see the body, than health workers whose aim it was to help them with their grief. In regards to this study, it is therefore likely that counselling offered by doctors and nurses during hospital visits and stays will be beneficial.

In conclusion, it is thought that the current study will assist in raising awareness of the loss parents of children with cystic fibrosis experience when they are told of their child's diagnosis. Furthermore, it is also thought that it can add to the literature and increase understanding of individuals' reactions to loss and the process of grief. In reading this study the most important thing to take away is the knowledge that although individuals may suffer the same loss this does not necessarily mean that they will experience the same grief. The reason for this is that as individuals, men and women recognise loss and express grief differently. Furthermore, overcoming grief should not be equated to one getting back to how they were before the loss. With the reality being that after loss one can never be the same. Rather what individuals do is adapt and adjust to a new level of functioning. In regards to coping with this grief it needs to be remembered that just as individuals grieve differently, they also cope differently, with different strategies suiting different people. I also want to acknowledge that while the hopes and dreams of the 'healthy' child have been lost, new hopes and dreams develop. In line with this, it can be said that although the news of a diagnosis such as cystic fibrosis is devastating there is still a life out there to be lived and a child to be loved. Therefore, studies such as this one, that help to identify factors that affect the grief experience of parents remain crucial in ensuring parents receive the help they need in coming to terms with their loss to enable them to keep living, be there for their child and make the most of the time they have together. In acknowledging this one can therefore see why continued research focusing on the various aspects of this loss is needed.

An explanation

My interest in looking at parents of children with cystic fibrosis stems from the fact that my younger sister, Sarah, has the disease. Growing up I never thought much about Sarah's illness. To the outside world she appeared just like everybody else, and was treated no differently. At home the medication and physiotherapy she required was simply included as part of the family routine.

In 2004 there was a case in Nelson where a father in his grief killed his five-month-old daughter who had just that day been diagnosed with a rare condition that had caused her brain to stop developing while she was in the womb. Although this girl did not have CF, the event got me thinking about my parents and how they felt when Sarah was diagnosed. It was about this time that I came to realise the shattering impact that such news had on parents.

In doing this study I feel that there is a danger that one could take a very negative view of this situation. I do not want to down play the negative, because the reality is that the prognosis of CF is not good. However, although there is this negative aspect to the disease, I also know there is a positive side. That is, while receiving a diagnosis of CF changes the world mothers and fathers once knew, many parents remain upbeat, taking the situation in their stride, and enjoying the life they have. Supporting this, one mother, in an interview with Jones et al. (1998a), commented that initially she thought she would have to stop her life in order to care for her sick child. What she came to realise, however, was that she could still pursue what she had wanted to pursue in regards to work and family life, with all that was needed was a few adjustments to accommodate for the demands of CF. Furthermore, another mother noted that she had found some strengths and positives in the situation which she never thought would have been possible.

Although some individuals will take a negative view, I believe that having a positive outlook about the situation and future is important. Researchers such as Gibson (1988, cited in Levers & Drotar, 1996) agree, finding that to have a belief that a cure is forthcoming was a valuable coping resource. Similarly, DeSpelder and Strickland (1999) noted that it has long been a truism in medicine that hope plays an important role in an individual's ability to cope with

illness. More specifically they noted that even when there is no scientific support, belief in the possibility of a cure may enhance an individual's quality of life, if not its duration.

In conducting this research I came across an analogy that I feel sums up this experience and parents positive outlook. The analogy suggests that having a child with CF is like planning a trip to Italy. Prior to going on this trip men and women read all the guide books about Italy so they know what it will be like when they get there. They may learn some Italian phrases, and set up an itinerary of the places they want to visit. When it comes time go, however, the plane they are travelling on flies past Italy and takes them to Holland, where they must stay. Initially they are upset as they had dreamed of going to Italy. Holland is not Italy and never will be. However, once they have caught their breath they begin to realise that Holland is a beautiful country, and that holidaying there can still be enjoyable and very rewarding (Kingsley, 1987).

For me, one of the most frightening aspects of CF would have to be the limited life expectancy. Although everyone knows that they will die one day, death is something men and women typically do not like to think about, let alone talk about. This silence is in turn encouraged by the fact that today men and women are living longer. Medical advances, for example, are saving those who in the past would have died at birth, and keeping those at the other end of life going for longer. Ignoring death in this manner, however, is harder to do when you know that your life is limited.

In doing this study, however, I have come to realise that being aware of one's mortality is actually a good thing. Jacques (1965, cited in Lemming & Dickinson, 1998), for example, observed that in confronting one's own mortality at middle-age, individuals deepen their capacity for love and enjoyment, and ultimately acquire more meaning in their lives. Similarly, Lemming and Dickinson (1998) write that in dying one often lives life to the fullest, noting that it has been said that some individuals live more in the final months of life knowing that the end is near than they had lived in previous years. Furthermore, Arthur Frank noted "critical illness teaches us that to be alive is to be constantly at risk, but the risk greater than dying is living less well" (cited in DeSpelder & Strickland, 1999, p.156).

The gist of what is being said here is that in being aware of their mortality individuals realise that life is precious and thus live it more fully. Supporting this thinking a 15 year-old boy with CF commented:

People with CF don't really expect to live to much more than an age of say 40 or 50, and I think it's just really important to have, you know 30 or 40 or whatever it is how many years and make the best of it. I think, you know, what's the use of living for 70 years, and it being a pretty ordinary 70 years, when you can live for 30, and have 30 excellent years. I think it's just really important to make the best out of life while you have it. (Jones, Jennings, Marrett & Patterson, 1998b)

Such thinking brings me to another driving force behind my study which was to bring grief and loss out into the open. Although death is occasionally the topic of conversation in my family, I am aware that in many households it is never mentioned. In all, feeling free to share one's thoughts and feelings (both positive and negative) within a family context is important with Saunders (1989) noting that families who close up when it comes to issues such as loss and death establish a poor climate for dealing with such things when they happen. In summing up, Saunders (1989) noted that while remaining open becomes harder the longer the stressful situation, the ability to remain open and receptive to each other is one of the primary factors in a positive outcome for families undergoing loss.

In concluding, I think it is fair to say that I have a real desire to help parents come to grips with a diagnosis such as cystic fibrosis. A desire to help them realise that although the diagnosis is not good, there is still a life to be lived and enjoyed, and a desire to help those who are really struggling to get back on their feet so that they can in turn make the most of the time they have with their child. In sum, although Amsterdam is not Rome, visiting Amsterdam can be a very meaningful experience, with the people who live there having much to teach individuals about the way they should live.

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Appendix A: Covering letter

University of Canterbury
Department of Psychology
PO Box 4800
Christchurch

4th June 2005

To whom it may concern,

My name is Johannah Betman. I am a fifth year psychology student at the University of Canterbury.

This year I am embarking on my master's thesis. The focus of my thesis is on the area of loss. Loss is a phenomenon that affects us all. Whether it be the loss of a job, skill, ability, relationship, health, finances, freedom or something we held dear; it is an event we will experience many times throughout our lives. For this reason it is an important area to study. Another reason I am interested in loss, is because of the fact that when we experience a loss, we experience grief. This grief, however, is not always acknowledged. The main reason for this being that it is widely believed by the general population that one only grieves when a death occurs.

The loss experience that I am interested in focusing on in my thesis is that experienced by parents who are informed that their child has a chronic life-threatening illness. I would like to look at how parents grieve this loss, and the impact that several factors have on this grieving process.

To be more specific, my objectives are:

- To validate the presence of grief, at the time of diagnosis. And to explore the form this grief takes.
- To discover the impact that gender, coping and perceptions (of the impact of the child's chronic illness on the parent) have on this grief.

Looking at the grief experience of parents is important, because effective care of one's child relies on their effective parenting. Gathering information on this experience from both men and women is also important as traditionally research on parents of chronically ill children has focused only on mothers.

It is hoped that this research will be able to identify areas in which we can better assist mothers and fathers as they cope with the news that their child has a life-threatening chronic illness. It is also hoped that this research will be able to create a better understanding and awareness amongst parents, doctors and nursing staff alike; of the feelings parents experience when informed of their child's diagnosis. Furthermore, in assessing the impact coping and perceptions have on grieving, and the sex differences that occur in grieving, the understandings of individual reactions to loss and the process of grief will be furthered.

In all, my ultimate objective in focusing on this area is to help parents better understand the pain they are feeling, move through their grief and get back up on their feet.

This is where I need your help. I would like to invite you to take part in this study by filling in the enclosed questionnaires. You have been contacted because you belong to the population in which I am most interested, and would like to specifically focus on. That population is parents of children with Cystic Fibrosis. I am interested in this population because my younger sister, Sarah, has Cystic Fibrosis. I would love to be able to learn more about how parents react to the diagnosis of Cystic Fibrosis, and how we can better help new parents come to terms with this diagnosis.

If you would like to take part simply fill in the enclosed questionnaires, then place them in the stamped self-addressed envelope, and send them back to me in the post. In all it should take you approximately 20 to 25 minutes to complete all of the questionnaires.

All questionnaires are anonymous. Each set of questionnaires has a number on the top right hand corner. This number is there so that when I am processing the data I know which questionnaires belong to the same individual. For example, all of your questionnaires may be labelled with a one. While another person's questionnaires will be labelled with a two, and so on.

As a thank you for participating you are invited to enter a draw to win one of two \$50 grocery vouchers. To go into this draw all you need to do is put your name and address on a piece of paper and put it inside the small white envelope enclosed. To ensure anonymity seal this envelope. Upon arrival your questionnaire will be checked to ensure everything has been filled in. Once this has been done your small envelope will be placed in the draw to win one of the grocery vouchers. Only two of these white envelopes will ever be opened. These will be those of the two winners, who need to be opened so that I know where to send the prizes. Once this has been done all of the small white envelopes will be destroyed.

Participation is completely voluntary. If you do not wish to take part in this study, simply put this letter and its contents in your rubbish bin.

If you wish to discuss this further please feel free to make contact with either me or my supervisor, Dr. Mark Byrd, at (03) 366-7001, ext. 7194.

Thankyou very much for your time.

Johannah Betman.

Appendix B: Questionnaire

**The Anonymous
Parental Grief Questionnaire.**

University of Canterbury

Department of Psychology

INFORMATION

Please read the following note before completing the questionnaires.

You are invited to participate as a subject in the research project entitled "Parental grief when a child is diagnosed with a life-threatening chronic illness. The impact of gender, coping strategies and perceptions," by completing the following questionnaires. Your participation is entirely voluntary.

Why is this study being done?

The aim of this project is to look at the grief experienced by parents when they are informed that their child has a chronic life-threatening illness. What I am interested in looking at is how these parents grieve and whether mothers and fathers grieve differently. I am also interested in how this grief is influenced by individual coping strategies, and perceptions of the impact of the child's chronic illness on the parent.

It is hoped that as a result of this study more will be discovered about the experience of grief and factors that influence it. It is further hoped that this information will be able to contribute to a greater understanding of the grieving process, and give assistance to both medical practitioners and the parents themselves. The ultimate goal being to help parents through the grief they experience when they are told their child has Cystic Fibrosis, and back up on to their feet.

What is involved in this study?

Your involvement in this project will involve filling in five anonymous self-report questionnaires. The questionnaires ask you about the grief you felt when your child was diagnosed, your coping behaviours, your perception of the impact that you feel your child's chronic illness has had on you, and your perception of your current level of distress when thinking back to this time

Please note that at no time do we ask for your name or any other identifying information. Your confidentiality is completely assured.

Completing the questionnaires should take approximately 20 to 25 minutes. All participants are being asked to complete the same survey.

How long will I be in the study?

Your participation should take 20 to 25 minutes. Once you send in your questionnaires your participation will be complete.

What are the risks of participating in this study?

In the performance of the tasks there is a risk of emotional distress caused by recalling the time your child was diagnosed. If you feel that you would like to talk to someone as a result of participating in this study counselling is available.

Talking through how you are feeling with someone can be helpful in that it enables you to express your thoughts in a supportive confidential environment. Which in turn can be useful in helping to lighten the load you may be carrying.

The counselling service I recommend to you is Life Line. Life Line is a professional telephone and email counselling service that is available nationwide 24 hours a day 365 days a year. You can contact Life Line in one of two ways. If you would like to talk to a counsellor call: 0800 543 354. If

on the other hand you would prefer writing about how you are feeling, rather than talking you can email a counsellor at ecounselling@lifeline.co.nz.

Also, please feel free to stop your participation in this study at any time.

What are the benefits of participating in this study?

We hope that in gathering and analysing the information in these questionnaires we will be able to shed light on the process loss. And in turn better assist those families experiencing loss.

As a thankyou for your participation in this study, you will go in the draw to win one of two \$50 grocery vouchers.

What about confidentiality?

Your participation is completely anonymous. We do not ask for any identifying information in the questionnaires. There will be no way for anyone to tell which survey you personally completed. Once the anonymous information from all the questionnaires has been entered into a computer, all questionnaires will be kept in a locked filing cabinet and then destroyed.

What are my rights?

Taking part in this study is completely voluntary. You may choose not to take part in this survey. You may withdraw your participation, including withdrawal of any information you have provided, until your questionnaire has been added to the others collected. Because it is anonymous, it cannot be retrieved after that.

By completing the questionnaires it will be understood that you have consented to participate in the project, and that you consent to publication of the results of the project with the understanding that anonymity will be preserved.

Who should I call with questions or problems concerning the study?

The project is being carried out as a requirement for a Masters thesis by Johannah Betman under the supervision of Mark Byrd, both of whom may be contacted at 03 366-7001, ext. 7194. Either one will be pleased to discuss any concerns you may have about participation in the project.

The project has been reviewed **and approved** by the University of Canterbury Human Ethics Committee.

Below you will find five questions that ask you for some demographic information. Answering these questions is important as it will assist me in analysing the information I receive.

1. Birth Date:

2. Gender: Male / Female (Circle one)

3. Occupation of the Primary Wage earner in your household:.....

(No need to be specific – Just the General Area is fine)

4. My child with Cystic Fibrosis is:

- A. My First Born
- B. My Second Born
- C. My Third Born
- D. My Fourth Born.

(Please circle the appropriate answer. If you have more than one child with Cystic Fibrosis, please answer this and the following two questions with reference to the first child only)

5. The age of your child when diagnosed with Cystic Fibrosis:..... (please be as specific as you can here by writing the number of months)

6. The current age of your child with Cystic Fibrosis:.....

Below are a series of general statements. You are to indicate how much you agree or disagree with them. Be as honest as possible. Remember, there are no right or wrong answers to these questions.

Read each item and decide quickly how you feel about it; then circle the number of the item that best describes your feelings. Put down your first impressions. NOTE: First determine if you agree or disagree with the item, and then determine to what extent you feel this (slight, moderate or strong).

Think back to how you felt when you first received the diagnosis of Cystic Fibrosis in your child, and answer all of these items about your feelings and actions **at that time**. (In doing this include all feelings and actions during the year following the initial diagnosis. Please do not include anything beyond this first year.) If you have more than one child with Cystic Fibrosis, please answer with reference to your experience with the first child only.

| | Agreement | | | Disagreement | | |
|---|-----------|----------|--------|--------------|----------|--------|
| | Slight | Moderate | Strong | Slight | Moderate | Strong |
| 1. I tended to be more irritable with others after the diagnosis | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. I frequently experienced angry feelings | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. My arms and legs felt very heavy | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. I had feelings of guilt because my health was good while my child's was not. | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. I felt lost and helpless | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. I had frequent headaches | 1 | 2 | 3 | 4 | 5 | 6 |
| 7. I cried easily | 1 | 2 | 3 | 4 | 5 | 6 |
| 8. Concentrating on things was difficult | 1 | 2 | 3 | 4 | 5 | 6 |
| 9. I felt extremely anxious and unsettled | 1 | 2 | 3 | 4 | 5 | 6 |
| 10. Sometimes I had a strong desire to scream | 1 | 2 | 3 | 4 | 5 | 6 |
| 11. Life had lost its meaning for me | 1 | 2 | 3 | 4 | 5 | 6 |
| 12. I was not feeling healthy | 1 | 2 | 3 | 4 | 5 | 6 |
| 13. I frequently felt depressed | 1 | 2 | 3 | 4 | 5 | 6 |
| 14. I had the feeling that I was watching myself go through the motions of living | 1 | 2 | 3 | 4 | 5 | 6 |
| 15. Life seemed empty and barren | 1 | 2 | 3 | 4 | 5 | 6 |
| 16. I had frequent mood changes | 1 | 2 | 3 | 4 | 5 | 6 |
| 17. Small problems seemed over whelming | 1 | 2 | 3 | 4 | 5 | 6 |
| 18. I lost my appetite | 1 | 2 | 3 | 4 | 5 | 6 |
| 19. I seemed to have lost my energy | 1 | 2 | 3 | 4 | 5 | 6 |
| 20. I seemed to have lost my self confidence | 1 | 2 | 3 | 4 | 5 | 6 |
| 21. I was usually unhappy | 1 | 2 | 3 | 4 | 5 | 6 |
| 22. I was awake most of the night | 1 | 2 | 3 | 4 | 5 | 6 |

Please Check: Did you circle a number for each statement?

These items deal with ways you've been coping with the stress in your life since you found out your child has Cystic Fibrosis. Please answer in regards to how you initially coped with the diagnosis (your coping during the first year). If you have more than one child with Cystic Fibrosis, please answer in response to your coping in relation to the first diagnosis.

There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

| | I haven't been doing this at all | I've been doing this a little bit | I've been doing this a medium amount | I've been doing this a lot. |
|--|----------------------------------|-----------------------------------|--------------------------------------|-----------------------------|
| 1. I've been turning to work or other activities to take my mind off things. | 1 | 2 | 3 | 4 |
| 2. I've been concentrating my efforts on doing something about the situation I'm in. | 1 | 2 | 3 | 4 |
| 3. I've been saying to myself "this isn't real." | 1 | 2 | 3 | 4 |
| 4. I've been using alcohol or other drugs to make myself feel better. | 1 | 2 | 3 | 4 |
| 5. I've been getting emotional support from others. | 1 | 2 | 3 | 4 |
| 6. I've been giving up trying to deal with it. | 1 | 2 | 3 | 4 |
| 7. I've been taking action to try to make the situation better. | 1 | 2 | 3 | 4 |
| 8. I've been refusing to believe that it has happened. | 1 | 2 | 3 | 4 |
| 9. I've been saying things to let my unpleasant feelings escape. | 1 | 2 | 3 | 4 |
| 10. I've been getting help and advice from other people. | 1 | 2 | 3 | 4 |
| 11. I've been using alcohol or other drugs to help me get through it. | 1 | 2 | 3 | 4 |
| 12. I've been trying to see it in a different light, to make it seem more positive. | 1 | 2 | 3 | 4 |
| 13. I've been criticizing myself. | 1 | 2 | 3 | 4 |
| 14. I've been trying to come up with a strategy about what to do. | 1 | 2 | 3 | 4 |
| 15. I've been getting comfort and understanding from someone. | 1 | 2 | 3 | 4 |
| 16. I've been giving up the attempt to cope. | 1 | 2 | 3 | 4 |
| 17. I've been looking for something good in what is happening. | 1 | 2 | 3 | 4 |
| 18. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping. | 1 | 2 | 3 | 4 |
| 19. I've been accepting the reality of the fact that it has happened. | 1 | 2 | 3 | 4 |
| 20. I've been expressing my negative feelings. | 1 | 2 | 3 | 4 |
| 21. I've been trying to find comfort in my religion or spiritual beliefs. | 1 | 2 | 3 | 4 |
| 22. I've been trying to get advice or help from other people about what to do. | 1 | 2 | 3 | 4 |
| 23. I've been learning to live with it. | 1 | 2 | 3 | 4 |
| 24. I've been thinking hard about what steps to take. | 1 | 2 | 3 | 4 |
| 25. I've been blaming myself for things that happened. | 1 | 2 | 3 | 4 |
| 26. I've been praying or meditating. | 1 | 2 | 3 | 4 |

Please Check: Did you circle a number for each statement?

The Following relates to questions regarding living with a chronically ill child. There are no correct or incorrect answers. You are asked to carefully read the questions and possible answers and to circle the number that you feel most accurately reflects your feelings and evaluations.

Please answer in reference to your perceptions in the year following the initial diagnosis. Not your perceptions now.

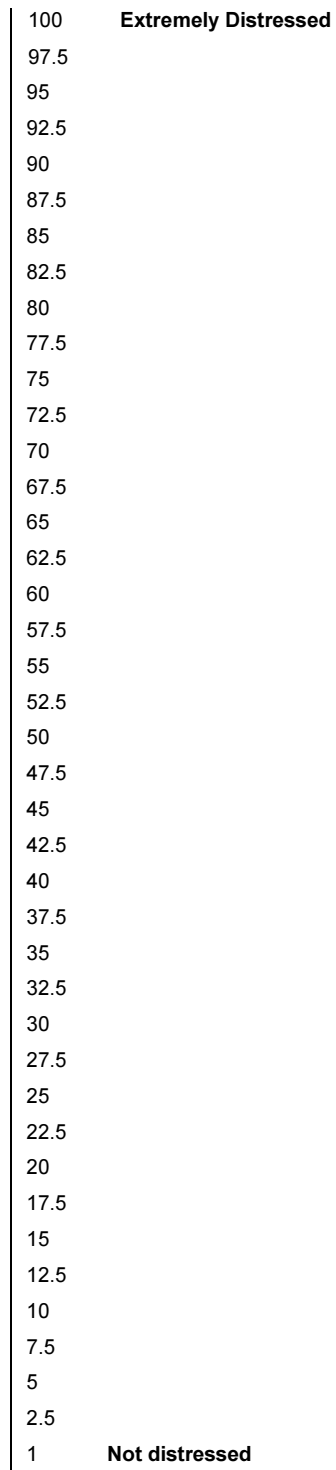
If you have more than one child with Cystic Fibrosis, please answer in response to your perceptions in relation to the child diagnosed first.

| | Totally agree | Somewhat agree | Doesn't affect me much | Somewhat disagree | Totally disagree |
|---|---------------|----------------|------------------------|-------------------|------------------|
| 1. I feel that life with the chronically ill child causes me to grow emotionally. | 1 | 2 | 3 | 4 | 5 |
| 2. I see the chronic illness of the child as a punishment from heaven. | 1 | 2 | 3 | 4 | 5 |
| 3. Since the chronic illness of the child the family has become united. | 1 | 2 | 3 | 4 | 5 |
| 4. Living with a child with a chronic illness has strengthened my ability to love. | 1 | 2 | 3 | 4 | 5 |
| 5. I see the chronic illness of the child as a challenge. | 1 | 2 | 3 | 4 | 5 |
| 6. My personal life has been affected by the chronic illness of the child. | 1 | 2 | 3 | 4 | 5 |
| 7. In making any decision, my first thought is how it will affect the chronic illness of the child. | 1 | 2 | 3 | 4 | 5 |
| 8. The chronic illness has caused me to never give up hope. | 1 | 2 | 3 | 4 | 5 |
| 9. My functioning at work has been affected by the on set of the chronic illness. | 1 | 2 | 3 | 4 | 5 |
| 10. I feel that since the onset of the child's chronic illness my life has stopped. | 1 | 2 | 3 | 4 | 5 |

Please Check: Did you circle a number for each statement?

The following is a “thermometer” scale, rated from 1-100. On this scale, please rate your **current level of upset** when thinking about the time you were told of your child’s diagnosis. Do this by indicating where on the thermometer you rate. The scale is scored from 1 (not distressed) to 100 (extremely distressed).

If you have more than one child with Cystic Fibrosis, please answer in response to the first child and their diagnosis.



This completes the study. Thank you once again for your participation in this important project.

