The Psychosocial Experience of Cystic Fibrosis: An Investigation of Personal Adjustment, Family Relationships, and Wider Community Perceptions of Adolescents and Young Adults with Cystic Fibrosis

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ABSTRACT

Affecting one in every 2500 children born in Australia, cystic fibrosis (CF) is a congenital disease which severely affects an individual’s respiratory and digestive functioning, with a typical presentation including breathing difficulty, recurrent chest infections, unusually salty sweat, infertility, and poor processing of lipids (Cystic Fibrosis Queensland, 2001). In recent years, the prescribed treatment regimens for individuals with CF have improved significantly, greatly increasing the lifespan of this population to around 40 years of age or beyond (Cystic Fibrosis Foundation, 2010); a substantial improvement from an estimate of children with CF surviving to their teens, at best, only three decades ago (Crosier & Wise, 2001). Consequently, the conclusions derived from early research examining the psychosocial adjustment of individuals and families coping with CF may now not be relevant for adolescents and adults with CF (Pfeffer, Pfeffer, & Hodson, 2003). Thus, the aim of the current research was to integrate and apply psychological theories that have been well tested with other chronic illness populations to examine the functioning of families with adolescents and young adults coping with CF.

The current research addressed this aim with three studies; a two-wave quantitative study examining illness perceptions, communication styles and psychological adjustment of young adults aged 16- to 25-years with CF (m = 19.81 years, SD = 2.84 years), and their parents (m = 49.83 years, SD = 5.49 years) over a six month period (Study 1); a cross-sectional quantitative study examining the awareness, knowledge, and perceptions of CF in the wider community which incorporated a sample of non-health based university students (m = 26.32 years, SD = 8.76 years) (Study 2); and a qualitative study utilizing telephone-based semi-structured interviews to more closely examine the individual, familial and social experiences of a subset of the young adults and parents from the longitudinal study (Study 3). The common-sense model of illness (Leventhal, Meyer, & Nerenz, 1980) was utilized to examine individuals’ cognitive representations of CF in the clinical and student-based samples. In addition to this, the social-cognitive processing model (Lepore, 2001) was used to examine parent-child communication in the CF sample and, complementary to indicators of patients’ and parents’ psychological distress, the construct of ‘sense of coherence’, being an individual’s beliefs about the predictability of their world and their ability to face health crises (Antonovsky, 1979), was also included to examine patient and parent adjustment.
Regarding the key findings of these studies, Study 1 demonstrated that: a) problems in parent-child communication and patients’ psychological distress are more likely when patients and parents perceive CF in a negative manner (e.g., having a number of consequences, low treatment efficacy) and b) that patients’ sense of coherence was inversely related to patients’ functioning on measures of psychological distress and was also predicted by both negativity in patients’ and parents’ representations of CF and problems in parent-child communication. From Study 2 it was identified that: a) while members of the general community appeared to be aware of the genetic basis of CF, few individuals had a good understanding of the symptoms associated with CF or implications of living with CF and b) when individuals were unsure of what CF was, they reported more negative perceptions of CF than both the patient and parent samples. Finally, Study 3 identified that for both patients and parents, managing health-related experiences and personal feelings toward CF were central to their experience of CF. Additionally, for patients, managing the implications of CF on personal relationships and interactions with individuals in the wider community were central to their experience. For parents, facilitating children’s CF treatment, and encouraging independence with CF management, as well as endeavouring to maintain other roles (e.g., parent to other children, coping with other life challenges) were also common themes reported.

These results have a number of clinical and theoretical implications. From a theoretical perceptive, this study demonstrated that the common-sense model of illness and the social-cognitive processing model explain significant variance in a range of adjustment indicators of CF patients and parents, and, thus, are appropriate theoretical frameworks for future research with families with CF. Additionally, it was also demonstrated that these models are inter-related and can be used to predict particular elements of patients’ psychosocial adjustment within each of the models. From a clinical perspective, the findings suggest that psychological interventions which focus on the way in which individuals and families conceptualise CF may assist in facilitating parent-child communication and enhancing patients’ psychological adjustment. Finally, these results also suggest that enhancing awareness of CF within the general community may assist in facilitating more favourable perceptions of CF and reduce patient distress arising from individuals’ lack of understanding of CF.
Statement of Originality

I declare that this work has not been previously submitted for a degree of diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another author except where due reference is made in the thesis itself.

Signed:
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CHAPTER 1 – OVERVIEW

Recent medical advances have resulted in a greatly increased life expectancy for individuals with Cystic Fibrosis (CF) (Crosier & Wise, 2001). This disease is now no longer considered to be a fatal disease of childhood; instead, the average life expectancy of an individual with CF in Australia is now approaching 40 years of age (Cystic Fibrosis Australia [CFA], 2010a). Given the increased life expectancy of individuals with CF, the results and implications of research undertaken in the 1980s and 1990s examining the psychosocial adjustment of individuals with CF may now not be so relevant for adolescents and young adults with CF (P. E. Pfeffer, J. M. Pfeffer, & Hodson, 2003). Hence, re-examination and further development of research in this field is required if patients and their families coping with this illness are to have the best chance at optimal adaptation.

When reviewing the current literature examining the psychosocial adjustment of individuals and families with CF, it was noted that few studies have utilised broad psychological theories to assist in the understanding of individuals’ psychological adjustment and family adjustment. However, when examining literature pertaining to other aspects of the patients’ and families’ experiences of CF, such as treatment adherence and social development in children with CF, structured theoretical frameworks have been applied (e.g., D’Auria, Christian, Henderson, & Haynes, 2000; Kettler, Sawyer, Winefield, & Greville, 2002). Thus, in order to provide the best psychological care for individuals and families coping with CF it would appear that the application of psychological theory to the examination of the psychosocial adjustment of this population is an important step towards achieving this goal. The central aim of the current study, therefore, was to test the applicability of two psychological models, which have had noted success in the explanation and prediction of the psychological functioning of individuals and families with a range of other chronic conditions, to the study of the psychosocial adjustment of individuals and families with CF.

The social cognitive-processing model of emotional adjustment to illness (Lepore, 2001), and the common-sense model of illness (Leventhal, Meyer, & Nerenzin, 1980) were applied as the key theoretical frameworks in this research. Lepore’s social-cognitive processing model examines the effect of strained social environments on patients’ cognitive processing of illness-related information. The theoretical basis of this model derives from numerous studies which have indicated that talking with trusted support persons facilitates cognitive processing of emotionally significant events, such as adversities encountered when coping with chronic illness (Clarke, 1993). According
to Lepore and his colleagues, patients reduce their discussion of illness related issues when they do not feel supported by friends and family, which can, in turn, increase patients’ psychological distress (e.g., Lepore, Silver, Wortman, & Wayment, 1996). Leventhal et al.’s common-sense model of illness suggests that the beliefs individuals hold about an illness encompass a number of domains (e.g., perceived symptoms, consequences, duration, cause, and curability) and recent applications of this model have identified that when an individual has negative perceptions of their illness (e.g., low curability, many consequences), these beliefs may contribute to the development of psychological distress (e.g., Millar, Purushotham, McLatchie, George, & Murray, 2005; Rees, Fry, Cull, & Sutton, 2004).

In addition to applying these two models to the examination of the psychosocial functioning of individuals and families coping with CF, an additional outcome measure was utilized in the examination of patients’ and parents’ psychological adjustment in the current research. Complementary to the measures of psychological distress (e.g., depression and anxiety), which are commonly included in studies in the health psychology domain, the construct of ‘sense of coherence’, being an individual’s beliefs about the predictability of their world and their ability to face health crises (Antonovsky, 1979), was also included in the current research. It was considered that this construct was particularly important to include in the current research as previous research with adolescents with CF identified that having a high sense of coherence was associated with more adaptive self-care practices (Baker, 1998). Additionally, recent research has also identified that social support may impact upon individuals’ sense of coherence in times of distress (e.g., Skarsater, Langius, Agren, Haggstrom, & Dencker, 2005). Thus, as the social-cognitive processing model was being used to examine elements of the social environment of CF patients, it was considered that sense of coherence was a particularly important outcome to include for theoretical, as well as practical, purposes.

Regarding the structure of the remaining chapters of the current research, Chapter 2 begins with an overview of the current medical status of CF, which is then followed by a review of literature pertaining to the individual, family-based, and social adjustment of individuals with CF. Chapter 3 then provides a detailed and critical review of the psychological models discussed above for application with the CF population. Following from this, Chapter 4 reviews how these models can be applied to extend the current understanding of the psychosocial experiences of individuals with CF. In addition to this, Chapter 4 also presents theoretical propositions as to how these
models may be inter-related and used in the prediction of particular elements of patients’ psychosocial adjustment within each of the models. In the remaining chapters, three studies testing this theoretical framework are presented.

Study 1, presented in Chapter 5, focuses predominantly on the adjustment of individuals with CF and their parents. In this study, cognitive representations of CF, communication styles within the family and the psychological adjustment of adolescents and young adults with CF and their parents were examined. These constructs were examined both cross-sectionally and longitudinally as data collection was repeated at two points in time, 6 months apart.

Study 2, presented in Chapter 6, presents an examination of the social world of individuals with CF, by examining the awareness, knowledge, and perceptions of CF of individuals in the general community. In this study, an experimental paradigm was also applied to examine whether the receipt of information about CF, and the source of this information, impacts individuals’ perceptions of both individuals with CF and CF more generally.

Finally, a qualitative study is presented in Chapter 7 which more closely examines the individual, familial and social experiences of young adults with CF and their parents. In this study, the sample included a subset of the young adults and parents participating in Study 1. While investigating concepts presented within the theoretical frameworks presented in studies 1 and 2, a semi-structured interviewing procedure was used in Study 3 to allow concepts which may be important to this population, but not covered in the models, to be identified. Following from this, the key findings and implications of all studies included in the current research are reviewed in Chapter 8 and directions for future research are identified.
CHAPTER 2 – THE EXPERIENCE OF CYSTIC FIBROSIS

Cystic fibrosis (CF) is one of the most prevalent congenital diseases, affecting approximately one in every 2500 children born in Australia (Cystic Fibrosis Association of Queensland [CFQ], 2001). While the phenotypic manifestations of CF primarily involve the functionality of the respiratory and digestive symptoms, the life threatening nature of the disease and impact of extensive treatments can also lead to a number of psychosocial implications for individuals with CF. This chapter will first review the medical basis and management of CF. Later sections will then explore the impact that CF can have on an individual, their family, and their social relationships, followed with an overview of approaches to psychosocial intervention with this group.

2.1 Overview of Cystic Fibrosis

2.1.1 Genetic Underpinnings of Cystic Fibrosis

Cystic fibrosis is caused by a mutation on the chromosome pair that is associated with chloride transportation in the sweat glands and the lining of the lungs, liver, pancreas, and digestive and reproductive systems. This abnormality is referred to as the Cystic Fibrosis Transmembrane Regulator (CFTR) protein, and has been attributed to a mutation on chromosome 7. Depending on the severity of the mutation, the problems associated with chloride transportation in individuals with CF can include deficits in the body’s ability to manufacture sweat, mucus and digestive fluids (Centre for Genetic Education [CGE], 2007a). Consequently, the mucus and digestive juices produced by individuals with CF are often overly thick and sticky which can obstruct small ducts and airways. Thus, common symptoms observed in a typical CF presentation include breathing difficulty, recurrent chest infections, unusually salty sweat, infertility and poor processing of lipids, resulting in poor weight gain and offensive bowel movements (World Health Organisation [WHO], 1996a).

Approximately one in 25 people in Australia hold one copy of the gene mutation that is linked to CF and these individuals are usually asymptomatic (CFQ, 2001). Those affected by CF have mutations on both chloride transportation related genes in the cells of the body. Hence, both parents of these individuals are carriers of the genetic mutation. As CF is a recessive genetic condition, a couple who are both carriers of the mutation have a one in four chance of having a child with CF with each pregnancy they have (CGE, 2007a). For individuals with a diagnosis of CF, there are currently over 1000 different mutations recorded for the gene involved in CF, which are classified into...
five different classes of CF. Mutation classes I, II, and III are associated with severe CF presentations (i.e., those with lung and pancreatic involvement) and classes IV and V are associated with more mild CF presentations (i.e., lung difficulties without pancreatic involvement) (Edenborbough & Morton, 2010). Thus, the clinical presentation of individuals with CF is highly variable (Wallis, 2003).

In Australia, CF is usually diagnosed within the first few months of life as all children are entitled to undergo a Neonatal Screening Test soon after birth which screens for a variety of genetic conditions (CGE, 2007b). Antenatal testing is also currently available for pregnant couples who are aware they are carriers of the CF gene. Newborns with a positive test for CF then undergo either (or, in some cases, both) genetic screening or a sweat-test (which assesses sweat chloride levels) to confirm the diagnosis (CFQ, 2001; Rosenstein & Cutting, 1998). Prior to 1990, however, CF was not included in the routine Neonatal Screening Test in Australia; thus, the pathway to diagnosis of CF was usually longer at this time (Balnaves, Bonacquisto, Francis, Glazner, & Forrest, 1995; Department of Health Western Australia, 2010). Parents or medical practitioners usually noted anomalies in the child’s development, such as digestion problems, salty tasting skin or failure to thrive. These concerns were usually referred to a paediatrician for further investigation. Once CF was identified as a potential cause by a paediatrician, a sweat test was usually undertaken (Cystic Fibrosis Foundation [CFF], 2010).

2.1.2 Medical Management of Cystic Fibrosis

The most comprehensive element of CF treatment is centred upon preserving and protecting the respiratory system. Severe breathing difficulties can occur in CF patients as overly sticky mucus can cause blockages in the airways of the lungs, potentially leading to hypoxia. To clear the chest blockages, physiotherapy of the torso, the use of aerosols (e.g., ventolin) and frequent participation in exercise are advocated (CFQ, 2001). The sticky mucus of CF patients also provides a niche for bacterial and viral infections; thus, most patients are also prescribed a variety of antibiotics. Although these procedures may bring some defence to respiratory system in childhood and adolescence; in later years, a lung transplant may be recommended to promote longevity if lung function is significantly compromised by infection and inflammation (Spahr, Love, Francois, Radford, & Meyer, 2007). In particularly acute cases of CF, transplantation may be required in childhood (Burton et al., 2009).
For individuals with severe cases of CF, other aspects of treatment are concerned with the function of the digestive system. For infants, one of the first clinical signs of CF can be a bowel obstruction present at birth originating from either a thickening of the infant’s faeces, or a mucus mass. Intestinal complications affect about one in five newborns with CF and, for about half of these cases, intestinal resection is a necessary treatment (Lu & Esquivel, 2010). Regarding pancreatic and liver involvement in CF, the genetic abnormalities observed lead overly fibrous ducts to develop in the pancreas. This obstructs the flow of enzymes into the stomach for food processing. Furthermore, as with mucus consistency, overly thick bile is produced by the liver which can block bile ducts. Thus, digestion is inhibited and nutrient malabsorption is observed in patients with severe CF. To overcome this, patients are required to ingest a range of enzyme supplements with every meal, and are additionally prescribed a high energy diet and further vitamin supplements (WHO, 1996a). Due to the loss of salt in the body of CF patients, salt replacement therapy (e.g., gastrolyte) may also be recommended to maintain the electrolyte balance (CFQ, 2001).

Recent research has also identified that problems with malabsorption of nutrients and co-occurring chronic inflammation of the lungs and related hypoxia may also lead to anaemia in up to one-third of CF patients (von Drygalski & Biller, 2008). Further complications stemming from abnormal digestive functions include the development of cysts within, and scarring of, both the liver and pancreas. This occurs in approximately 10-20% of CF cases, originating from the accumulation of bile and enzymes in the pancreas and liver, respectively, which attack these organs’ tissues (Bhardwaj et al., 2009; WHO, 1996a). Stemming from this, liver failure and portal hypertension are possible complications of CF. This may lead to the recommendation to pursue a liver transplant (Lu & Esquivel, 2010). Regarding the pancreas, blockages to the exocrine ducts can lead to glucose intolerance and insulin resistance in the body which can ultimately lead to CF-related diabetes (CFRD). Approximately 50% of patients with CF will receive a diagnosis of CFRD by age 30 usually requiring treatment with insulin injection and additional dietary modifications (Adler, Gun, Haworth, & Bilton, 2007; Richards, 2008).

To monitor the clinical status of individuals with CF, a ‘tune-up’ hospital visit is undertaken annually. Tune-ups extend for about two weeks and are attended even when no obvious complications are experienced. In this period, patients also undergo a review of their medication schedule, physiotherapy regimen, nutritional plan and assessment of their coping and adjustment to the illness. It is also common that antibiotics are
delivered to patients intra-venously at this time, especially if severe respiratory infection has been diagnosed (Royal Children’s Hospital Melbourne, 2005; University of Arkansas for Medical Students, 2007).

While CF is a life-threatening disease, the availability of medical treatments for the central symptoms and complications of CF have lead to a greatly increased life-span for individuals with this condition (Crosier & Wise, 2001). While CF was considered to be a fatal disease of childhood two decades ago, for a baby born today with CF, it is expected that they may live to around 40 years or beyond (CFF, 2010). Recent CF patient registry data from Canada (Canadian Cystic Fibrosis Association [CCFA], 2008) and the UK (Dodge, Lewis, Stanton, & Whistler, 2007) estimate the median age of survival for CF patients to now be at least 45 years of age. Thus, while bouts of acute illness or CF-related complications may occur across the lifespan (WHO, 1996a), overall, patient outcomes have substantially improved (CFA, 2010a). Further, following the isolation of the CF gene in 1989, much research has continued into the utilisation of gene therapy for CF treatment. To date, over 400 CF patients have been involved in gene-therapy clinic trials. While a cure for CF may still be a number of years away, significant progress has been made in the last two decades in determining possible cell types for intervention and suitable gene types to be delivered (Griesenbach & Alton, 2009).

2.1.3 Paediatric to Adult Care Transitions

Implied by the congenital nature of CF, the treatment regimens described above are conducted from diagnosis and continued throughout the lifetime of CF patients. In childhood, parents or other caregivers are usually responsible for the execution of these procedures in conjunction with regular health care provider input (CFQ, 2001). To facilitate parental uptake of treatment responsibilities, a number of studies have examined ways to enhance parents’ coping and efficacy with CF treatment responsibilities (e.g., Hodgkinson & Lester, 2002; Mullins, Olson, Reyes, Bernardy, Huszti, & Volk, 1991; Patterson, 1985), as with methods to enhance children’s adherence to physiotherapy and mealtime routines (e.g., Janicke, Mitchell, & Stark, 2005; Modi & Quittner, 2006).

By around the age of 17 years, however, most adolescents have acquired responsibility for the majority of the self-care aspects of CF treatment (Hamlett, Murphey, Hayes, & Doershuk, 1996). It is noted, however, that it is common for adolescents with CF to go through a period of reduced adherence to treatment. While a number of factors are likely to contribute to this, both qualitative and quantitative
research findings suggest that the balancing of physical and psychosocial needs contribute. As such, oppositional behavioural, forgetting and time management problems have been identified as possible barriers to adherence (George et al., 2010; Modi & Quittner, 2006). Furthermore, systemic factors such as lack of understanding of treatments or condition and compromised relationships with health care professionals may also contribute (George et al.; Segal, 2008). Studies are now also beginning to examine the role of mood and adjustment in adherence (Cruz, Mariel, Quittner, & Schechter, 2009).

While most adolescents with CF are involved in the management of self-care responsibilities at home, the age of transition from paediatric to adult hospital care is more variable, and can occur as early as 14 years, or as late as 25 to 30 years (Anderson, Flume, Hardy, & Grey, 2002). It is recommended that early discussion and progression of transition procedures should occur to reduce transition anxiety and resistance in both the individual and their caregivers (Conway, 2004; Cowlard, 2003). Additionally, organisational and collaborative support from both the family and health care providers, and well-informed, graduated increases in responsibility have been identified as key factors associated with a smooth transition process (Conway, 1998; Wang, McGrath, & Watts, 2010; Wedgwood, Llewellyn, Honey, & Schneider, 2008).

Considering both the gravity of the transition process from paediatric to adult care and the number of elements involved in the management of CF, it can be appreciated that the lived experience of CF can at times be challenging for individuals and their families (Ievers & Drotar, 1996). The discussion will now move to an examination of the lived experience of CF, addressing how the typical developmental experiences of individuals may be impacted by living with this condition. A particular focus will be given to the examination of the psychological adjustment of individuals with CF.

### 2.2 Cystic Fibrosis and the Self

#### 2.2.1 Childhood and Cystic Fibrosis

In the first few years of life for a child with CF, health-related and psychological outcomes are most strongly impacted by parental adjustment to the CF diagnosis and parental ability to adhere to the required treatment regime for their child (Quittner, DiGirolamo, Michel, & Eigen, 1992). In particular, poor infant-mother attachment, and poor management of, or poor child response to, CF-related treatments are associated with poorer health and emotional outcomes in younger children (Duff, 2001; Ernst, Johnson & Stark, 2010).
During the school years parental adjustment continues to have a significant impact upon the child’s illness behaviours and coping, with less adaptive family functioning being associated with negative health behaviours (DeLambo, Ievers-Landis, Drotar & Quittner, 2004; White, Miller, Smith & McMahon, 2008). However, across childhood, intra-individual factors also begin to predict both health-related and psychological outcomes.

Overall, research suggests that children with chronic illnesses are at a greater risk for adjustment difficulties than children without chronic illness (e.g., Burke & Elliott, 1999; Lavigne & Faier-Routman, 1992). However, some reviews of children’s adjustment to CF (e.g., Duff, 2001; Berge & Patterson, 2004; Quittner & DiGirolamo, 1998) suggest that the reported range of increased risk for adjustment difficulties is variable, with some studies suggesting no significant differences in adjustment when compared to healthy controls unless physical functioning is severely compromised (Pfeffer et al., 2003).

Nonetheless, it has been reported that the odds of depressed individuals with chronic illnesses being non-compliant to medical treatment is three times higher than that for patients without mood difficulties. Some studies also suggest that anxiety may impact compliance, however the findings are mixed and when found, effects appear to be smaller than those for depression (DiMatteo, Lepper, & Croghan, 2000). While the relationship between psychological functioning and treatment adherence requires further investigation in the CF population (Cruz et al., 2009), treatment adherence has been demonstrated to be a strong predictor of physical functioning in CF (Abbott & Gee, 1998). Thus, it is important that persons involved in the care of children with CF be aware of the most prominent concerns for this population, and the factors that lead to these difficulties. With consideration of these factors, both the psychological and physical functioning of CF patients is more likely to be enhanced (Gotz & Gotz, 2000; Smith & Wood, 2007).

Regarding the psychological adjustment of children with CF, anxiety-based internalising disorders (Bregnballe, Thastum, & Shiotz, 2006; Thompson, Gustafson, Hamlett, & Spock, 1992a; Thompson, Gustafson, George, & Spock, 1994) and oppositional externalising disorders (Thompson et al., 1992a; Thompson et al., 1994) are reported to be the most common presentations in children with adjustment difficulties. Other psychiatric conditions, such as depression, may also occur (Burke & Elliott, 1999), but are less prevalent (Thompson et al., 1992a; Thompson, Gustafson, Gil, Godfrey, & Bennett Murphey, 1998).
Research suggests that children’s perceptions of their CF-related functioning, as opposed to the relative severity of their illness, account for significant variance in their adjustment. Specifically, children’s perception of illness-related stress, efficacy in illness management, and self-worth have been reported to predict overall psychological adjustment (Thompson et al., 1998). Further to this, in parallel with children’s cognitive development in the early primary years, which increases psychosocial awareness, children with CF may develop the perception that they are ‘different’ to their healthy peers and become more aware of the nature and severity of their illness (Ernst et al., 2010; Turkel & Pao, 2007). The realisation of the implications of CF can be challenging for children at this time, leading to psychological distress (D’Auria, Christian, & Richardson, 1997; Williams, Corlett, Dowell, Coyle, & Mukopadhyay, 2009). In addition to this, a study examining the adjustment of 7 to 11 year olds with a range of chronic conditions found that maternal perceptions of the impact of the child’s illness on the family, a child’s perception of parental acceptance, and the child’s perceptions of their physical appearance and social acceptance were positively associated with, and significantly predicted the child’s level of anxiety, depression, and global self-worth (Immelt, 2006).

2.2.2 Adolescence and Cystic Fibrosis

When individuals with CF reach adolescence, the realisation of the severity of their illness may again become apparent, and better understood, as parents usually begin to transfer CF-related treatment responsibilities to their children at this time (Hamlett, Murphy, Hayes, & Doershuk, 1996). It is also noted that pulmonary symptoms typically worsen in adolescence (Hegarty, MacDondald, Watter, & Wilson, 2009; Segal, 2008). Further, recent research also shows that the clinical status of an individual’s CF when entering an adult clinic is associated with survival into later adulthood. A higher body mass index, greater lung capacity, and exclusive use of oral antibiotics at entry into adult care have been identified as factors which increase probability of survival to at least 40 years; whereas more aggressive lung infection (e.g., pseudomonas aeruginosa acquisition) and referral from a paediatric clinic in a low socio-economic area was predictive of death before 30 years of age (Simmonds, MacNeill, Cullinana, & Hodson, 2010). Thus, the importance of keeping up with treatment regimes is usually emphasised to adolescents by individuals involved in their care (Greenop, Glenn, Ledson, & Walshaw, 2010).

It is common though, that while adolescents with CF may recognise the need for emphasis on their health care, normative socio-cognitive changes such as the
development of a sense of infallibility and social re-orientation toward the peer group and away from the family unit may decrease motivation to complete treatment-related activities (Ernst et al., 2010; Konstam, 2007). Thus, mood is often negatively impacted when adolescents perceive that their social interactions and other aspects of ‘everyday’ life are limited by treatment regimes or hospitalisations (Schwartz & Drotar, 2009; Taylor, Gibson, & Frank, 2008a; Venning, Eliott, Wilson, & Kettler, 2008). Gender differences in disease progression also emerge in adolescence, with females generally experiencing greater symptom exacerbation than males (Hegarty et al., 2009).

Consistent with observed changes in clinical status and illness awareness during adolescence, changes are also observed in individuals’ perceived health status during this period. On average, adolescents with chronic illnesses report lower health-related quality of life than younger cohorts without chronic illness (Petersen, Schmidt, Bullinger, & the Disabkids Group, 2006). Further, females are more likely to report lower health-related quality of life than males at this time (Gee, Abbott, Conway, Etherington, & Webb 2003b).

Another common concern of adolescents, which is often exacerbated by CF-related symptoms, pertains to body image. Given the difficulties with nutrient absorption observed in severe CF cases, it is likely that an individual with CF will be of a thin stature even when a high-calorie diet is followed. For adolescent boys, a tall, muscular stature is commonly desired and valued by the peer group (Furnham, Badmin, & Sneade, 2002), which is usually difficult to achieve for males with CF (Segal, 2008; Harrop, 2007). Conversely, for adolescent girls being thin is often desired (Furnham et al.). While it may then appear that adolescent girls with CF may be more confident in regards to body image than their male counterparts, girls may still be embarrassed about eating a high calorie diet as this is not part of the ‘accepted’ image related to being thin in the peer group (Duff, 2001; Furnham et al.; Segal).

In addition to the exacerbation of some of the typical psychosocial challenges of adolescence, there are also specific CF-related concerns that can negatively impact teenagers’ psychosocial adjustment. Although paediatric and adult care facilities may aim to facilitate a smooth transition process for their patients (Conway, 2004), it appears that adolescents and young adults with CF may still hold negative opinions regarding their transition experiences. In a recent qualitative study patients reported that they felt unprepared for their transition, and had concerns around having shorter appointments and having more formal (i.e., less personal and friendly) relationships with the staff in the adult clinics than they had in their paediatric treatment (Tuchman, Slap, & Britto, 2008).
Regarding the psychological adjustment of adolescents with CF, similar patterns to the adjustment of younger children with CF are observed. Anxiety disorders are the most common internalising disorders experienced by older children and adolescents with CF, with significantly fewer mood disorders observed (Goldbeck, Beiser, Hinz, Singer, & Quittner, 2010; White et al., 2008). While it is noted that treatment adherence may decrease for a period in adolescence (Modi & Quittner, 2006), externalising disorders which are commonly observed in younger children with CF (Thompson et al., 1992a), however, decrease in prevalence in the older childhood and teenage years (White et al., 2008).

Comparable to the prevalence of anxiety in the general population, gender differences have been observed in the prevalence rate for anxiety for individuals with CF, with more females experiencing anxiety than males (Goldbeck et al., 2010). Interestingly, White et al. (2008) also noted that increased anxiety in adolescents with CF appears to be associated with increased treatment adherence. It was suggested by White et al. that it is probable that individuals with anxiety disorders are likely to also be anxious about their illness which may lead to a more fastidious approach to illness management. Similarly, Abbott, Dodd, and Webb (1996) reported that increased worry and a reduced sense of personal control over CF was related to greater treatment adherence.

While much of the literature examining the adjustment of teens with CF describes negative outcomes for this group, a review of quantitative studies which have examined young people’s experiences of chronic illness (Venning et al., 2008) also suggest that, by late adolescence, individuals with chronic illness begin to develop a more balanced view of their illness. While Venning et al. did identify themes related to negative perceptions of illness (i.e., feeling uncomfortable in their body and their social world; seeing the illness as disrupting ‘normal’ life), themes related to proactive negotiation and management of chronic illness were also identified (i.e., seeing the experience of chronic illness as not all bad; examining what others can do to help; examining what the individuals themselves could do to enhance coping). The findings from this review are consistent with other studies which have suggested that acceptance of CF and optimism towards the future can assist individuals in coping with their concerns more effectively (Abbott, Hart, Gee, & Conway, 2008; Berge, Patterson, Goetz, & Milla, 2007; Gjengedal, Rustoen, Wahl, & Hanestad, 2003; Pendleton, Cavalli, Pargament, & Nasr, 2002).
In particular, it has been reported that acceptance of illness accounted for unique variance in the prediction of anxiety, depression, and disability in adolescents and young adults with CF (Casier et al., 2008). Thus, while adolescence may be a time when teens experience new challenges related to both typical psychosocial development and specific CF-related issues, further cognitive development in later adolescence allows a more balanced life view to develop (Ernst et al., 2010). This is consistent with the development of coping strategies across childhood, which suggests that a larger repertoire of coping strategies is employed by adolescents than younger children. Having a greater range of available coping strategies allows for greater flexibility and improves chances of adapting effectively during times of distress (Schmidt, Petersen, & Bullinger, 2003).

2.2.3 Adulthood and Cystic Fibrosis

The transition from adolescence to adulthood brings with it a range of new experiences and developmental challenges for individuals both with and without chronic illness. During the late teens and early twenties individuals begin to break away from their family of origin to pursue financial and emotional independence. With this, individuals begin to develop their careers, move away from the family home, pursue romantic relationships and develop their own leisure interests (Santrock, 2005).

For late adolescents and young adults without chronic illness this process is often gradual. For example, children may leave the family home temporarily and return for short or extended periods, or children may achieve semi-independence financially with some support continuing from parents (Konstam, 1997; Lowton, 2002). For individuals with CF transitioning to adulthood, the same process is usually observed, yet the process may be even more gradual (Hamlett et al., 1996; Walters, Britton, & Hodson, 1993). It is to be noted, though, that when independence does occur, young adults with CF often report that they feel as though they are more mature, stronger, sensitive, and compassionate when they compare themselves to their healthy peers. This character development is perceived as being a positive consequence of having CF (Lannon Palmer & Boisen, 2002). This notion has also been noted by Jessup and Parkinson (2010) who discussed that families with children with CF (spanning from toddlers to adult children) appeared to have a particular appreciation for life and a propensity to reflect on life experiences in such a way that promotes personal growth.

For late adolescents and young adults with CF a number of extra factors need to be negotiated when making plans to live outside of the family home and when obtaining
employment than would usually be taken into consideration. Before living independently, individuals with CF need to feel confident in performing daily physiotherapy, keeping stock of, and taking their medications, and scheduling clinic appointments (Lannon Palmer & Boisen, 2002). In addition to confidence in performing self-care activities, it appears that time-management and planning are important factors in actually completing CF-related treatment activities.

White, Stiller, and Haensel (2007) examined treatment adherence in Australian adults with CF and reported that being ‘too busy’ or ‘too tired’ were the most common reasons cited by participants for not adhering to prescribed treatment regimens; being similar to reasons that are also cited for non-adherence in younger populations (George et al., 2010; Modi & Quittner, 2006). An unanticipated finding for White et al. was that individuals who work or study full-time were more likely to adhere to exercise regimes than individuals not in full-time employment. Nevertheless, White et al. also reported that, overall, rates of treatment adherence were lower than medical recommendations for the group as a whole. Results from qualitative research suggest, however, that adults with CF will often improve their adherence rates, at least temporarily, following negative health consequences from non-compliance (Berge et al., 2007). This finding is consistent with a recent review of health behaviour which suggested that somatic changes are a common trigger for patient-initiated health practitioner visits, even in the context of ongoing health concerns (H. Leventhal, Weinman, E. Leventhal, & Phillips, 2008).

When individuals with CF consider moving away from home or explore work or study opportunities, logistical factors also impact decisions made. Factors such as distance from the individual’s CF clinic, or at least proximity to a local hospital or medical surgery are usually taken into consideration. Living closer to a treatment facility decreases both travel time and the likelihood of treatment-related activities being perceived as having an undue impact on other life commitments. Further, easier access to medical assistance may also provide individuals with CF a greater sense of support or security if an infection was acquired or any other acute complication occurred (Lannon Palmer & Boisen, 2002). Given parents are identified as a primary support person for illness-related concerns for adult patients, individuals with CF may also choose to live within close proximity to their parent’s home (McGuffie, Sellers, Sawicki, & Robinson, 2008; Walters et al., 1993).

Similar considerations are usually taken into account when individuals with CF consider travelling overseas. Individuals need to ensure that adequate medical care will
be available if required and sufficient medications are collected before departure or can be replenished in the desired destination. Travel is also usually preferred with a close friend or relative as a travel buddy (CFA, 2010b).

Regarding the attainment of employment or engaging in further study, again both CF-specific and logistical factors, such as proximity of treatment facilities, have been demonstrated to be influential. Illness status may impact an individual’s decision to pursue work or study. In general, individuals with more severe illness and treatment commitments are less likely to obtain employment or begin study (Havermans, Colpaert, Vanharen, & Dupont, 2009). Research also indicates that employers’ perceptions of individuals with CF may also influence the likelihood of actually obtaining employment when it is desired. Edwards and Boxall (2010) reported that individuals with CF often get the sense that they are perceived as ‘sick’ and considered less able to work effectively than individuals without CF. Concordantly, other research findings suggest that individuals with CF are more likely to be employed if they do not disclose their illness to their employer (Walters et al. 1993). It is suggested than an employer’s medical understanding of CF and their ability to accommodate any needs of an individual with CF (e.g., space to complete treatments) is likely to influence whether or not an individual with CF will be considered for a position (Edwards & Boxall).

While it is noted that individuals with CF who pursue work or study opportunities may have less severe disease and fewer treatment commitments, it appears that either work or study has a reciprocally positive effect on perceptions of health-related quality of life status. A recent study examining the psychosocial impact of employment on adults with CF (predominantly in their mid 20s) reported that, even after controlling for medical status (e.g., lung capacity, body-mass index, pseudomonas aeruginosa status), participants who worked or studied part- or full-time reported better physical and social functioning and stronger perceptions of role engagement than participants who did not work (Havermans et al., 2009). Thus, while there may be challenges to obtaining employment for individuals with CF, it appears that there are additional benefits to achieving financial independence when employment is obtained.

Examining the development of romantic relationships for individuals with CF, research indicates that the majority of young adults with CF have been involved in a serious romantic relationship or have dated by the time they reach adulthood (e.g., Modi, Quittner, & Boyle, 2010). Likewise, no differences were found between adults with CF and healthy controls in regards to living arrangements, with comparable percentages of individuals from both groups co-habiting with a partner or spouse.
(Goldbeck et al., 2010). It does appear, however, that some individuals with CF perceive that their illness does impact their relationships. One study suggested that one-third of men and one-quarter of women perceive that their CF makes it difficult to establish or maintain romantic relationships (Gee, Abbott, Conway, Etherington, & Webb, 2003a). Yet, encouragingly, no relationship was found between illness severity and marital satisfaction for couples with one partner with CF (Delelis, Christophe, Leroy, Vanneste, & Wallaert, 2008).

One area which may be a concern in relationships for individuals with CF, however, pertains to sexual and reproductive functioning. Individuals with CF are more likely to report less satisfaction with sexual activity than a healthy comparison group (Shepherd et al., 1990) and women with CF commonly describe themselves as not being sexually attractive (Coffman, Levine, Althof, & Stern, 1984). Men with CF may too hold psychosexual concerns, with some men feeling emasculated by reduced fertility (Sawyer, Tully, Dovey, & Colin, 1998). Infertility in males arises from the gene anomalies associated with CF causing obstruction of the vas deferens and seminal vesicles. However, as viable sperm is still produced in males with CF, they are able to father children if in vitro fertilisation (IVF) is used (Edenborough & Morton, 2010; Tsang, Moriarty, & Towns, 2010). To the current author’s knowledge, no studies have yet examined whether negative perceptions of reproductive ability in males with CF changes after having a partner give birth following IVF treatment.

For women with CF, the ovaries are unaffected by the genetic anomalies associated with CF. Some reduction in the ability to conceive may be observed due to the cells of fallopian tubes, uterus, cervix and vagina being affected by abnormalities in chloride transportation which can lead to the production of sticky mucus in these regions (Tsang et al., 2010). But, for most women, a natural conception is possible (Edenborough & Morton, 2010). While there is some debate in the literature as to whether pregnancy has a negative effect on CF health status, most recent research suggests that pregnancy does not significantly shorten the lifespan of women with CF. However, pregnancy may be risky for women with significant CF-related complications or those who are experiencing transplantation organ rejection prior to conception (Goss, Rubenfeld, Otto, & Aitken, 2003; Edenborough & Morton).

Given the number of developmental tasks faced during the transition from adolescence to adulthood, this can be a challenging time for all young people (Konstam, 2007). As there are additional factors considered during this process for individuals with CF, it is not surprising that the literature tends to suggest that this group experiences a
greater incidence of psychological difficulty than healthy peers. In a sample of German CF patients and community controls (Goldbeck et al., 2010), it was found that while adolescents with CF did not differ to individual controls in the frequency of anxiety or depression, differences in rates of anxiety were observed between young adults and controls. Individuals with CF were found to have elevated anxiety scores. However, no differences were found in rates of depression for those with and without CF in the young adult and older adult groups.

Other findings from Goldbeck et al. (2010) suggested that, across the age cohorts, significant differences were found in rates of both anxiety and depression. The frequency of both clinical presentations increased from young adulthood to older adulthood. Further analyses indicated that the increase in the frequency of depression across adulthood was greater for persons with CF than community controls, and overall, women were found to have higher anxiety scores than men. Goldbeck et al. also examined the relationship between mood and CF disease severity. It was concluded that life threatening events, such as transplant listing increased the risk of depression in individuals with CF; whereas more acute health events, such as the a recent diagnosis of CF-related diabetes, presented greater risk for the experience of anxiety.

Similar to Goldbeck et al.’s (2010) findings, Sawicki, Sellers, and Robinson (2008) found that half to two-thirds of adults with CF reported anxiety and depressive symptoms (i.e., worrying; irritability and sadness). Further, females reported a significantly higher frequency of worrying and irritability than males. However, other authors have reported comparable rates of anxiety and depression in adult samples of individuals with and without CF (Havermans, Colpaert, & Dupont, 2008). Further, in a sample of adults aged 18 to 49 with CF, no significant effects of gender, age, or illness severity were found for a number of psychological parameters (Anderson et al. 2002). It is noted that Goldbeck et al.’s sample (670 participants) was significantly larger than that of most other studies on the psychological adjustment of adolescents and young adults with CF. Thus, the non-significant results found in Havermans et al. and Anderson et al.’s studies may reflect reduced power in their analyses, or the sampling of a more well-adjusted group of participants. It is also noted that for individuals with CF who may not experience clinical levels of distress, health-related events, such as health exacerbations or complications stemming from CF may lead to periods of transient distress (Collins & Reylonds, 2008).

Taken together, it appears that adults with CF appear to be at greater risk for adjustment concerns and psychological distress than younger cohorts. Yet, as
highlighted in the discussion of the adjustment of younger children with CF and the transition to adulthood, CF is not a journey that is experienced alone. Parents play a central role in supporting their children’s well-being in childhood and later support their transition to managing their illness independently and achieving other forms of independence in adulthood (DeLambo et al., 2004; Ievers & Drotar, 1996). The current discussion will now turn to a review of the experience of CF for parents and the family as whole.

2.3 Cystic Fibrosis and the Family

2.3.1 Parental Adjustment

The receipt of the diagnosis of CF for a child can be highly distressing for parents. It is acknowledged that the initial period following diagnosis is particularly challenging as parents need to learn the particulars of their child’s illness and the treatments needed to be carried out at home to keep them healthy (Carpenter & Narsavage, 2004; Jedlicka-Kohler, Gotz, & Eichler, 1996; M. Kharrazi & L. Kharrazi, 2005). This becomes even more challenging if parents are having their first child as they are usually learning to manage more generic aspects of parenting (e.g., feeding and bedtime routines) while coping with their emotional responses to the diagnosis and managing typical household stressors (e.g., financial concerns) concurrently (Eiser, Zoritch, Hiller, Havermans, & Billig, 1995).

Greater illness-specific and general stress levels, as well as increased incidence of mood disturbance, are observed in parents of CF children when compared to parents of children without chronic illness (Quittner, DiGirolamo, et al., 1992). Specifically, recent research suggests that up to 50% of parents of children with CF may experience clinically significant symptoms of anxiety and up to 30% of parents in these families may experience clinically significant symptoms of depression. Dual presentations are also common (Driscoll, Montag-Leifling, Acton, & Modi, 2009).

Within families coping with CF, mothers commonly report greater levels of anxious and depressive symptoms than fathers (Driscoll et al., 2009; Mullins et al., 1991). This pattern is likely to be associated with the general finding that mothers have a more central care-giving and family management role within families with children with CF when compared to fathers (Hodgkinson & Lester, 2002; Nagy & Ungerer, 1990) and when compared to mothers in families not affected by chronic illness (Quittner, Opipari, Regoli, Jacobsen, & Eigen, 1992). This finding is also consistent with distress levels observed between mothers and fathers of childhood cancer patients (Sloper, 2000).
It is noted, however, that social norms may impact fathers’ reporting of emotional difficulties. More traditional social norms suggest that males should show more control over emotions and display less vulnerability to distress than females. Such norms decrease the likelihood of men expressing emotional distress and seeking assistance, either professionally or among social networks (Moller-Leimkuhler, 2002; Stanton, Revenson, & Tennen, 2007). Consistent with this notion, a recent qualitative study of fathers’ perspectives of caring for a child with CF suggested that men do experience a number of emotional difficulties associated with this role and, at times, do not feel comfortable expressing these difficulties (Hayes & Savage, 2008). Common themes reported among fathers included constant worries about child’s health, difficulty discussing their concerns about CF, and a tendency to focus on the present in order to avoid experiencing distress related to difficulties their child may face in the future. Thus, it appears that while mothers of children with CF may report more difficulties than fathers, fathers’ distress can still be significant (Driscoll et al., 2009; Esdaile & Greenwood, 2003).

Examining the factors that lead to increased psychological distress for parents of children with CF, the literature suggests that both illness-specific factors and more general risk factors contribute to the development of psychopathology. Driscoll et al. (2009) reported that, for mothers of children with CF, depressive symptoms increased as child lung function decreased and as their own anxiety levels increased. Yet, for fathers, depressive symptomology was only associated with mothers’ levels of depression, and their own anxiety level. Fathers’ depressive symptomology increased as their anxiety increased and as mothers’ depression increased. The overall health status of the child, however, was not associated with the anxiety levels of either the mother or father. In an older study examining adjustment of mothers of children with CF (Thompson, Gustafson, Hamlett, & Spock, 1992b), elevated child illness severity was associated with increased maternal anxiety. Another study by Driscoll and her colleagues (Driscoll, Johnson, Barker, Quittner, Deeb, & Geller et al., 2010) also examined predictors of depression in caregivers of children with CF or Type 1 Diabetes. These results suggested that increased family stress and lack of employment outside of the home are also risk factors for caregivers’ distress.

Other research also suggests that particular coping strategies are also related to parental adjustment in families of children with chronic illness. Frequent use of self-blame predicted higher levels of depression in parents of children with CF, and frequent use of behavioural disengagement predicted increased anxiety in this group (Wong &
Heriot, 2008). In a study of parental adjustment in paediatric cancer, self-blame was also reported to be positively related to parental anxiety and depression. For this sample, increased substance use was also associated with elevated levels of depression and the use of active coping was a protective factor in predicting anxiety (Greening & Stoppelbein, 2007).

A number of studies have also identified the positive influence that a strong support network from both within the family (e.g., Coyne, 1997; Greening & Stoppelbein; Thompson et al., 1992b) and that from health professionals (e.g., Coyne; Hodgkinson & Lester, 2002) can have on parents coping with their child’s chronic illness. Thompson et al. reported that family supportiveness was inversely related to anxiety in mothers of children with CF and Greening and Stoppelbein reported that increased use of social support reduced anxiety in mothers of child cancer patients. Recent research has also identified that parents’ use of religion as a coping mechanism following their child’s diagnosis of CF may lead to better psychological adjustment over time (Grossoehme et al., 2010).

2.3.2 Family Functioning

While previous sections have examined predictors of both child and parent coping and adjustment, including an examination of the child’s illness factors on parent adjustment, the reciprocal effect of each party’s psychological adjustment has been less well examined. However, there is a body of literature to suggest that psychological functioning of individuals within a family and the functioning of the family as a unit can impact each family member’s adjustment.

Following from the coping literature discussed above, research findings also indicate that parental coping style can have a significant impact upon children’s adjustment in families with CF. Wong and Heriot (2008) reported that among parents, use of self-blame and experience of despair for their child’s future predicted difficulties in children’s psychological adjustment. Conversely, if parents were hopeful about their child’s future, this promoted more adaptive child adjustment.

While the findings are mixed as to whether having a child with a chronic illness enhances a family’s likelihood of having difficulties in family functioning (Herzer et al., 2010), a review of the impact of family functioning on the adjustment of children and adolescents with chronic illness identified a general trend for greater family conflict and greater parental maladjustment to be associated with increased patient psychological distress and behavioural disturbances (Drotar, 1997). There is also additional evidence
from prospective research to suggest that less adaptive family functioning can also negatively impact the health status of children with CF over time (Patterson, McCubbin, & Warwick, 1990).

Other research with paediatric cancer survivors suggests that the quality of relationships with parents in adulthood is related to the quality of other adult relationships in the survivors’ lives. The results of a cross-sectional study suggested that having a more influential (e.g., assisting in organisation of the child’s activities) and encouraging relationship with fathers predicted a lower chance of having poor adult relationships; and having more involved and discordant relationships with mothers increased the chance of having poor adult relationships (Hill, Kondryn, Mackie, McNally & Eden, 2003). These findings are consistent with research with families with a range of childhood chronic illnesses which reported that greater involvement from fathers was related to decreased maternal distress, increased marital satisfaction and more favourable family functioning (Gavin & Wysocki, 2006).

Hill et al.’s (2003) findings are also concordant with research suggesting that parental over-involvement can negatively impact the psychological functioning of children and adolescents (Cappelli, McGarth, McDonald, Katsanis, & Laselles, 1989; Durst et al., 2001) and adults (Peek, 2001) with CF. Interestingly, Cappelli et al. reported that parents of healthy children and those with CF did not differ on estimates of maternal and paternal care and over-protectiveness. However, maternal and paternal, over-protectiveness of children with CF was found to be significantly related to child psychological adjustment, whereas this relationship was not found for families with healthy children. For healthy families, maternal care and paternal control were related to children’s adjustment.

Thus, it appears that both the involvement of mothers and fathers in families with children with chronic illness impact their child’s outcomes, but with each parent having different roles. It seems that while mothers’ support is crucial in the management of illness in younger years, the process of ‘letting go’ and supporting a child’s autonomy is also an important process. Conversely, it appears that consistent involvement from fathers enhances child and family adjustment.

The literature also suggests that measures of overall family functioning are not only significant predictors of children’s adjustment in families coping with chronic illness, but also predict parental adjustment. Using a sample of families with children with a range of chronic conditions, it was identified that parental perceptions of family cohesion (i.e., supportiveness, openness of communication, interaction of family
members) significantly impacted upon their psychological adjustment (Dewey & Crawford, 2007). A more general finding from this study was that parents with children who have chronic illness reported significantly less family cohesion than parents of healthy children.

Regarding further effects of family cohesion on the adjustment of families, it appears that the psychological adjustment of siblings and the functioning of parents as a couple are also impacted. It is suggested that families cope more effectively with childhood chronic illness when the illness demands are ‘put in their place’ and balanced with the physical and psychosocial needs of all members of the family (Cohen, 1999). However, most families report that achieving this balance can be difficult and, at times, parental relationships with each others and with non-ill children may be compromised (Cohen; Quittner, Opipari et al., 1992; Foster, Eiser, Oades, Sheldon, Tripp, & Goldman et al., 2001).

The available literature tends to indicate that couples with children with chronic illnesses are at a higher risk for martial problems than couples with healthy children (Quittner & DiGirolamo, 1998). For both mothers and fathers, conflicts over child-rearing practices and reduced recreational time have been identified as factors which predict decreased marital satisfaction. Additionally, frustration in their role in the family accounted for significant variance in marital satisfaction for mothers, whereas couple interaction was another significant predictor of marital satisfaction for fathers (Quittner, Espelage et al., 1998).

Examining the adjustment of siblings of children with chronic illness, a meta-analysis of studies published between 1967 and 2000 suggested that this group are at greater risk of psychosocial distress than children without siblings with a chronic illness (Sharpe & Rossiter, 2002). In particular, internalising presentations were the most common concern in siblings of children with chronic illness. Sharpe and Rossiter suggested that this may be related to the general observation that siblings often assist in the care of a sibling with chronic illness, and while they may comply with parental and sibling requests for assistance, frustration may still be experienced as a part of this role. Other authors have also acknowledged that even when siblings are accepting of the care needed for their ill-siblings, concern and worry for their sibling’s health is also likely to contribute to the emotional adjustment of siblings of individuals with chronic illness (Murray, 2000).

Other reviews of the literature on sibling adjustment (i.e., Bluebond-Langner, 1996) have also suggested that while there may be some evidence to suggest that
siblings of ill children are at increased risk of distress, major psychological disorders may still be relatively rare. Instead, more transient periods of dysfunction may be more common following particular stressors, and issues with social adjustment may be more greatly impacted than overall psychological functioning. Further, Bluebond-Langner’s review and discussions on sibling adjustment also acknowledged research which suggests that siblings of ill children may experience some developmental gains from their experiences in that they may develop an increased sense of empathy, sensitivity and maturity at a young age.

Other research has identified circumstances which may lead to increased risk for psychological distress in siblings. Distress may be experienced if siblings perceive that they are not receiving as much attention from parents or have as much individual time spent with their parents as their ill sibling receives (Foster et al., 2001; Quittner & DiGirolamo, 1998; Quittner & Opipari, 1994). In accordance with this finding, based on the themes derived from qualitative research with families with a child with CF, Bluebond-Langner (1996) discussed that parental attempts to ‘normalise’ their ill child’s experience of illness by endeavouring to treat these children equally to other children (e.g., splitting up chores evenly between all siblings) usually has a positive impact on siblings’ perceptions of family dynamics and their overall adjustment.

Bluebond-Langner (1996) also discussed that sibling adaptation to and perception of CF is largely impacted by the ill child’s adjustment and their parental approaches to illness management and to coping with the child’s illness. Likewise, Murray (2000) noted that outcomes for siblings can also be impacted by the amount of support they receive from their parents, wider family members and professionals. As with the adjustment of parents, the greater the social supports available for siblings, the greater the likelihood of positive adjustment.

2.3.3 Cystic Fibrosis Treatment – Family Processes

Up to this point, the discussion of the impact of indicators of family functioning has been related to adjustment parameters in only the psychological domain. Yet there is further evidence to suggest that family functioning can also impact the transfer of CF treatment responsibilities from parent to child in the later childhood and adolescent years which may ultimately impact health outcomes (DeLambo et al., 2004).

It is generally observed that parents decrease their involvement in the management of their child’s CF treatments across adolescence. It is noted, however, that parents may re-engage in their monitoring or assistance with treatments if adolescents
are presumed to not be adhering to their treatment regimen, or if symptoms exacerbate (Modi, Marcie, Slater, Drotar, & Quittner, 2008). Qualitative explorations of the transfer of the responsibility for physiotherapy for CF from parent to child (Huyard, 2008; Williams, Mukhopadhyaym Dowell, & Coyle, 2007) have also noted this pattern of ‘re-negotiation’ of treatment responsibility across childhood and adolescence.

Other investigations have examined predictors of treatment adherence in older children and adolescents (DeLambo et al., 2004) and adults (Kettler, Winefield, Sawyer, & Greville, 2001) with CF and identified the role of family functioning in this treatment transfer process. The results of these studies indicated that family relationship quality was positively related to child’s treatment adherence. Qualitative research also suggests that children with chronic illness feel more comfortable being involved in collaborative decision making about treatment decisions and treatment responsibilities when they feel that their parent is genuinely requesting their input and will be responsive to their suggestions; in short, when they perceive their opinion as being truly valued (Miller, 2009). Children in this study also reported that they were less likely to engage collaboratively with parents when they sensed they were in a ‘bad mood’ or had a tendency to worry excessively. Another qualitative study with young adults and health care specialists also identified that transfer of treatment responsibilities from parent to child may be more difficult when a parent is experiencing psychological distress or is having trouble ‘letting go’ of their care-giver role (Iles & Lowton, 2010). This was noted by both the young adults with CF and health care specialists.

Parental adjustment and mood during treatment transition may also be impacted by additional stressors that may derive from the co-ordination of their child’s treatment (Coyne, 1997). Recent findings suggest that when the transition from paediatric to adult care is disjointed, or if children required assistance from multiple units, parents may often be required to play an organisational role in the co-ordination of services. As parents are likely to be unfamiliar with the new service providers, service co-ordination can be burdensome (Miller et al., 2009).

Thus, given the literature previously discussed identifying the impact of parental over-involvement on child outcomes and also the prevalence of parental distress in families with a child with chronic illness, it is suggested that a number of families with adolescents with CF may be experiencing difficulty with the treatment transfer process. Accordingly, a number of researchers and medical professionals have begun to derive psycho-educational programs to assist children in gaining responsibility for their treatments and to assist parents in ‘letting go’ of their central carer role. One family
Based program reported encouraging results with increases in knowledge, self-management and positive coping of children, including adolescents (Bartholomew et al., 1997).

While there may be obstacles to overcome in the transition process, by the time individuals with CF reach adulthood most have assumed responsibility for the majority of their treatments (Hamlett et al., 1996). It is noted, however, that even if an individual with CF is living away from home and may have a partner or friends who are able to assist them with treatments if necessary, family members may still be called upon to provide care or support during periods of acute severe illness or prolonged difficulty (McGuffie et al., 2008). Hence, it appears that parents may continue to play a key role in supporting their child with CF throughout their lifetime even if, at times, parental involvement is resisted.

Given the range of treatment responsibilities and family co-ordination roles that parents may adopt in managing both their child’s illness and general home duties, it is not surprising that there are research findings to suggest that some aspects of the bond between parents and their ill child may be negatively impacted. The results of an Australian study have indicated that although adolescents reported that family members and friends provided them with equal amounts of emotional support, adolescents perceived the family as providing significantly less companionship than friends (Graetz, Shute, & Sawyer, 2000). Graetz et al. also identified that unsupportive behaviours from the patients’ family and friends (e.g., perceived ‘nagging’ to take medications, disparaging remarks being made about the young person) predicted decreased psychological adjustment. Conversely, supportive behaviours in the social network were found to have no significant relationships with outcomes, suggesting that negative experiences have a larger impact on adjustment than positive experiences. Given the frustration that parents may experience when attempting to transfer treatment responsibilities to what may seem at times to be an unwilling recipient (Foster et al., 2001), it seems fair to assume that parental reminders to engage in treatment may have a negative impact on adolescents if this frequently occurs.

Integrating these research findings surrounding family functioning and patient outcomes, it would appear that although the parents of children with CF provide a tremendous amount of practical support for their children, difficulties may arise in providing support in other domains (Graetz et al., 2000). The general and illness-specific stressors that parents of children with CF experience may detract from their ability to provide the level of emotional support required to assist their children in
coping effectively with their own concerns. Findings such as these have lead to the
suggestion that the peer network is also important in the well-being of individuals with
CF; a suggestion endorsed in recent research (e.g., Herzer, Umfress, Ajaddeff, Ghai, &
Zakowski, 2009). The discussion will now turn to an examination of peer relationships
for individuals with CF, identifying both their role in supporting psychosocial
development and challenges that may arise in these relationships.

2.4 Cystic Fibrosis and the Social World

2.4.1 Positive Peer Relationships

Beginning in childhood, the formation of relationships outside of the family unit
is a key aspect of psychosocial development (Santrock, 2005). In adolescence and
young adulthood, these relationships are particularly relevant as individuals begin to
form their own identity and interact with others with whom they feel similar and
connected to. Central to this, the sense of being accepted by peers and developing
intimate friendships and romantic relationships becomes particularly important as the
experience of positive peer interactions can be indicative of both concurrent and future
psychosocial functioning of adolescents (Ernst et al., 2010; Gumpel & Ish-Shalom,
2003; Konstam, 2007; Taylor, Gibson, & Frank, 2008b). Further, an individual’s
perceived failure or success at these psychosocial tasks of adolescence has the potential
to impact motivation and performance in academic (Guay, Boivin, & Hodges, 1999)
and vocational (Tan, Toomey, & Hawkins, 2000) pursuits.

Herzer et al. (2009) examined the effect of cross-domain buffering in social
supports for children aged 11 to 18 with Type 1 diabetes, asthma, and CF. Herzer et al.
postulated that support from friends may buffer against distress attributed to
problematic relationships with parents (i.e., over-protection and rejection), and positive
relationships with parents would buffer against negative outcomes stemming from
problematic relationships with peers (i.e., rejection). The results of this study indicated
that negative effects of parental overprotection and rejection, such as decreased child
health-related quality of life, decreased self-concept, and increased emotional/
behavioural difficulties, were only observed for children reporting low peer support. For
children reporting high levels of peer support, only minimal negative effects from
problematic relationships with parents were noted. Conversely, the results of this study
did not find evidence to suggest that supportive relationships with parents buffer the
negative impact of problematic peer relationships on children’s mental health.
Thus, Herzer et al.’s (2009) results suggest that peer relationships provide adolescents with chronic illness with a unique form of support that parents may not be able to provide. These results also extend upon Graetz et al.’s (2000) results, discussed in the previous section, which suggested that unsupportive behaviours from family and peers may have a greater impact on psychological health than supportive behaviours. Similarly, the results of another recent empirical study suggest that while children with CF, on average, do not experience significantly more bullying or ostracism than healthy children, they react more strongly and perceive this as a threat to having psychosocial needs fulfilled (e.g., having a sense of belonging, having control over the environment, having a meaningful existence and having a good sense of their self-esteem). This highlights the value of close peer relationships for individuals with CF (Twyman et al. 2010).

In a review of literature examining the experience of living with a chronic illness in adolescence, Taylor et al. (2008b) identified the most common themes that were presented across relevant studies. Taylor et al. also reported that adolescents rated developing and maintaining friendships as the most important aspect of their lives, followed by being normal/getting on with life, the importance of family, attitude to treatment, experiences of school, relationship with the healthcare professionals, and the future. Within the domain of developing and maintaining friends, Taylor et al. discussed that adolescents report the most positive adjustment when they were able to interact fully with their friends and ‘do the things that they do’ (p. 3085). It has been noted, though, that this is often complicated by the treatment regimes required to maintain health which can greatly impact the availability of spare time to interact with friends for children with chronic illness (Christian & D’Auria, 1997). For individuals with CF who are able to engage in sports as a part of their treatment regimen, however, there is evidence to suggest that this may assist in facilitating some social interactions (Hebestreit, Bar-Or, & Muller, 2003).

2.4.2 Challenges in Peer Relationships

As exemplified above, for adolescents and young adults coping with a chronic illness, such as CF, the normal psychosocial challenges of adolescence and young adulthood may be complicated by aspects of coping with their illness (Pfeffer et al., 2003; Taylor et al., 2008b). One particular factor which causes much angst during the establishment of friendships is the decision of whether or not to disclose that one has a chronic illness (La Greca, Bearman, & Moore, 2002). Graetz et al. (2000) reported that
20% of the adolescents with CF who were interviewed in their research expressed concerns about disclosing their diagnosis to their friends. Consequently, disengagement with peers was reported by some individuals, which greatly limited their social network. Extending these observations, more recent studies (i.e., Badlan, 2006; Gjengedal et al., 2003; Taylor et al., 2008b) have also identified that some adolescents with CF may actively try to conceal their illness and related treatments or forgo treatment regimens in an attempt to ‘feel normal’, have more time for social interaction and to avoid rejection by their peers.

Communication and relationship research, however, suggests that increased self-disclosure in close friendships is likely to strengthen these relationships by increasing their level of intimacy (Graham, Huang, Clark, & Helgeson, 2008; Magsamen-Conrad, Greene, Banerjee, & Bagdasarov, 2008). Thus, adolescents and young adults with CF may increase the quality of their close friendships by disclosing their health status. Additionally, Panchankis (2007) has also emphasized the negative psychological impact of trying to conceal a stigma over a prolonged period of time. Thus, disclosing one’s illness status may also reduce psychological tension and concerns about being ‘found out’ (Lowton, 2004). Yet, these benefits do not necessarily hold when considering the impact of disclosing one’s illness to a wider social network, such as the peer group as a whole.

In a review of peer relations of youth with chronic health conditions, La Greca et al. (2002) suggest that the visibility of an illness and the impact it has on participation in social activities moderates the relationship between disclosure to the larger peer group and social outcomes. It appears that when an illness does not have any ‘visible’ symptoms, and there is little impact on social participation, disclosure to the peer group may not be detrimental to the young person. However, illnesses with noticeable physical symptoms and those that reduce the ability of the young person to engage in social activities may be associated with negative reactions from the peer group when the illness is disclosed. La Greca et al. also discussed that peer group factors such as developmental age and gender may also impact the relationship between disclosure and peer acceptance.

Accordingly, Christian and D’Auria (1997) noted that children with CF report that disclosing their illness status to peers can be the most challenging when younger. This is most likely due to limitations in cognitive ability leading children to have difficulty in explaining how their behaviours (e.g., taking tablets at lunch times) relate to symptoms and their overall diagnosis. From adolescents’ reports of their childhood experiences, it appeared that peers responded best to more concrete information that
was related to specific symptoms that did not involve discussing CF (e.g., “I take pills to help me digest my food). Adolescents reported that their peers often confused CF with other illnesses, such as AIDS, which lead to unfavourable evaluations.

Considering the results of empirical studies examining peer interactions of chronically ill adolescents, it appears that individuals with CF may experience some level of mistreatment by peers (e.g., Meijer, Sinnema, Bijstra, Mellenbergh, & Walter, 2000), although the findings are mixed (e.g., Twyman et al., 2010). Meijer et al. identified that adolescent girls with CF displayed a higher level of assertive behaviour than healthy girls and suggested that this may develop from having to cope with negative peers reactions. This pattern was not, however, found for boys, who tended to have lower social skills than healthy boys. Meijer and colleagues suggest that, for boys, a response to negative peer interactions that is perceived as aggressive may lead to physical altercations which chronically ill boys may not be physically equipped to handle. Hence, more submissive responses to peer reactions may be more common.

Qualitative research with adults with CF suggests that the processes through which individuals decide to disclose their illness or not are somewhat different to that of children. Specifically examining CF disclosure within the family context, it has been reported that if individuals with CF, or their parents discussed CF with family members it usually occurred as a process of enlisting social support (Coates, Gregory, Skirton, Gaff, Patch, & Clake et al., 2007). However, Coates et al. also noted that, given the recessive genetic nature of CF, some individuals may feel obligated to disclose in order to inform other family members of genetic risk of having a child with CF.

In a broader examination of disclosure, Lowton (2004) reported adult accounts of CF disclosure appear to fall along a continuum. In situations where it is unlikely that another person will ‘discover’ an individual’s CF status, such as a casual encounter in a shopping mall, it is unlikely that CF would come into a conversation. However, as a friendship is pursued with an individual or as a long-term interaction is entered into, such as a romantic relationship or employment arrangement, CF is more likely to be disclosed as the negative consequences of not doing so may seem to outweigh not disclosing. For example, negative consequences may involve losing a partner if they desired to have children and the person with CF could not have children, or being dismissed by an employer as many sick days may be needed in the future. Lowton also noted that in more intimate relationships, the reaction that was expected from the other party was also a factor reported to influence adults’ decision to disclose their CF. The more negative a reaction was expected to be, the less willing an individual was to disclose.
Similar findings to Lowton (2004) have also been reported by recent quantitative research by Modi et al. (2010) who identified a number of factors which impact the disclosure decisions of individuals with CF. Modi et al. reported individuals with CF were more likely to disclose to relatives and close friends than to dating partners, work superiors/teachers, colleagues, neighbours and other casual acquaintances; suggesting that level of perceived intimacy impacts the disclosure decision. The results of this study also indicated that individuals were less likely to discuss their illness with individuals in the workplace if their illness was less severe. Further, women were also more likely to disclose to close friends and dating partners than males. Similar to Lowton’s findings, Modi et al. also found that while negative reactions following disclosure were relatively uncommon, negative reactions were most likely to be received from dating partners and work superiors/teachers.

Recent empirical and qualitative studies have consistently identified two aspects of CF as particularly socially challenging: frequent coughing and discharge of sputum and the ingestion of enzymes at meal times (Foster et al., 2000; Harrop, 2007; Pfeffer et al., 2003; Williams et al., 2009). Qualitative studies (e.g., Christian & D’Auria, 1997) and personal accounts of young adults living with CF presented at a recent conference conducted by Cystic Fibrosis Victoria also verified these empirical reports and suggest that negative reactions to CF symptoms may continue in the years beyond adolescence. Twenty-four year old G. Brown (personal communication, September 14, 2008) reported that the ingestion of enzyme tablets at meal times may be associated with social problems when individuals who are not aware of the patient’s condition draw their own unfavourable conclusions as to what the drugs are used for. Brown and W. van Praag (personal communication, September 14, 2008) also communicated that individuals often display disdain to the often loud and phlegmy-sounding cough of CF patients and their need to discharge sputum after coughing. This may occur regardless of whether the individual has disclosed their illness or not.

Consistent with these concerns, research findings also indicate that some individuals with CF may actively seek out support and friendship from other individuals with CF as they feel more understood and less pressured to conceal their symptoms than with healthy individuals (D’Auria et al., 2000; Christian & D’Auria, 1997; Ravert & Crowell, 2008). Given the implementation of cross-infection policies in CF care facilities to reduce the transmission of more aggressive lung infections (e.g., pseudomonas aeruginosa acquisition) face-to-face contact with other peers with CF may be limited, however, social networking and chat sites have assisted with the facilitation
of communication within this group (Johnson, Ravert, & Everton, 2001). A qualitative study conducted by Lowton and Gabe (2003), however, has also acknowledged a unique challenge that may arise from interaction with other peers with CF. Individuals with more mild cases of CF discussed that they felt ‘fraudulent’ stating that they have CF after having observed other individuals with more severe cases of CF during their tune-up clinic visits. One participant in this study stated that it was only when they themselves had an exacerbation of symptoms that they felt they were not a fraud.

As individuals with CF now have a greatly increased life expectancy, most young adults with CF will enter either the workforce or further education after completing high school (Ren, 2008). Thus, helping this population to make the transition into these social environments is of great importance (Hodson, 1997). Considering the potential social challenges that could occur at this time, it may be expected that a large body of psychosocial intervention research and a number of support programs would exist for adolescents and young adults who are experiencing difficulty (Christian, 2003; Herzer et al., 2009). On the contrary, however, few can be identified. It is further noted that few psychosocial interventions for families with children with CF can also be identified within the current literature. A review of both psychosocial and family based interventions that have been empirically tested and reported in the literature is examined in the following section.

2.5 Psychological Support for Individuals and Families Coping with Cystic Fibrosis

2.5.1 Individual and Psychosocial Interventions

The majority of psychological interventions identified for individuals with CF focus on physical symptom management and reduction, with few examining emotional adaptation (Plante, Lobato, & Engel, 2001; Quittner, Modi, & Roux, 2004). This observation has also been acknowledged more recently by Glasscoe and Quittner (2009) who reviewed psychological interventions with individuals with CF and their families which met criteria to be considered in a randomised-controlled trial or quasi-randomised controlled trial. In this review, only one study was identified which focused primarily on the emotional adjustment of individuals with CF or their family members. This study examined parental adjustment (i.e., Chernoff, Ireys, DeVet, & Kim, 2002) and will be discussed in the next section on family-based interventions.

In their review of group interventions for paediatric illnesses, Plante et al. (2001) also made the more general observation that there were few well-controlled studies of emotional support programs across all paediatric illnesses. Recent interventions have
begun to evaluate different psychological and support-based interventions aimed at providing emotional support and promoting skill development in individuals with CF, which are discussed below. Given that these studies do not meet criteria as randomised- or quasi- controlled trials, it is acknowledged that there are short-comings to the psychometric measurement of outcomes, participant recruitment strategies and other aspects of methodology. Thus, the purpose of this brief review and discussion of psychosocial approaches to supporting the emotional adjustment of individuals with CF is to give examples of current ideology as opposed to providing a guide to implementing psychological care.

It is also to be noted that, for the general consumer, there are a number of websites available which provide up to date information and chat forums for children and adults with CF, and their families, which appear to have a number of active members (e.g., CysticFibrosis.com, 2011; Norvartis Pharmaceutical Corporation, 2010). Recent research also suggests sites which enable participants to detail their experiences about CF (i.e., patient blogs) may give health-care providers a unique perspective on individual’s experiences which may lead to enhanced patient care (Heilferty, 2009).

The most comprehensive program developed for children with CF which targets common issues faced by eight- to 12-year olds reported in the current literature is the Building Life Skills Intervention (Christian & D’Auria, 2006). The intervention involved both individual and group components. The topics covered in individual sessions included: finding out about aspects of the CF diagnosis, explaining CF-related differences, dealing with teasing about CF, and keeping up with peers during physical activities. The group component was conducted with up to four children in each group with CF and covered: explaining CF to peers, dealing with teasing, and keeping up with peers during physical activity. Initial results of the program appear promising, with participants reporting significant decreases in the impact of illness and loneliness scores over nine months post-intervention compared to individuals with usual care.

Two programs (Johnson et al., 2001; MacDonald & Greggans, 2010) could be identified that focused on the adjustment of older children with CF. Johnson et al.’s intervention was an internet-based support program for children aged 13 to 18 years, and aimed to increase interactions between, and support of teenagers with CF. The internet was chosen as the delivery medium as face-to-face interactions between people with CF is generally limited due to the potential for cross infection of different strains of chest-infecting viruses and bacteria (Campana, Taccetti, Revenni, Masi, Audino, & Sisi et al., 2004; Littlewood, 2007). The program gave users access to a website with CF-
related information, resources, and email interaction with other individuals with CF. Unlike Christian and D’Auria’s (2006) program, no specific psychosocial intervention was incorporated. Results of the program did not indicate a change in the teenagers’ perceptions of the internet as being a place to receive support, nor was there a significant change in the participants’ CF knowledge. This may be due to the availability of other chat forums for individuals with CF, as noted previously. However, of the 37 participants in the study over three-quarters did email another person on the network at least once every two weeks and participants reported feeling as though they had more friends they could relate to and perceived that they had increased their understanding of CF.

MacDonald and Greggans (2010) implemented a befriending program for individuals with CF aged eight- to 18- years with the aim of improving concerns for young people with CF such as self-esteem, boredom and isolation when having hospital stays, and providing ‘time out’ and networking for carers of children with CF. Volunteers were recruited from the local community in a region of Scotland, and were screened for suitability to work with a young person with CF and provided with appropriate training for their ‘befriending’ role. Again, this program did not include any psychometric adjustment indicators.

The themes that arose from post-intervention interviews with the children, their carers, and assigned ‘befrienders’ suggested that, overall, most individuals involved found the befriending relationship rewarding and the program did assist children in having a distraction from their illness and an outlet to discuss personal concerns. However, it was noted that some befrienders felt that more training could have been useful to assist them in understanding not just the basic medical underpinnings and consequences of CF, but also the more specific CF-related jargon or ‘lingo’ used by families who have been coping with CF for a number of years. Befrienders perceived that having to ask what certain terms meant negatively impacted rapport building. This reflection is consistent with concerns of other authors who suggest that professionals with specific knowledge of CF are best equipped to assist individuals to manage their emotional concerns in the context of chronic illness (e.g., Quittner, Barker, Snell, Grimley, Mariel, & Cruz, 2008). Another limitation MacDonald and Greggans’s program noted by some children was that, at times, the duration of the befriending relationships was not discussed early on. Thus when this relationship ceased, some children reported distress if they had become particularly close with the befriender.

For adolescents with CF, one study examining the efficacy of a cognitive-behavioural (CBT) intervention to assist in the management of emotional concerns has
been identified in the current literature (i.e., Hains, Hobart Davies, Behrens, & Biller, 1997). Further, Hains and colleagues also examined the efficacy of CBT intervention for adults with CF which aimed to enhance their emotional adjustment (i.e., Hains, Davies, Behrens, Freeman, & Biller, 2001). Hains et al. (1997) conducted an intervention with five adolescents, aged 13- to 15- years, who were referred for psychological assistance by medical staff from their regular CF clinic. The intervention consisted of nine hour-long sessions conducted weekly incorporating cognitive restructuring of CF-related concerns and the training of problem-solving skills. As rated by participants and their parents, pre- to post-treatment results indicated that four of the five adolescents had significant reductions in ratings of anxiety and all participants had reductions in the use of negative coping strategies.

Hains et al. (2001) ran a similar 8-week intervention with four young adults, aged 22- to 26-years, also referred for assistance by medical staff. The results of the intervention were mixed. One participant improved on all outcome measures (i.e., anxiety, anger, coping, or functional disability). Two participants improved on one of the measures, and one participant did not improve on any of the indicators of adjustment. In appraisal of these less encouraging results, Hains et al. (2001) suggested that the pre-treatment concerns of this group were very specific to each of the participants and, thus, the outcome measures may not have accurately reflected treatment gains.

2.5.2 Family-based Interventions

As noted previously, Glasscoe and Quittner’s (2009) review of psychological intervention studies focused on those which attempted to enhance the emotional adjustment of individuals with CF by providing them with individual or group-based support. Conversely, the interventions reviewed in this section include those which have provided education or support to family members of an individual with CF with the aim of enhancing the emotional adjustment of these wider family members or that of the individual with CF.

Chernoff and colleagues (Chernoff et al. 2002; Ireys, Chernoff, DeVet, & Kim, 2001) conducted a 15-month randomised, controlled trial of a community based support program for families with children aged 7- to 11-years with CF, Type 1 diabetes, sickle cell anaemia, and more severe cases of asthma. One hundred and thirty-six mother-child dyads were randomly assigned to receive one of two interventions. The control group received a phone number of a mother who also had a child with chronic illness who they could call when requiring support. The intervention group received two forms of
support. Children received seven home-based support sessions supplemented with follow-up telephone conversations and written correspondence from three paediatric specialists. The aim of this support was to enhance children’s self-esteem and self-concept. Additionally, the mother in the intervention group also received a similarly structured intervention of home-based and telephone-based support, with the addition of some community-based activities aimed to enhance parents’ sense of support. This support was facilitated by ‘experienced’ mothers of children with the same illness as each participant’s child.

Ireys et al. (2001) reported that the intervention was effective in reducing mothers’ anxiety levels, but not depression levels when post-interventions measures were compared to the control group. They also noted that mothers with compromised physical health themselves particularly benefited from the intervention. Regarding child outcomes, Chernoff et al. (2002) reported that the intervention was successful in increasing the overall adjustment scores of children, with children with low physical self-esteem particularly benefiting from the intervention.

Byron, Burton, Tostevin, and Madge (2000) also conducted a home-based intervention with families of children aged eight years and older. Again, families were randomly assigned to either an intervention group or waitlist control group. The intervention group received four or more home visits from a psychologist and nurse from their local hospital over a six month period with the aim of trying to assist families in developing rapport with members of their CF team and reducing psychological difficulties within the family. The results indicated that families involved in the intervention group had greater clinic attendance and more stable health status over time. Parents in the intervention group were also noted to have an improvement in well-being post-intervention as compared to parents in the control group.

As facilitating home-based interventions can be costly and time intensive for professional facilitators, group-based support programs are often offered for parents and children at hospitals or other treatment facilities. Brown, Krieg, and Belluck (1995) reviewed common hospital-based approaches to parental support for coping with the care of a child with CF. Brown et al. indentified two parent groups which commonly were run within CF clinics. Firstly, support was often requested by parents in the first few years of parenting a child with CF. Support was also often required by families in later years when children approached young adulthood and the paediatric-to-adult care transition took place. Hospital-based support groups for intervention in the early years usually involved psycho-educative components and open discussion forums for parents.
and were run for up to one year. Support groups for the older CF groups were designed to assist parents in supporting their child’s independence and to teach skills to assist parents in relinquishing their responsibility for their child’s health status.

Themes indentified from parent reflections following their involvement in either the early years or older CF support group conducted in a hospital in New York suggested that positive gains were obtained during program participation (Brown et al., 1995). Parents in both the early years and older CF group reported feeling supported in expressing CF-related concerns, such as guilt and resentment toward their child’s CF, the impact of CF on their family’s lives (e.g., healthy siblings), and anxiety about keeping up with the treatment regimen. More specific concerns addressed by the early years group included learning the specifics of conducting daily treatments and adjusting to the diagnosis. For the older CF group, parents reported feeling comfortable to express concerns such as feeling excluded or helpless once their children were given responsibility for their care.

Programs have also been established specifically to assist parental communication in households with children with CF in the aim of enhancing family functioning. Schroder, Casadaban, and Davis (1988) reported the results of a two-day interpersonal and problem-solving skills based intervention for couples parenting a child or adolescent with CF. Ratings made by trained observers indicated that parents’ communication and problem-solving skills have improved from pre- to post-workshop. Further, self-rated parental perceptions of their self-esteem and of their marital and family functioning pre- and post-intervention suggested that most benefits were gained by participants who originally had reported low self-esteem and compromised marital and family functioning. Participants with scores below average were observed to have significant improvements on all measures, whereas improvements were not observed for participants who scored above average on these measures.

Other programs have also been reported which have focussed more specifically on providing group-based education about CF to families with the aim of reducing family distress and increasing treatment efficacy. Goldbeck and Babka (2000) reported the results of a program run with 16 families with children under 12-years of age with CF. In this program, both children and parents received information about CF, however, they attended separate, age appropriate, sessions. The results of this intervention suggested that only families who had strained family functioning, and parents with reduced optimism or poor child treatment compliance pre-intervention reported treatment gains post-intervention. The aggregate data, however, suggested that the
group received few treatment gains, and, on some measures of child adjustment, distress increased directly following the intervention.

When comparing Goldbeck and Babka’s (2000) results to the more pronounced gains of other programs involving more support-based or cognitive-behavioural interventions (e.g., Byron et al., 2000), it may be suggested that giving families information about CF without providing specific mechanisms to assist them in processing and coping with the different aspects of the diagnosis may have the potential to increase distress. However, a more long-term benefit of group-based education programs may be that they assist families with CF to develop a network of other families who understand their experiences and who may provide support following the cessation of the program (Goldbeck & Babka, 2000).
CHAPTER 3 – PSYCHOLOGICAL THEORY AND CYSTIC FIBROSIS

The previous chapter presented an overview of the psychosocial adjustment of persons with CF and their families. Taken together, the literature tends to suggest that, across the lifespan, individuals with CF and other family members are at an increased risk for psychosocial distress than individuals and families who are not coping with chronic illness (e.g., Berge & Patterson, 2004; Quittner, DiGirolamo, et al., 1992). However, there is both within- and between-group variation noted within the literature; with some studies suggesting few significant differences between individuals and families with and without chronic illness (e.g., Herzer et al., 2010; Pfeffer et al., 2003) and others suggesting extensive differences (e.g., Lavigne & Faier-Routman, 1992). Further, for studies that do suggest that there is a greater risk for psychological distress when coping with chronic illness, these findings are based on group averages, meaning that some individuals within the group may not be experiencing any distress, whereas others may be experiencing extreme levels of distress (e.g., Howell, 2007).

What is evident from the literature, however, is that there are few well-tested psychological interventions to assist individuals and families coping with CF to address difficulties with psychosocial adjustment if such concerns arise. It is likely, however, that there are a number of mental health professionals across the globe who do have expertise in working with families coping with CF and who may have unpublished data on their approaches. Yet, for other chronic illnesses such as cancer and heart disease, a number of psychosocial interventions have been discussed in the literature which have reported significant treatment gains for both the individual coping with the illness (e.g., Oldenburg, Perkins, & Andrews, 1985; Pitceathly, Maguire, Parle, Tomenson, & Creed, 2009; Thornton, Andersen, Schuler, & Carson, 2009) and their family (e.g., Kayser, 2005; Lewis et al., 2008; Scott, Halfford, & Ward, 2004).

It is recognised that these psychosocial interventions for cancer and heart disease populations are predominantly founded on strong theoretical frameworks. Thus, it is suggested that future individual or family-based interventions aiming to enhance the psychological adjustment of individuals and families coping with CF would best be grounded in well-tested psychological theory (Brown, Small, & Palmer, 2008; Ievers & Drotar, 1996). This chapter will review psychological models which have been well tested with other chronic illness populations and which are likely to have direct applications to furthering our understanding of the experience of CF, and psychosocial treatment planning which may derive from this understanding.
While studies examining the psychosocial adjustment of individuals and families coping with CF have included a number of individual constructs such as adjustment indicators (e.g., depression, anxiety) and family adjustment indicators (e.g., observed family functioning), few have used broader theories to assist in the understanding of individuals’ psychological adjustment and family adjustment. However, when examining other aspects of adjustment in CF, a number of studies can be identified where broader psychological theories have been applied. These include the application of social-cognitive theory in treatment adherence (e.g., Abbott et al., 1996; Kettler et al., 2002); stress and coping models in examinations of coping style and adjustment (Burke & Elliott, 1999; Schmidt et al., 2003; Wong & Heriot, 2008); and the ecological model as a basis for health care interventions (e.g., Kazak, 2006; Wang, et al., 2010) and as a framework for the examination of social development (e.g., D’Auria et al., 2000).

Extending the application of psychological models to specific elements of adjustment to CF, the following sections detail two psychological models which have had noted success in the explanation and prediction of the psychological functioning of individuals and families coping with a range of other chronic illnesses including cancer (e.g., Ben-Zur, 2001; Lepore & Helgeson, 1998), diabetes (e.g., Beveridge, Berg, Wiebe, & Palmer, 2006; Edgar & Skinner, 2003), and heart disease (e.g., Baigi, Hildnigh, Virdhall, & Fridlund, 2008; Benyamini, Medalion, & Garkinkel, 2007). Specifically, the social cognitive-processing model of emotional adjustment to illness (Lepore, 2001) and the common-sense model of illness (Leventhal et al., 1980) are reviewed and the utility of these models in the study of the psychosocial adjustment of individuals and families coping with CF is discussed. In addition to providing a theoretical framework to assist the prediction of psychosocial functioning in the context of CF, the final section of this chapter reviews another psychological model which may be particularly useful in measuring an additional aspect of psychological adjustment of the CF population. The construct of ‘sense of coherence’, drawn from Antonovsky’s (1979; 1987) salutogenic model of health and illness, is reviewed and its application to adjustment of individuals and families coping with CF is discussed. This integrative approach is consistent with current directions in health psychology research which aim to apply theory with the intent of providing a more complete understanding of health behaviour and enhance the practical applications of these findings (Hagger, 2009).

As this is the first combined application of these models to the understanding of the lived experience of CF, the studies derived to test these models, presented in
Chapters 5 to 7, are intended to primarily be exploratory; thus aiming to provide a richer understanding of this population as opposed to testing specific extensions of well-tested theory. However, while the models examined in this chapter were selected due to their efficacy in explaining the psychosocial adjustment of individuals and families with chronic illness, these theories were also selected as they are predicted to be inter-related to each another. Thus, some predictions are made as to how these models may be used in conjunction with one another to examine both the psychosocial adjustment of individuals and families with CF and test theoretically based predictors of adjustment. These proposed relationships are discussed in Chapter 4.

### 3.2 Social Cognitive Processing Model

#### 3.2.1 Social Cognitive Processing Model - Overview

The social cognitive processing model of emotional adjustment to illness (Lepore, 2001) was developed from research examining the processes involved in cognitive processing of traumatic events and the effect that the social environment has on these processes. This model is now primarily applied to the examination of the social environment of individuals with chronic illnesses (Lepore & Kernan, 2009). In particular, examination of couples’ adjustment when one spouse has cancer has been a recent area of application (e.g., Lepore & Helgeson, 1998; Lepore & Revenson, 2007). Thus, this review of the social cognitive processing (SCP) model begins with an overview of these theoretical underpinnings and current conceptualisation of the model. A discussion of the empirical studies which have tested the SCP model’s utility in explaining patient outcomes then follows.

#### 3.2.2 Cognitive Processing of Traumatic Events

The American Psychiatric Association (APA, 1994) describes a ‘trauma’ as an experience that induces terror or helplessness in an individual and is perceived to threaten either their own, or another’s, life or well-being. Under this definition, the diagnosis of a life-threatening or otherwise debilitating illness can be considered a trauma for affected patients and their loved ones. This contention has been supported by the results of recent research examining psychological adjustment to illness. Such studies have reported data suggesting that the diagnosis and experience of myocardial infarction (Wiedemar et al., 2008) or breast cancer (Cordova, Studts, Hann, Jacobsen, & Andrykowski, 2000) can elicit a post-traumatic stress response in some patients. Additionally, it has also been reported that while only a small percentage of cancer patients experience the three key
symptoms of a traumatic response (i.e., intrusive thoughts of the disease; attempted avoidance of such thoughts and hyper-psycho-physiological arousal) to an extent that would warrant a formal diagnosis of post-traumatic stress disorder (APA), a substantial proportion of patients experience some or all of these symptoms at a subsyndromal level (Cordova, Andrykowski, Kenady, McGrath, Sloan, & Redd, 1995).

From theorists as early as Freud, it has long been recognised that if a traumatic event is not confronted and integrated into one’s self-concept, memories of the event intermittently appear in one’s consciousness (Rachman, 1980). With these memories, the emotional and physiological reactions that occurred in the experience of the original trauma episode often co-occur (APA, 1994). Later theorists, such as Horowitz (1997), further investigated this phenomenon, describing these experiences as cycles of intrusion and avoidance. It is proposed that this cycle continues due to a ‘completion tendency’ which represents “…the human mind’s ability to continue to process new information in order to bring up to date the inner schemata of the self and the world” (p. 93).

Horowitz (1997) further considered that revisions of schemas are necessary as effective decisions and consequent actions in one’s environment can only be enacted when an individual’s inner model of the self and their environment is in accordance with their actual capabilities and surrounds. These suggestions have also been endorsed in more recent research (Langlois, Ladouceur, Patrick, & Freeston, 2004). Thus, it appears that for cognitive change to occur it is an essential prerequisite for the traumatic memories to be present in conscious awareness (Brewin, Dalgleish, & Joseph, 1996; Wastell, 2005). However, as the intrusive thoughts are accompanied with extreme psychophysiological reactions, they are pushed out of consciousness. This prevents cognitive integration and perpetuates the intrusion-avoidance cycle (Creamer, Burgess, & Pattison, 1992).

Piagetian theory suggests that cognitive change required to complete information processing of an event occurs through one of two processes: assimilation or accommodation. Assimilation occurs when incoming information is shaped and incorporated into a pre-existing schema. On the contrary, accommodation results when information cannot be easily integrated into a pre-existing schema, and instead the schema is changed to match the incoming information (Kudler, 2000). To give an example of these processes, in the case of processing of CF-related concerns, assimilation would occur if a patient attributed a disease complication to sub-optimal self-care. This would help the patient regain a sense of control over the illness, in that changing future health behaviour may prevent future complications; therefore,
maintaining a self-schema that CF is controllable. Conversely, a different cognitive sequel may arise if the patient was informed by their doctor that this complication is part of the natural progression of CF and required modification to their treatment regimen. In this instance, accommodation would occur if their pre-existing schema of CF being controllable was modified to posit that only symptoms, not the disease itself, are controllable once diagnosed.

From the completion hypothesis, it is suggested that once traumatic information is either assimilated or accommodated into self-schemas, and the self once again becomes coherent, the emotional and physiological responses associated with the memory will dissipate (Horowitz, 1997). Yet, an alternate explanation of psycho-physiological adaptation to traumatic memories also exists. It is suggested that if an intrusive thought is experienced consistently in either a benign or positive context, the pairing of the thought to a negative reaction will diminish and be replaced with an association to a more positive one (Rachman, 1980). Yet, Lepore (2001) considers that this ‘desensitization’ process would only be associated with a reduction in the emotional severity, not frequency, of intrusive thoughts as cognitive processing of the trauma has not actually occurred.

3.2.3 Social Influences on Cognitive Processing

Recent research indicates that after a trauma has been experienced most people have a tendency to discuss their distress, and studies have further demonstrated that both conversing and expressively writing about a trauma can have psychological and physiological benefits for those recovering from a stressful incident (e.g., Booth & Petrie, 2002; Lutgendorf & Ullrich, 2002; Pennebaker & Francis, 1996; Symth, Anderson, Hockmeyer, & Stone, 2008). Talking or writing about a trauma brings related memories into consciousness, thus making them available for cognitive processing (Lepore, Ragan, & Jones, 2000).

Yet, differences in the beneficial effects of writing and talking are observed. Clarke (1993) posited that while writing may foster coherency through imposing a structure on the emotional expression, the more spontaneous and fragmented nature of talking may engender more opportunities for gaining insight. Clarke also proposes that the dual nature of conversation also leads the speaker to generate new perspectives of their situation as the listener may also input their opinions and experiences which may differ to that of the speaker.

It is suggested by Lepore (2001) that when considering the noted benefits of emotional expression on cognitive resolution of a stressor, it may not necessarily be
talking per se that leads to enhanced outcomes. Instead, Lepore advocates that responses of the listener may have an effect on the cognitive processing and psychological outcomes of the discloser; hence, the conceptualisation of the social cognitive processing model. The results of research examining communication between early stage breast cancer patients and their partners indicated that unsupportive partner responses were associated with patients’ increased use of avoidant coping. In turn, the use of avoidant coping was related to greater psychological distress (Manne, Ostroff, Winkel, Grana, & Fox, 2005). As avoidant coping can include cognitive evasion of a stressor (Holahan, Moos, & Schaefer, 1996), it is suggested that it is through this process that an unsupportive environment exerts its negative effect on cognitive processing (Lepore, 1997; Lepore et al., 1996).

Lepore (2001) also acknowledges the opinion (e.g., Clarke, 1993) that reduced disclosure may also have detrimental effects on cognitive processes. This may occur through decreasing one’s opportunity to be exposed to others’ perspectives of the trauma, which otherwise may have cultivated further psychological insight and integration. Finally, it is suggested that disclosure may enhance cognitive processing as it has been demonstrated to reduce emotional arousal, which decreases the likelihood of cognitive avoidance of the memory (Lepore, 1995). Taken together, the SCP model therefore proposes that when individuals can discuss their traumatic experiences in a comfortable and supportive environment, cognitive processing will be facilitated, thereby increasing the likelihood of psychological recovery from the trauma.

3.2.4 Social Constraints

Lepore (2003), however, has observed that not all individuals receive the support they desire from family members and other intimate acquaintances after experiencing a stressor. Thus, such individuals are not being exposed to the most favourable recovery environment and are affected by ‘social constraints’. Lepore defines such circumstances as “social conditions, and perceptions of those conditions, that lead trauma victims to feel they are unsupported, misunderstood, or otherwise alienated from their social network when they are seeking social support or attempting to discuss trauma-related thoughts, feelings, or concerns” (p. 1). Social constraints can be examined between a patient and any division of their social network, such as any relative or friend (Lepore & Helgeson, 1998). However, the patient-partner dyad is most commonly examined (Lepore, 2003).
From SCP theory, it is hypothesized that when individuals function in a constrained social environment, they will feel less comfortable about discussing their concerns. The diminished discussion of concerns is then theorised to impede cognitive processing and psychological resolution of the trauma. Complementary to this process, an unconstrained environment is proposed to enhance disclosure, thus facilitating processing of the trauma and aiding in psychological recovery (Lepore et al., 1996; Lepore & Kernan, 2009).

3.2.5 Empirical Applications of the Social Cognitive Processing Model

The first empirical evaluation of the effects of social constraints on individuals’ adaptation to trauma was Lepore et al.’s (1996) study which assessed the impact of constraining behaviours from a partner on the functioning of bereaved mothers who had recently lost an infant to sudden infant death syndrome. The results indicated that social constraints from partners moderated the relationship between both mothers’ intrusive thoughts and talking and their intrusive thoughts and depressive symptoms. For ‘constrained’ mothers, a greater number of intrusive thoughts were associated with less talking and more distress; whereas for ‘unconstrained’ mothers, having more intrusive thoughts was associated with greater frequency of talking and less distress. Lepore (1997, paper presented at the Society of Behavioural Medicine [San Francisco, CA] as cited in Lepore 2001) replicated this pattern of results with a sample of breast and colon cancer patients. In support of the SCP model, these findings demonstrate that when a high number of intrusive thoughts were encountered, unconstrained individuals were able to express themselves which facilitated adaptation. Conversely, constrained individuals were unable to discuss their concerns with their family and friends which intensified their distress.

In a large sample of prostate cancer patients, Lepore and Helgeson (1998) demonstrated the relationship between both intrusive thoughts and avoidance and social constraints from the patients’ wives and other family members. Consistent with previous studies (e.g., Lepore et al., 1996), intrusive thoughts were found to be less distressing when experienced in an environment with low constraints than in a highly constrained environment. Likewise, more disclosure was observed in men with frequent intrusions when in an environment with low constraints than in an inhibiting social framework. Further, in support of the literature that posits the beneficial effects of having a supportive significant other (e.g., Pistrang & Barker, 2005), the effects of social constraints from wives on outcomes were stronger than the effects of constraints
from wider family and friends. Lepore and Helgeson also demonstrated that although a higher level of constraints was associated with greater avoidance of trauma-related thoughts, and avoidance was also positively associated with patient distress, avoidance only partially mediated the relationship between constraints and distress. Also taking into consideration past SCP research, Lepore and Helgeson proposed that social constraints may increase psychological arousal which may impact on distress to a greater degree than avoidance.

The impact of social constraints on the cognitive processing and emotional adjustment of men with prostate cancer was further investigated in a study that extended Lepore and Helgeson’s (1998) research by examining the differential effects of emotional expressivity on the SCP model. Agustdottir et al. (2010) proposed that the match between an individual’s need to discuss their feelings and concerns would interact with the opportunities to speak from within the environment. In this study, the overall estimate of social constraints was derived from two measures; constraints from a partner and another significant other (e.g., wider family member or friend). The results did support the proposed ‘matching hypothesis’. While emotional expressivity did not significantly contribute to the prediction of cognitive intrusions, anxiety, or depression, both social constraints and the interaction of social constraints and emotional expressivity did predict intrusions and adjustment. Men who scored high on both emotional expressivity and social constraints reported the highest levels of anxiety, depression and intrusive thoughts. Regarding the prediction of cognitive avoidance, only social constraints was a significant predictor. The greater the level of constraint reported, the more cognitive avoidance reported by participants.

Devine, Parker, Fouladi, and Cohen (2003) examined the impact of perceptions of social support on skin and renal cancer patients’ psychological adjustment over a one month period after an experimental treatment. Although an alternate measure of interpersonal dynamics was employed (the Interpersonal Support Evaluation List) the moderating effect of restrictions to open emotional expression and intrusions on patient distress again replicated Lepore et al.’s (1996) and Lepore and Helgeson’s (1998) findings. Additional analyses also indicated that cognitive intrusions and avoidance mediated the relationship between perceptions of the social environment and mental health rating. This is contrary to the findings of Lepore and Helgeson who did not find avoidance to be a significant mediator of constraints and distress in their research. However, as only the combined total of the intrusions and avoidance measures was used in Devine et al.’s analysis and not separate intrusion and avoidance sub-scale scores, it
cannot be determined whether avoidance accounted for a significant amount of unique variance in the mediating relationship.

Further teasing out these relationships, Cordova, Cunningham, Carlson, and Andrykowski (2001) did separate the effect of intrusions and avoidance in the examination of their links to social constraints and psychological adjustment. Utilising a sample of breast cancer survivors and their significant others, Cordova et al. found that intrusions mediated the relationship between constraints and patient depressive symptomatology, while avoidance did not play a mediating role in this relationship. Other analyses examined the proposition that avoidance may compromise patient outcomes in a similar manner to social constraints by reducing patients’ tendency to discuss their cancer. Although talking partially mediated the relationship between avoidance and well-being, Cordova et al. noted that avoidance appears to have a more direct link with outcomes. However, across much research it appears to be a common finding that avoidance plays a less consistent role in the cognitive processing models than intrusions (Brewin et al., 1996).

Other authors have more closely examined the specific role of avoidance in predicting patient outcomes and suggested that different effects may be observed when this relationship is examined longitudinally, as opposed to cross-sectionally (DuHamel et al., 2004; Lutgendorf, Anderson, Larsen, Buller, & Sorosky, 1999). It is noted, however, that DuHamel et al. and Lutgendorf et al. examined only the cognitive processing of health-related information from an individual perspective, not examining the role of social facilitation in this process.

Lutgendorf et al. (1999) utilised a sample of gynaecological patients and demonstrated that while intrusions at both diagnosis and 6-month follow-up predicted anxiety and depression at follow-up, avoidance was only a concurrent predictor of anxiety at 6 months. It was proposed that while avoidance may protect a patient from experiencing distress in the short term, when this is continued over time it prevents processing of the trauma, and, therefore, inhibits emotional resolution.

This pattern of results was also observed by DuHamel et al. (2004) who examined the cognitive processing of fear for children’s well-being in mothers of children undergoing bone marrow or stem cell transplantation. DuHamel et al. reported that while intrusions mediated the relationship between mothers’ fear and distress (anxiety and depressive symptomatology) at the time of the child’s transplant, no direct relationship between avoidance and distress was observed at time 1. At follow up, 3 months post-transplant, mothers’ distress was directly related to concurrent avoidance,
with avoidance at time 1 being associated with avoidance at follow-up. Thus, both a
direct and indirect effect of avoidance on distress over time was demonstrated in this
study. In addition to this, concurrent ratings of intrusions did not have a direct effect on
distress at follow-up; avoidance at time 2 also mediated this relationship.

As noted earlier, most studies examining the effects of social constraints on
patients’ adjustment to illness have utilised groups which have recently experienced the
shock of a diagnosis of cancer, or have experienced extreme emotional distress due to an
illness-related event (i.e., loss of a child). Recent research, however, has acknowledged the
role that social constraints may have in the management of illnesses over time (Braitman
et al., 2008). Braitman and colleagues proposed that high levels of social constraints
may negatively impact self-care behaviours in adults with Type 1 or Type 2 diabetes.
Conversely, they suggested that illness-related discussions occurring in a supportive
environment may assist individuals in developing self-care goals and strategies for
diabetes management; increase their exposure to individuals who are coping
successfully; and facilitate habituation to illness-related distress. In this study, the
overall estimate of social constraints was derived from three measures; constraints from
a partner, family, and friends.

In their analyses Braitman et al. (2008) only included the measures of social
constraints and cognitive intrusions from the SCP model. In this study, frequency of
intrusive thoughts was used as a measure of incomplete cognitive processing. Results
indicated that social constraints was significantly related to self-care behaviours in
individuals with diabetes. Further, self-efficacy in self-care ability, anxiety
symptomatology and depressive symptomatology were all found to significantly
mediate the relationship between constraints and self-care. Thus, these results suggest
that high social constraints in a patient’s social environment decrease their self-care
self-efficacy and increases distress, which ultimately compromises their self-care
behaviour. Regarding cognitive intrusions, social constraints was again a significant
predictor of this measure with anxiety playing a significant mediating role. This differs
to past studies (e.g., Cordova et al., 2001) which suggest that intrusions mediate the
relationship between constraints and distress. Yet, overall, these results present
preliminary evidence that the SCP model is effective in predicting patient outcomes for
both recently diagnosed patient groups and those who have been managing their illness
for a number of years.

In addition to examining short-term and long-term outcomes resulting from
incomplete processing of illness-related information, research with the SCP model has
also begun to examine predictors of social constraints in cancer populations. Quartana, Schmaus, and Zackowski (2005) acknowledged previous studies which have suggested that significant others may become overwhelmed by a stressful situation themselves and become less able, over time, to provide support to patients. Quartana et al. extended the results of this research to suggest that when patients have a high baseline level of anxiety and high social support needs then significant others will be more likely to become overwhelmed by the patients’ needs and disengage with them, leading to increased patient perceptions of social constraints. Using a mixed sample of cancer patients, Quartana et al. found support for this hypothesis, but only for female patients. Female patients’ needs for emotional expression moderated the relationship between neuroticism and social constraints. Patients scoring high on measures of both neuroticism and emotional expressivity scored significantly higher on perceptions of social constraints than patients scoring high on neuroticism but not emotional expressivity.

Herzer, Zakowski, Flanigan, and Johnson (2006) also examined the development of social constraints in a mixed sample of cancer patients. They hypothesized that discrepant beliefs about illness held by a patient and their partner may contribute to the development of social constraints. Accordingly, Herzer et al. examined the impact of both patient and partner perceptions of threat of illness recurrence on patient perceptions of social constraints. Contrary to predictions, the results suggested that only patients’ perceptions of illness threat predicted social constraints. Both partners’ perceptions of threat and the interaction between patients’ and partners’ perceptions did not account for significant variance. Herzer et al. suggested that as most patients had completed their cancer treatments before participating in the study they may not have been as dependent on their social network to assist in coping with the cancer experience as a sample of newly-diagnosed patients or those who are actively involved in treatment may have been. Herzer et al. also suggested that partners may not have expressed their own views of the cancer to the patient, and thus, patients may not have known if their partner held discrepant views. Accordingly, this may have negated any negative effects of patient-partner view discrepancy.

### 3.3 Common-Sense Model of Illness

#### 3.3.1 Common-Sense Model of Illness - Overview

In its simplest form, the common sense model ([CSM], Leventhal et al., 1980) of illness describes how individuals schematically store and structure illness-related information, with different illnesses having their own cognitive network. The model,
however, has also been applied to link negativity and positivity in individuals’ perceptions of coping strategies and patient outcomes when coping with a specific illness (Hagger & Orbell, 2003). As introduced in the previous section, this model has most recently been utilized in studying how congruence between a patient and their partner’s illness representations and perceptions of patient adjustment impact patient outcomes. The following review further examines these applications of the CSM, and demonstrates their applicability to research with the CF population.

3.3.2 Self-regulation of Illness Behaviour

The study of cognitive representations of illnesses derived from the early work of Howard Leventhal and colleagues (e.g., Leventhal, Singer, & Jones, 1965) who examined cognitive processes in fear. These early studies led to research which considered the cognitive processes involved in perceiving illness threats and resulted in the development of the self-regulatory model of illness behaviour (Leventhal et al., 1980, see Figure 1). This paradigm is described as the ‘common sense’ model of illness representations as it describes a ‘lay’ view of how individuals interpret and process illness related information (Hagger & Orbell, 2003).

![Figure 1. The Common Sense Model of Illness Representations (Hagger & Orbell, 2003 derived from Leventhal et al., 1980).](image-url)
The CSM assumes “…that people have an active information processing system which leads them to generate both a representation of illness and an emotional reaction to this illness” (Scharloo & Kaptein, 1997, p. 104) and describes the process of interpreting a perceived disruption to one’s health (illness representation), the coping mechanisms used to eliminate or manage this health threat, and appraisal of the effectiveness of these strategies (Lau, 1997; H. Leventhal, Brissette, & E. A. Leventhal, 2003). All experiences that an individual has with an illness either create new cognitive representations of that disease, or are integrated into pre-existing schemas if experiences with the illness have previously occurred (H. Leventhal et al.). For example, the experiences described in Chapter 1 in relation to the diagnosis and treatment of CF and experiences that emanate from the social interactions of CF patients result in new ideas about CF that shape patients’ cognitive representations of their illness.

3.3.3 Illness Representation Domains

Early qualitative and quantitative studies using exploratory and confirmatory methods suggested that illness representations within the self-regulatory model of illness behaviour encompass five domains; identity (i.e., symptoms associated with the illness); cause (i.e., factors involved in illness aetiology); consequences (i.e., beliefs of the severity of the illness and its impact on psychological, physical, social and economic functioning); time-line (i.e., how long the illness is predicted to last), and controllability (i.e., whether or not the illness is thought to be curable, [added by Lau & Hartman, 1983]) (Lau, 1997; H. Leventhal et al., 2003; Petrie, Jago, & Devcich, 2007). Each of these domains incorporates both abstract and concrete descriptions of illness. For example, when an individual experiences a symptom, a somewhat unconscious process of searching semantic memory is undertaken to assign a label to their experience. A schematic representation based on the concrete somatic experiences of the illness is then linked to the illness’ abstract labels (Hagger & Orbell, 2003; H. Leventhal et al.).

In the mid 1990s John Weinman and his colleagues suggested that while Leventhal’s self-regulatory model of illness behaviour, in particular illness representations, was extremely useful in conceptualising the experiences of individuals with illness, challenges and limitations in applying this model to empirical studies had been observed (Weinman, Petrie, Moss-Morris, & Horne, 1996). In particular, it was noted that the use of semi-structured interviews in early studies to investigate patients’ perceptions were time consuming and led to variations in the quality and quantity of responses obtained from participants. Weinman et al. further noted that some early quantitative measures of
illness perceptions lacked psychometric rigor. In response to this, Weinman et al. developed the Illness Perception Questionnaire (IPQ) to measure the key domains of illness representations identified within the self-regulatory model of illness behaviour.

Since the release of the IPQ, a large number of studies across a range of illness populations have successfully utilised this measure to investigate patients’ illness representations (Hagger & Orbell, 2003; Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002). Yet, Weinman and colleagues noted that the internal consistencies of the timeline and controllability subscales reported in a number of studies using the IPQ were less consistent than those reported for the other subscales. It was also further considered that the emotional representations component of Leventhal et al’s (1980) self-regulatory model of illness behaviour was also an important construct to be concurrently assessed when measuring illness representations. As noted in Figure 1, emotional representations are proposed to impact on coping style, emotional outcomes and health outcomes in addition to illness representations. Moss-Morris et al. also considered that it would be beneficial to add a subscale examining the patient’s meta-cognitive beliefs about their overall understanding of their condition and its implications; termed ‘illness coherence’.

Accordingly, Moss-Morris et al. (2002) developed the Illness Perception Questionnaire-Revised (IPQ-R) to address these psychometric and conceptual concerns. In IPQ-R, the original identity, cause, and consequence subscales were retained; the timeline and controllability subscales were reconceptualised to measure the chronicity and cyclical nature of illness on separate subscales by separating perceptions of personal control over illness from beliefs about treatment efficacy. Finally, two subscales were added, one measuring emotional representations of illness, and the other measuring illness coherence. Since the IPQ-R’s release, the additional domains suggested by Moss-Morris et al. have been endorsed as providing additional understanding within the CSM framework (Leventhal et al., 2008).

Overall, the investigation of the experience of illness using the CSM has been successful with a range of health conditions including myocardial infarction (e.g., Brink, Karlson, & Hallberg, 2006; Lau-Walker, 2004; Lau-Walker, 2006; MacInnes, 2006); chronic fatigue syndrome (e.g., Heijmans & De Riddler, 1998a; 1998b); asthma (e.g., Kaptein et al., 2008; McGrady, Rosenthal, Roberts, Britto, & Yi, 2010); rheumatoid and oesteo-arthritis (e.g., Groake, Curtis, Coughlan, & Gsel, 2005; Kaptein, et al. 2010; Schiaffino, Shawaryn, & Blum, 1998; Sharpe, Sensky, & Allard, 2001); and breast cancer (e.g., Anagnostopoulos & Spanea, 2005; Kritpracha, 2004; Millar et al.,
2005). Such studies have indicated that although proposed domains of illness perceptions are relatively stable for different health conditions, the pertinent content of each domain differs from illness to illness (Heijmans & De Riddler, 1998a; 1998b). Even within a particular illness, the representations may differ from patient to patient, or change over time (Petrie et al., 2007; Shiloh, Rashuk-Rosenthal, & Benyamini, 2002).

3.3.4 Illness Representations of Cystic Fibrosis

The first study to apply the CSM to the study of CF, as identified by the current author, was a qualitative study conducted with a sample of adults (average age 24 years) (Chapman & Bilton, 2004). Chapman and Bilton confirmed that even when using a semi-structured interview format presenting topics such as quality of life, body image, ethical and social issues related to genetic conditions, and CF treatment adherence, the themes identified in patients’ discussions of CF were centred on the illness representation domains outlined in the CSM. This suggests that quantitative studies using measures such as the IPQ-R would be appropriate with the CF population. A particularly interesting finding from Chapman and Bilton’s research was that the CF patients were found to vary in their level of understanding of the genetic basis of their illness. Regarding the applications of this finding, the authors suggested that parents of children with CF need to gain an accurate understanding of the illness so that they can discuss such issues with their children at age-appropriate levels. It was also recommended that patient understanding of CF should be assessed during paediatric-adult care transition. Following this, any areas in which the patient lacks understanding can be addressed at the beginning of their adult care. This may, in turn, assist in enhancing treatment adherence.

Other researchers working with the CF population (e.g., Kettler et al., 2002) have also highlighted the utility of applying the CSM to the study of treatment adherence for this population. Following these suggestions, Bucks, Hawkins, Skinner, Seddon, and Horne (2009) assessed the role of illness and emotional representations in the prediction of treatment adherence in a sample of adolescents (11- to 17- years) with CF. Consistent with previous studies, Bucks et al. reported that treatment adherence was poorest in older adolescents. Of the illness representation domains, perceptions regarding the efficacy of treatment control and perceived chronicity of CF mediated the relationship between age and adherence. Adolescents reported greater adherence to treatment when they perceived their illness as being chronic and that the treatment available would be useful in improving health.
While not applying a measure of illness representations, previous research with the CF population has identified that an individual’s assessment of the severity of their symptoms can differ to ratings obtained from clinical measures (e.g., lung functioning) (Sawicki et al., 2008). Further, past research has also indicated that an individual’s perceptions of their CF-related functioning, as opposed to the relative severity of their illness, account for significant variance in their reported adjustment. Specifically, children’s perceptions of illness-related stress, efficacy in illness management, and self-worth have been reported to predict overall psychological adjustment (Thompson et al., 1998). While no studies, to date, can be identified by the current author which have specifically applied the CSM to the examination of the clinical measures of depression or anxiety in adolescents and young adults with CF, one study was identified (i.e., Sawicki, Sellers, & Robinson, 2011) which has examined the role of illness perceptions in predicting health-related quality of life in adults with CF.

Recruiting a large sample of adults with CF (average age 35 years) Sawicki et al. (2011) identified that illness perceptions held by individuals with CF were more strongly related to psychosocial aspects of adjustment rather than physical aspects of health-related quality of life. Perceiving more consequences of illness was associated with less favourable ratings of body image, health perceptions, emotional functioning, social functioning, role functioning and treatment burden. Conversely, reporting a high level of understanding of CF (illness coherence) was predictive of better emotional, social, and role functioning. Additionally, perceiving more personal control over CF was related to more favourable health perceptions and emotional functioning. Thus, Sawicki et al.’s findings provide a solid base to compare the relationships obtained between depressive and anxious symptomatology and illness and emotional representations presented in Chapter 5.

In addition to this, research which has applied the CSM to examination of the adjustment of other populations of adolescents and young adults who have been coping with a chronic illness since childhood may be particularly relevant to the prediction of the adjustment of individuals with CF. Specifically, adolescents and young adults with Type 1 diabetes may be a suitable population for comparison as parents are usually responsible for treatment management and appointment scheduling when children are young, with a transition of care responsibilities throughout the adolescent years, as observed with CF populations (Silverstein et al., 2005; Williams, 1999).
3.3.5 *Illness Representations and Patient Adaptation*

Research utilising the CSM with adolescents and young adults with Type 1 diabetes has identified that illness representations are predictive of coping style and adjustment within this population. Edgar and Skinner (2003) reported that the perceived impact of diabetes and symptom perception were significant predictors of both depressive and anxious symptomatology and positive well-being of an adolescent sample. Perceptions of treatment efficacy were also found to predict positive well-being. Overall, perceiving less impact of diabetes and more symptom control was associated with adaptive psychological adjustment. Further analyses examining the relationship between coping and outcomes indicated that greater use of cognitive restructuring was associated with less depressive symptomatology and increased perceptions of positive well-being. One finding, however, that was not consistent with the CSM was that the use of cognitive restructuring did not mediate the relationship between illness representations and psychological adjustment. Nouwen, Law, Hussain, McGovern, and Napier (2009) also applied the CSM model to the study of psychological adaptation of an adolescent sample with Type 1 diabetes. Consistent with Edgar and Skinner’s findings, Nouwen et al. reported that psychosocial adjustment to diabetes was enhanced when fewer consequences of diabetes were perceived and participants’ perceived ability to complete treatments was high.

While not utilising a CF or Type 1 diabetes sample, another recent study applying the CSM model (i.e., Gould, Brown, & Bramwell, 2010) is considered to be particularly relevant to the study presented in Chapter 5 given the focus on psychological adjustment of adolescents and young adults with CF. Gould et al. examined the relationship between illness representations, coping strategies and mood disturbance of women with gynaecological cancer. Significant relationships were identified between many of the illness representation domains and mood state. Specifically, perceiving the cancer as cyclical, having many consequences, having a reduced sense of personal control and treatment efficacy and a reduced understanding of illness was related to greater mood disturbance. Examining the mediating effect of coping styles, other results indicated that a use of denial and disengagement as a coping mechanism mediated the relationship between both perceptions of a cyclical timeline of illness and psychological adjustment and that of illness coherence and adjustment. Having a reduced understanding of illness and holding perceptions of illness as being cyclical predicted greater use of denial and disengagement as a coping strategy. In turn
more frequent use of denial and disengagement increased psychological distress. No other significant mediating relationships were identified.

Research with other chronic illness populations has also exemplified the use of illness representations in prospective studies of patient psychological adaptation. These studies are particularly relevant to the current discussion as a longitudinal design was utilised in the study presented in Chapter 5. This design was chosen in response to reviews of the CF psychosocial literature which have highlighted a paucity of prospective studies for this group (e.g., Berge & Patterson, 2004; Pfeffer et al., 2003). Millar et al. (2005) demonstrated that illness representations were predictive of psychological distress in women who had recently undergone treatment for breast cancer. At 3- and 6-month follow-up, identity was a significant predictor of distress. Timeline also accounted for a significant proportion of variance in distress at 6 months, and again at 12 months follow-up. Those with greater distress perceived more symptoms and a shorter timeline for the breast cancer, suggesting that they may be pessimistic about survival.

Recent research has also presented findings supportive of illness perceptions predicting psychological adaptation over time. One study reported that the psychological aspects of quality of life of patients 6-months after experiencing a moderate to severe physical injury were predicted by three domains of illness representations (Chaboyer, Lee, Wallis, Gillespie, & Jones, 2010). In addition to adaptive psychological adjustment at 3-months post-injury, perceiving fewer physical symptoms, having fewer negative emotional representations of illness and perceiving a shorter timeline of illness 3-months post-injury predicted greater psychological adjustment at 6-months post-injury. Similar results were obtained by Frostholm et al. (2007). In this study, a large sample of patients reporting new or recurring physical symptoms to their general practitioner were recruited. Patients who perceived their illness as having serious consequences and being likely to occur for a long time, and who had negative emotional representations of the illness at the time of their initial medical consultation reported decreased mental health on a measure of quality of life at 12 and 24 months follow-up.

3.3.6 Illness Representations in a Social Context

The review of CSM literature thus far has been centred on the representations of the individual coping with illness. However, Leventhal et al. (1997) acknowledged that the study of illness representations and illness management also needs to acknowledge
the role of the social context. This suggestion has more recently been endorsed in a review of the applications of illness representations. Broadbent (2009) noted that a patient’s family is particularly important in determining their health related behaviours. However, studies of psychosocial adjustment of adolescents and young adults with CF have also noted the impact of social relationships on patients’ adjustment (e.g., La Greca et al., 2002). Recent studies on illness perceptions have begun to incorporate these suggestions and have examined illness perceptions in a social framework.

Specifically, studies (e.g., Benyamini et al., 2007; Figueiras & Weinman, 2003; Heijmans, de Riddler, & Bensing, 1999) have begun to examine the congruence between the illness representations of both an ill patient and significant others in their life and the effects this has on physical and psychological outcomes for the patient. A small body of research has also begun to examine the similarity between healthy individuals’ perceptions of an illness and the perceptions of those with the illness (e.g., Anagnostopoulos & Spanea, 2005) as it is also suggested that this may impact upon the provision of social support for individuals with illness. To the author’s knowledge, no studies of this nature have yet been undertaken with a sample of CF patients. Hence, the review of this research will examine studies using other chronic illness populations.

3.3.6.1 Representations of Illness in Healthy Individuals

The results of current illness representations research suggest that even if a disease is commonly discussed and acknowledged in the general population, it does not necessarily guarantee that healthy individuals will have accurate knowledge of its medical implications or an accurate understanding of the lived experience of the illness. In an investigation of the illness representations of three groups of women: those with no history of breast disease, those with benign breast disease, and women with breast cancer, Anagnostopoulos and Spanea (2005) reported that women without breast cancer perceived this illness more negatively than women with breast cancer. Healthy women perceived breast cancer as having more consequences, being less curable, more influenced by environmental causes, and less influenced by chance than women with malignancies.

A recent study (Vollman et al., 2010) comparing the illness perceptions of depression held by individuals with depression and those of a sample reporting no previous diagnoses of depression found a similar pattern of results to Anagnostopoulos and Spanea (2005). Vollmann et al. reported that the never-depressed group held stronger perceptions of depression being caused by risk factors, immune related factors, and accidental and chance factors than the depressed group. The never-depressed group
also perceived depression as having more consequences, less chance of being effectively treated, and more likely to attract a strong emotional reaction following diagnosis than the depressed group. Conversely, a comparison of the illness representations of individuals with anorexia nervosa and a lay population’s perceptions of anorexia nervosa presented an opposite effect (Holliday, Wall, Treasure, & Weinman, 2005). Holliday et al.’s results suggested that lay individuals viewed anorexia nervosa as less chronic, under more personal and medical control, and less distressing than individuals with a diagnosis of anorexia.

As no examination of perceptions of CF or other paediatric illnesses conducted with the general population could be identified, it cannot be reliably predicted whether lay perceptions of CF would be similar to, more negative, or more positive than those of people with CF. However, as it is suggested that many individuals respond negatively to the symptoms of phlegm-sounding coughing and frequent enzyme ingestion to assist in illness management (G. Brown, personal communication, September 14, 2008; Foster et al., 2000; Harrop, 2007; Pfeffer et al., 2003; W. van Praag, personal communication, September 14, 2008), it is suggested that negative perceptions of CF may be derived from these observations. The study reported in Chapter 6 presents data pertinent to this suggestion. This study examines the relationship between the illness representations of CF in healthy individuals and related likeability ratings of individuals with CF.

### 3.3.6.2 Dyadic Illness Representations

Most studies examining illness representations in dyads have focused on patient-spouse relations, acknowledging that although spouses are an obvious source of support for patients experiencing a chronic illness, the ways in which a patient and spouse conceptualize illness and individually cope with stressors may differ (e.g., Figueiras & Weinman, 2003). Hence, the majority of the studies reviewed here incorporate this dyad. One study (Olsen, Berg, & Wiebe, 2008), however, has been identified which has examined the impact of parent-child illness representation congruence in a sample of adolescents with Type 1 diabetes.

While no studies have applied dyadic illness representations to a sample of CF patients and their parents, the results of research examining the agreement between parent and child ratings of health-related quality of life does lead to the suggestion that it is likely that differences in illness representations may be identified within this dyad (Britto, Kotagal, Cheiner, Tsevat, Atherton, & Wilmot, 2004; Havermans, Vreys, Proesmans, & De Boeck, 2006). Using a sample of children 6- to 13- years and their
parents, Havermans et al. reported that, compared to their parents’ perceptions of their quality of life, children reported significantly fewer respiratory symptoms, greater emotional functioning, greater perceptions of body image, and greater CF treatment burden. In an older sample of children and adolescents with CF (10- to 17- years) and their parents, Britto et al. presented results suggesting that adolescents hold more positive perceptions regarding their health-related quality of life than their parents. Adolescents were found to have significantly more positive perceptions of their health and to perceive fewer limitations to their role functioning due to physical, psychosocial, or behavioural concerns than parents rated for their children.

Applying the CSM, Olsen et al. (2008) reported that mothers of adolescents with diabetes maximised the severity of the illness compared to the adolescents. Mothers perceived the illness as being more chronic, having more consequences and adolescents having less control over outcomes than the adolescents perceived. It was suggested that mothers may express such views to counter the more optimistic, and possibly unrealistic, view of the illness observed in the adolescents. Accordingly, after controlling for adolescents’ own representations, incongruence in representations between the mother and adolescent was associated with negative emotional adjustment. The significance of this relationship, however, depended upon the analysis used to calculate representation dissimilarity (i.e., significant when mean square differences were used, but not when mean difference in representation scores was used).

Olsen et al. (2008) suggest that the sums of squares approach is more sensitive to change than the mean difference approach. In this study, the squared difference between parent and child scores was calculated for each item on scales of interest and then summed to give a dissimilarity score. Mean differences, however, were calculated by simply comparing total scale scores. It is noted that the mean difference approach is used more widely in the dyadic illness representation literature than the sums of squares approach. Thus, given that support was only found for Olsen et al.’s predictions using the latter approach, more replications of both use of the sums of squares approach and application of dyadic illness perceptions to the study of adjustment of adolescents with diabetes are needed before strong conclusions can be drawn based upon this literature.

In relation to studies examining patient-spouse perceptions, Heijmans et al. (1999) examined the effect of dissimilarity of spousal illness representations on patient adaptation to their illness in a mixed sample of Chronic Fatigue and Addison’s Disease patients. The main findings from this research were similar to that of Olsen et al. (2008) in that incongruence in representations adversely affected patient functioning. However,
in this case, it was found that minimization of a patient’s health concerns by a spouse appears to be more detrimental than spouses having a more severe perception of the patient’s illness than the patient holds themselves. Minimisation was found to be associated with greater patient psychological distress. It was suggested that minimisation of the patient’s concerns lead the patient to not feel supported or understood by their partner. Heijmans and De Riddler further suggested that to gain a greater understanding of these dyadic relationships, future studies should incorporate longitudinal designs to examine how each spouse’s illness perceptions mutually affect each other over time. As previously noted, this suggestion was incorporated into the design of the study reported in Chapter 5.

A recent study examined the impact of carers’ illness representations on the adjustment of survivors of oesophageal cancer (Dempster et al. 2011). In this study, an alternate statistical approach to the more common mean difference approach was also used. Dempster et al. suggested that carers’ illness representations would moderate the effect of the survivors’ representations on patient psychological outcomes. In addition to demographic variables and coping styles, survivor and carer illness perceptions accounted for significant variance in patient reports of depressive and anxious symptomatology. In the examination of anxious symptomatology, the interaction between survivors’ and carers’ perceptions of illness consequences accounted for significant variance. Survivor anxiety was greatest when both survivors and carers perceived a number of consequences of cancer. In the examination of depressive symptomatology, the interaction between survivors’ and carers’ understanding of illness accounted for significant variance. Here, survivor distress was greatest when survivors’ understanding of illness was low and carers’ perceived understanding was high. Thus, these results suggest that both carer-survivor perception discrepancy and mutual negativity in perceptions can be predictive of negative outcomes.

Figueiras and Weinman (2003) examined the congruence of illness representations in male myocardial infarction (MI) patients and their partners. This study identified that patients who were in a relationship where they shared similar positive identity and consequence representations (i.e., fewer MI symptoms and consequences acknowledged) had better physical, psychological, and sexual functioning and fewer restrictions in social and recreational functioning than patients who did not share similar positive representations with their partner in these domains. Likewise, a shared perception of the illness having a short duration was related to lower levels of disability, and greater shared sense of control over the illness corresponded with more
dietary changes. It is noted that in this study a group-based approach (ANOVA) was used in analyses examining the impact of similarity of dyadic illness representations on patient outcomes; with dyads being assigned to groups based on the positivity or negativity of patients’ and partners’ illness perceptions.

A second study had also adopted Figueiras and Weinman’s (2003) group-based approach to the examination of the effect of dyadic illness representations on patients’ psychological adjustment (Sterba, R. F. Devillis, B. M. DeVillis, Jordan, & Baucom, 2008). Utilising a sample of women with rheumatoid arthritis, Sterba et al. reported that patients who shared similar positive views with their partner about personal control, consequences, and understanding of illness reported better psychological adjustment than patients who shared similar negative views with their partner. Additionally, regarding perceptions of illness being cyclical, patients in dyads who shared similar negative views of illness reported better psychological adjustment than patients in couples with discrepant views. In another study with male MI patients, Franks, Hong, Pierce and Ketterer (2002) found that after controlling for spousal well-being, patient age and self-rated health, greater spousal agreement of patient health predicted fewer depressive symptoms and greater positive affect in the patients. In this study, a group-based analytical approach was also used. However, differing to Figueiras and Weinman (2003), illness perception similarity variables were entered into regression-based analyses as dummy coded variables.

When the results of these studies examining the effect on dyadic illness perceptions on patient adjustment are considered together, it appears that mutually negative perceptions and discrepant illness perceptions within dyads may lead to patient distress, whereas mutually positive perceptions may promote adaptive patient outcomes. This is also consistent with more general findings in couples coping research where more constructive and reciprocal approaches to coping in a dyad lead to more positive outcomes for each party (Bodenmann, 2005).

Extending upon the applications of dyadic illness perceptions in examining patient outcomes, Benyamini et al. (2007) examined the effect of patient and partner illness representations on male and female MI patients’ perceptions of support received from their partner, and partners’ perceptions of how much support they provided to the patient. Benyamini et al.’s results established that patients who had more positive illness representations than their partner reported receiving high levels of social support from their partners. Likewise partners’ reports of providing more social support to the patient were associated with patients having more positive representations than their partners.
Benyamini et al. suggested that more positive illness representations may be related to more adaptive active coping strategies where patients actively seek social support. It was also noted that as a cross-sectional design was employed, it could not be determined whether illness representations in the couple influenced the provision of social support or whether the effects observed were a product of the reverse effect (i.e., support influencing patient representations).

As noted previously, a number of the studies examined above describe the negative effects that incongruence in illness representations between partners can have on both physical and psychological outcomes of individuals with chronic illness. One study, however, has also extended research using the illness representation framework by trying to explain the processes which lead to incongruence in illness perceptions between partners. Romero, Lindsay, Dalton, Nelson and Friedman (2008) examined the coping styles used by women facing a diagnosis of breast cancer, the patients’ and partners’ assessment of patient adjustment to illness, and patient mood. Using a mediation analysis Romero et al. identified that patients’ use of avoidant coping lead to incongruence in partners’ and patients’ perceptions of adjustment, which subsequently was associated with patient mood disturbance. Romero et al. suggested that wives’ use of avoidance would have lead to decreased communication in the couple, leading partners to be less informed as to their wives’ adjustment, hence, leading to incongruence. In a meta-analysis of illness perceptions research, Hagger and Orbell (2003) identified that perceiving one’s illness to have many symptoms, a long duration and having many consequences is associated with the use of avoidant coping. Thus, it appears that negative representations may lead to avoidant coping, which could subsequently decrease shared understanding of the patient’s illness in the dyad, and increase patient distress.

### 3.4 Sense of Coherence

#### 3.4.1 Overview – Sense of Coherence

Antonovsky (1979) proposed that when a person develops an orientation to life which focuses on problem solving, and where they believe they have the aptitude and support available to manage potential challenges, they could be described as having a high sense of coherence (SOC). This construct is a central factor in Antonovsky’s (1979) salutogenic model of health and illness, which differs from most other conceptual frameworks applied in health psychology, as it focuses on the maintenance and promotion of health, as opposed to examining the derivation of disease (Antonovsky, 1987). This model is briefly reviewed in the following section. This is
followed with a discussion of the recent developments in SOC research and its application to describing the adjustment of individuals with CF. In particular, the potential for SOC change in adulthood during stressful health experiences and the impact of social support on these changes are examined.

3.4.2 *The Salutogenic Model of Health and Illness*

Antonovsky’s (1979) salutogenic model of health and illness conceptualises health and disease as being two extremes of a continuum. Salutogenesis comprises one extreme and refers to a state of optimal physical well-being, described within this conceptual framework as “health-ease”. At the opposite end of the continuum is pathogenesis, being a state of ill-health, “dis-ease”. Antonovsky (1979; 1987) suggested that an individual’s current state of well-being is a function of the stressors they have encountered and the coping resources they have available to challenge the stressor. Thus, the salutogenic model explains how people can maintain optimal health while encountering stressful experiences. In this context, these individuals are proposed to have enhanced coping resources when compared to groups who are not managing aptly with stressors. Comparatively, those with decreased coping ability, who become stressed, are suggested to place strain on their body’s resources and, thus, are more likely to become ill (Lindstrom & Eriksson, 2005).

In the salutogenic model, the factor suggested to influence one’s adopted approach to coping is their SOC (Antonovsky, 1979). This construct was originally theorized to be a stable disposition comprising three constituent factors (Geyer, 1997). The first, comprehensibility, is a cognitive factor incorporating the degree to which an individual believes future life experiences will be predictable, ordered, and unambiguous. Next, manageability relates how confident one is that they have adequate resources available to them either internally or in their immediate environment to cope with stressful situations, hence being the behavioural and instrumental components of SOC. Finally, meaningfulness is a motivational factor that examines the extent to which demanding events are perceived as challenges worth confronting (Lindstrom & Eriksson, 2005).

Antonovsky (1979; 1987) proposed that SOC begins to develop during childhood and later stabilises in early adulthood. SOC is theorised to be a product of one’s biological and psychological traits, as well as cultural tenets, and social experiences (Lindstrom & Eriksson, 2005). Positive traits and experiences that occur in the early stages of life are described by Antonovsky to be ‘generalised resistance resources’, whereas negative circumstances and personality characteristics are termed as
generald resources”. From the interplay of these factors, the individual’s resultant SOC is described to fall along a continuum, where having weak internal resources (e.g., low self-esteem) and a less stable environment (e.g., lower SES or cultural instability) would lead to low SOC. Comparatively, strong internal resources and environmental stability would lead to higher perceptions of comprehensibility, manageability and meaningfulness (Antonovsky, 1990).

3.4.3 Sense of Coherence and Adaptation to Life Events

As SOC is described as a coping resource that can protect individuals from experiencing adverse reactions to stressful or traumatic events, a number of studies have examined the relationship between SOC and a number of psychological outcomes and coping behaviours after the experience of unpleasant life circumstances. One study could be identified which has applied the measurement of SOC to the CF population. In this study SOC was examined in relation to self-care behaviour (Baker, 1998; Baker & Denyes, 2008). Baker and colleagues predicted that basic conditioning factors (similar to generalised resistance resources/deficits [Antonovsky, 1987]) such as demographic, medical and psychosocial variables would predict adolescents’ self-care agency, where SOC was thought to be a central factor. In addition to SOC, self-care agency was also theorized to consist of power components (i.e., perceived value of health and self-care ability) and general intelligence. In turn, the three components of self-care agency were hypothesised to predict both general health and CF-specific self-care behaviours. The results demonstrated that basic conditioning factors were significantly related to self-care agency. In regards to predicting actual self-care behaviour, while SOC and power components of agency were found to be significant predictors, intelligence was not.

Examining the application of these results, Baker (1998) suggested that while adolescents with CF may commonly experience life events which undermine the development of SOC, protective factors such as support from family and health care providers may aid these individuals in developing a reasonable degree of SOC. In turn, having a well-developed SOC may assist individuals in implementing adequate self-care regimes. In the context of discussions from Chapter 2, which have recognised that the transition from paediatric to adult care can be challenging for some individuals with CF and their families (e.g., Iles & Lowton, 2010), Baker’s research highlights the importance of the examination of SOC when studying this population.

Research with other patient populations has examined the relationship between SOC and other measures of psychological adjustment. In a number of cross-sectional...
studies, recruiting a number of different populations (e.g., individuals with varied chronic illness and psychiatric diagnoses, individuals who have experienced a traumatic stressor, and population-based samples) it appears that SOC has a strong inverse relationship to both depressive (Chumbler, Rittman, & Wu, 2008; Engelhard, van der Hout, & Vlaeyen, 2003; Henje Blom, Serlachius, Larsson, Theorell, & Ingvar, 2010; Hittner & Swickert 2010; Myrin & Lagerstrom, 2008) and anxious symptomatology (Black & White, 2005; Henje Blom et al.; Konttinen, Haukkala, Uutela, 1998) and a strong positive relationship with positive affect (Oztekin & Tezer, 2009; von Bothmer & Frilund, 2003).

Consistent with Antonovsky’s (1979) propositions, having a high SOC has also been reported in a number of studies to be a protective factor following trauma experiences. Individuals with higher SOC are less likely to experience post-traumatic stress symptomatology than individuals with lower SOC following exposure to a traumatic event (e.g., miscarriage of child [Engelhard et al., 2003]), car accidents [Frommberger et al., 1999], diagnosis of haematological cancer [Black & White, 2005], and threat or experience of serious injury of fire-fighters [Dudek & Konarek, 2000]).

3.4.4 Stability of Sense of Coherence in Adulthood

While Antonovsky (1979; 1987) theorised that SOC stabilizes by early adulthood and provides individuals with a protective factor to assist in the utilisation of coping strategies following challenging life events, recent research appears to suggest that challenging events in later life may further shape one’s SOC. This view is consistent with Janoff-Bulman (1992), who suggested that although most individuals have a strong sense of self-worth and invulnerability to misfortune, the experience of trauma has the potential to challenge one’s core beliefs about the world.

Since cross-sectional research examining the relationship between SOC and distress cannot determine the direction of effect, it is equally plausible that a traumatic stressor may impact upon one’s SOC as SOC may influence one’s interpretation of the stressor (Geyer, 1997). Supporting this contention, Margalit, Leyser, and Avraham (1989) found that fathers of children with developmental and physical disabilities had lower SOC than fathers of healthy children. When reviewing these results, Geyer noted that it is improbable that parents’ SOC would impact upon the children’s functional status. Thus Margalit et al.’s findings provided early evidence of life events continuing to shape SOC in adulthood. Geyer also concluded that more longitudinal studies examining SOC need to be conducted with a range of populations as these designs allow for identification of individuals’ variations in SOC over time.
More recent research has also demonstrated that carers of children with special needs may be particularly vulnerable to encountering reductions in SOC when compared to parents of normally developing children. Pisula and Kossakowska (2010) reported that mothers and fathers of children with autism had significantly lower SOC than parents of typically developing children. In this study parental gender was not related to SOC ratings. However, Olsson, Larsman, and Hwang (2008) reported mothers of children with intellectual disability reported lower SOC than fathers of children with intellectual disability and both mothers and fathers of children without intellectual disability. Olsson et al. suggested that female carers may be particularly vulnerable to reductions in well-being due to the general finding of mothers having a larger care-giving role than father in families of children with a disability (e.g., Quittner, Opipari et al., 1992).

However, the observation of a gender difference in SOC ratings has been observed in a number of studies. Such findings have indicated that males may have a stronger SOC than females. This finding has been reported in studies utilising a number of different samples, including adult patients with heart disease (Bergman, Malm, Karlsson, & Betero, 2009), a population-based samples of adolescents (Myrin & Lagerstrom, 2008) and adults (Konttinen et al., 2008; Nilsson, Leppert, Simonsson, & Starrin, 2010; Valimaki, Vehvilainen-Julkunen, Pietila, & Pirttila, 2009). Accordingly, it may be suggested that both female gender and the experience of challenging life events negatively impact SOC in adulthood. It would then appear that, in addition to applications of SOC to the examination of the adaptation of adolescents and young adults with CF, the examination of the SOC of parents of children with CF may also be particularly relevant to studies attempting to obtain further understanding of this population. The study presented in Chapter 5 examines this proposition.

Changes in SOC have also been observed in populations other than parents of children with special needs. One study reported that the SOC of severely injured accident patients treated in an intensive care unit significantly decreased over the first six months after their accident, stabilizing at this lower level at 12 months post-accident. In the same study, however, SOC was found to be stable in a comparison sample of rheumatoid arthritis patients over the same two year period, further emphasising the impact of a traumatic event on SOC change (Schnyder, Buchi, Sensky, & Klaghofer, 2000).

In other longitudinal research, Snekkevik, Anke, Stanghelle and Fugl-Meyer (2003) found that although median SOC in a sample of patients with multiple trauma (serious injury to multiple regions of the body) was stable over a 3-year period, individual decreases in some patients were observed over the admission, discharge and follow-up
periods. This finding supports Geyer’s (1997) critique of analyses used to assess SOC over time and suggests that some patients may be at risk of decrements in SOC following challenging events, while other individuals may be more resilient. Thus, further research may be needed to determine influential factors in SOC change in adulthood. In addition to these findings, recent research has also demonstrated that SOC may also increase in adults following a particular event. In a sample of adults with clinical levels of depression, patient SOC ratings significantly increased following treatment (pharmacological and/or counselling) for depression and improvements were maintained over a 4-year follow-up period (Skarsater, Rayens, Peden, Hall, Zhang, & Agren et al., 2009).

What is to be noted about the implications of these recent studies is that they are not contesting Antonovsky’s (1979; 1987) contention of SOC being a stable disposition. These studies are instead suggesting that SOC can be weakened to a lower level, or strengthened to a higher level, which will persist over time after a traumatic event for some individuals (Schnyder et al., 2000). This pattern can be discriminated from the cycle of depressive and anxious symptomatology experienced after trauma which is found to peak initially after the event and dissipate to normal levels within the first 12 months post-trauma (Ganz et al., 2004).

3.4.5 The Impact of Social Support on Sense of Coherence

As it is acknowledged that if SOC may continue to be shaped by life events in adulthood for some individuals, further understanding of these processes may be obtained by examining environmental and intra-individual predictors of SOC in adulthood. In a large population-based sample derived from the Canadian National Population Health Survey, Wolff and Ratner (1999) conducted a multivariate analysis examining a range of environmental and psychosocial variables as predictors of SOC in adults. Consistent with Antonovsky’s (1979; 1987) predictions, the results demonstrated that chronic stress was the largest predictor of SOC. Although accounting for less variance, childhood stressors, current perceptions of social support and social involvement and recent life events were also significant predictors. While the finding that childhood stressors predicted SOC was consistent with Antonovsky’s contentions, the latter predictors identified by Wolff and Ratner are factors concurrent with participant’s SOC ratings. This was not predicted in Antonovsky’s early research. Thus, it may be suggested that the psychosocial environment of an individual may moderate the impact of challenging life events in adulthood. A caveat of Wolff and Ranter’s study, however, was their use of forward stepwise regression. This technique is
considered by some statisticians (e.g., Hair, Black, Babin, Anderson, & Tatham, 2006) to be an atheoretical and unreliable form of multiple regression and may misrepresent unique relationships held between the dependent and predictor variables.

However, other research also suggests that social support may be an important factor in predicting SOC in adult samples. Nilsson, Holmgren, Stegmayr, and Westburg (2000) identified that low SOC was related to low perceived health and low social and emotional support in a large patient group with chronic stomach ailments. It was further reported that similar relationships were identified in a comparison sample with no health difficulties, which may suggest these relationships are robust. Additionally, the effects of SOC and social support on patient psychological outcomes were investigated in an organ donor transplant sample (Erim et al., 2008). Erim and colleagues also found a significant positive relationship between SOC and social support. In a prospective study, Skarsater et al. (2005) reported that a strong social network may play an important role in the restoration of SOC after mental illness. Skarsater et al. examined depression, support, and SOC indices across 12 months in patients having their first major depressive episode who were not receiving treatment. The results indicated that those who had significantly improved over 12 months had both higher perceived social support and SOC than those who did not improve at follow-up.

Two studies, however, have presented findings contrary to those discussed above. Hildingh, Fridlund, and Baigi (2007) reported no relationship between SOC and perceptions of social support in a recently discharged cardiac sample. However, as SOC was relatively low across the majority of the sample, the low variability in SOC may have prevented a significant association from being identified. Further, Mizuno, Kakuta, and Inoue (2009) only reported a weak correlation between perceptions of social support and SOC in a sample of patients with gastrointestinal tract cancer. However, Mizuno et al. noted that the overall level of social support reported by patients in this sample was lower than levels reported in other studies with cancer patients. Thus, this may have contributed to the discrepant results obtained in this study.

With the results of all studies examining perceptions of social support and SOC taken together, overall, this research tends to support the contention of a supportive social network being positively associated with SOC. However, further study of these relationships in prospective research is needed to confirm these associations. Further to this point, as previous studies have primarily examined cross-sectional bivariate relationships, it may still be argued that SOC may influence how a person utilises their social network, as opposed to the usual reverse interpretation.
CHAPTER 4 – THE APPLICATION OF PSYCHOLOGICAL THEORY TO THE PSYCHOSOCIAL EXPERIENCE OF CYSTIC FIBROSIS

The previous chapter introduced three psychological models which are considered to have particular utility in the exploration of the psychosocial adjustment of adolescents and young adults with CF and their parents. The social cognitive processing (SCP) model (Lepore, 2001) has been demonstrated to assist in outlining the processes through which a perceived unsupportive social environment impacts upon an individual’s processing of illness-related concerns and subsequent psychological adjustment (e.g., Lepore & Helgeson, 1998). The common-sense model (CSM) of illness (H. Leventhal., et al., 1980) explains how individuals cognitively represent and store illness-related information and how one’s perceptions of illness impacts upon the approaches they adopt to cope with illness-related threats. In studies applying CSM (e.g., Gould et al., 2010), both illness representations and coping styles have been demonstrated to impact an individual’s psychological adjustment. Recent applications of the CSM have also demonstrated that the illness representations held by significant others in a patient’s environment can also impact upon the patient’s perceptions of support received (e.g., Benyamini et al., 2007), coping style (e.g., Romero et al., 2008) and psychological outcomes (e.g., Dempster et al., 2011); additionally, another branch of research with CSM has identified that community members’ perceptions of common illness may differ significantly from patients’ perceptions which may impact social interactions (e.g., Anagnostopoulos & Spanea, 2005). Finally, empirical research investigating the construct of sense of coherence (SOC) from Antonovsky’s (1979; 1987) salutogenic model of health and illness was also reviewed and this research demonstrated that an individual’s perceptions of predictability, manageability and meaningfulness of their life and events within it also impact psychological adjustment (e.g., Henje Blom et al., 2010).

This chapter reviews the unique applications of these models to the examination of the psychosocial experience of CF as well as further discussing theoretical linkages between each of the models. Additionally, this chapter also discusses methodological concerns within the SCP model and the CSM which have been highlighted by some authors (e.g., Lepore & Helgeson, 1998; Olsen et al., 2008) and suggests plans for the resolution or reduction of these concerns. The studies presented in Chapters 5 to 7 then test these applications and extensions of the CSM, SCP model, and SOC with the CF population, their family members, and members of the general community.
4.1 Cystic Fibrosis, the Self, and the Family – Application of Theory

4.1.1 Population Selection

As discussed in Chapters 2 and 3, the period of transition from paediatric to adult care and the associated transfer of treatment-related responsibilities in the home can be challenging for both adolescents and young adults with CF, and their parents (e.g., Hamlett et al., 1996; William et al., 1997). Further to this, prior to the implementation of enhanced treatment protocols for individuals with CF which followed the isolation of the CF gene, the number of individuals surviving into adolescence and adulthood was limited, and thus, it has only been in recent decades that research examining the adjustment of this population with large samples has been possible (Crosier & Wise, 2001). Additionally, studies that were able to recruit this population prior to the early 1990’s which examined issues such as parent and child psychological adjustment, family dynamics and future outlook may no longer be relevant to the current population of families with CF given the significantly enhanced average age of survival (P. E. Pfeffer et al., 2003).

Given the points reviewed here, adolescents and young adults with CF aged 16- to 25- years and one person nominated by the patient as primary carer (usually a parent) were recruited in Study 1 (Chapter 5) with the overall aim of gaining a greater understanding of individual and family-based adjustment during the treatment transition period. To assist in the ease of expression and reader understanding throughout the remainder of this manuscript, adolescents and young adults with CF will be referred to as ‘patients’ and nominated care-givers will be referred to as ‘parents’.

4.1.2 Application of the Social Cognitive Processing Model to Cystic Fibrosis

The review of individual and family based adjustment for individuals with CF presented in Chapter 2 highlighted that support received from the social environment and the psychological adjustment of individuals within this environment can have a significant impact on the psychological adjustment of individuals with CF (e.g., Cappelli et al., 1989; Graetz et al., 2000; Peek, 2001; Wong & Heriot, 2008). Thus, to extend this body of literature, it would appear that having a model to demonstrate how factors within the social environment may specifically impact the adjustment of individuals with CF would be particularly useful.

Given the reported success of the SCP model in explaining the impact of support from the social environment on patient adaptation to a range of illnesses it was proposed in the current research that this model would also be useful in the investigation of the
psychosocial experiences of adolescents and young adults with CF. Although no studies have examined the prevalence of trauma symptomatology in individuals with CF, the research of Braitman et al. (2008), who successfully applied the SCP model to the study of self-care management of diabetes patients, suggests that this model is appropriate to be used in the conceptualisation of ongoing illness-related concerns and not just those that occur at the time of diagnosis.

However, while the experience of CF for the patient may not include a period of ‘shock’ following diagnosis like it may for parents (Quittner, DiGirolamo et al., 1992); the lived experience of CF may, at times, trigger elevated distress for patients. Particularly challenging experiences with CF may include encountering acute bouts of illness or CF-related complications requiring hospitalization (WHO, 1996a). Further, as children and adolescents begin to appreciate the unrelenting nature of their illness and the uncertainty of their future health, these realisations may also exert a large toll on their emotional well-being (Gee et al., 2003). Thus, these examples also suggest the original application of the SCP model to more traumatic illness-related events may still be relevant to the CF population.

Research with the CF population suggests that adolescents and young adults often obtain independence from the family unit later than individuals without chronic illness (Hamlett et al. 1996; Walters et al., 1993). Further, parents may maintain a key support role in treatment activities for their children even after they leave the family home (McGuffie et al., 2008). It is, therefore, suggested that the measurement of perceived social constraints from parents would be particularly relevant for this population. While it may be argued that, given the key role of parents in treatment activities across childhood and beyond, parents would be unlikely to disengage in CF-related discussions; the discussion of CF-related treatment protocols and CF-related emotional concerns are two distinct areas. Accordingly, research has suggested that parents may be more skilled in providing support for the first domain rather than the latter (Graetz et al., 2000). Specifically, parents who themselves are struggling with their own concerns around the life-threatening nature of CF or more personal emotional concerns may be less equipped to provide emotional support for their children than those who are coping well.

To summarise, the study presented in Chapter 5 is the first known to the current author to examine the SCP model both for CF patients and specifically within a parent-child dyad. The sample recruited for these studies was not selected to particularly focus on patients currently experiencing acute bouts of illness. Thus, from the empirical
investigations of the SCP model reviewed in the previous section, it is suggested that the pattern of relationships expected from the CF population will be more similar to the results obtained at follow-up in studies using cancer patients (e.g., Lutgendorf et al., 1999), rather than results obtained closer to the time of diagnosis. Similarities to Braitman et al.’s (2008) research with the diabetes population were also expected.

4.1.3 Application of the Common Sense Model of Illness to Cystic Fibrosis

As reviewed in Chapter 3, recent research has identified the utility of examining the illness representations of CF patients. This research has examined the relationship between patients’ cognitive representations of CF and their quality of life (Sawicki et al., 2011) and treatment adherence (Bucks et al., 2009). However, no studies have examined the relationship between clinical measures of adjustment of CF patients (i.e., depression, anxiety) and their cognitive representations of CF. These relationships were examined in Study 1 of the current research. Further to this, Study 1 of the current research is the first to examine the role of parents’ representations of CF and investigated their role in predicting both parents’ and patients’ distress. This application of the CSM to parents’ perceptions of CF builds upon recent studies which have compared the illness perceptions of adolescent diabetes patients and their parents (Olsen et al., 2008) and also adds to the literature examining the effect of parental functioning on psychological outcomes of the children with CF (e.g., Drotar, 1997; Wong & Heriot, 2008).

Further to this, the study presented in Chapter 5 also examined new pathways linking parent and child functioning, being the first study to apply dyadic illness perceptions with a sample of CF patients and their parents. Given, the number of previous studies which have suggested that mutually negative illness perceptions and discrepant illness perceptions in a dyad lead to diminished patient psychological adaptation (e.g., Figueiras & Weinman, 2003; Heijmans et al., 1999), it is considered that these constructs are particularly important to examine in the CF population.

4.1.4 Sense of Coherence and the Social Cognitive Processing Model in Cystic Fibrosis

Baker (1998) examined the impact of SOC on self-care behaviour of adolescents with CF and identified that having a strong SOC is a factor which predicts enhanced self-care. While this research suggested that SOC is an important construct to examine within the CF population, no other studies can be identified which have applied this construct with this group. Thus, Study 1 of the current research is the first known study
to examine the relationship between SOC and other psychosocial outcomes in a CF population. Further to this, this study is also the first known to examine SOC in parents of children with CF. Following from the findings of other studies of parents of children with physical or developmental disabilities (e.g., Pisula & Kossakowska, 2010) parents of children with CF may be predicted to have lower SOC compared to parents of children without special needs. Thus, these additional points of study will also add to the body of literature examining the psychosocial adaptation of adolescents and young adults with CF, and parental functioning in families with CF.

4.1.5 Suggested Relationships Between the Applied Models

Another aim of the current research was to examine potential relationships between the SCP model, the CSM and SOC. Given that current research has acknowledged relationships between both social support and dyadic illness representations (e.g., Benyamini et al., 2007) and social support and SOC (e.g., Nilsson et al., 2000) it was then plausible that social constraints may have a similar but inverse relationship to these two constructs. Accordingly, each of these extensions is discussed in detail below. Specific predictions were made regarding i. the role of dyadic illness representations in the derivation of patient perceptions of social constraints, and ii. the impact of social constraints on the individual’s SOC for parent-child dyads in families with CF.

4.1.5.1 Predicting Social Constraints – Dyadic Illness Representations

The first proposed extension to the SCP model is the effect of the degree of congruence between patients’ and parents’ illness representations on social constraints. Two previous studies examining potential predictors of social constraints suggested that similarity between patients’ and partners’ beliefs about illness (Herzer et al., 2006) and partners’ receptiveness to patients’ social support needs (Quartana et al., 2005) are likely to predict social constraints perceived by a patient.

While Quartana et al. (2005) found that female cancer patients’ need for emotional expression moderated the relationship between patient neuroticism and perceptions of social constraints, Herzer et al. (2006) reported that partner perceptions of illness threat and the interaction between cancer patients’ and partners’ perceptions of threat did not account for significant variance in patients’ perceptions of social constraints. Herzer et al. suggested that this null-effect may have been due to most participants having completed their cancer treatments and possibly not requiring as much social support at the time of data collection. It was also suggested that partners
may have concealed any discrepant views from patients. Given that both parents and patients are both actively involved in the transfer of CF treatment responsibilities during the transition from paediatric to adult care, it is reasonable to suggest that discrepant views may be more apparent in this dyad and may have a greater effect than that observed within Herzer et al.’s sample as treatment is ongoing in this CF population.

Further, while Herzer et al. (2006) only examined threat of illness recurrence, the current author suggests that examining a wider range of parent and child views about CF may highlight other illness-related perceptions which may contribute to the development of social constraints. As research examining dyadic illness representations (Benyamini et al., 2007) has presented results suggesting that discrepancies in patients’ and partners’ views of illness can impact patients’ perceptions of social support and partners’ reports of social support provision, it is suggested in the current research that dyadic illness representations may then also impact patients’ perceptions of social constraints.

When considering an individual’s illness representations, they can be described, overall, as being positive or negative; with more positive perceptions incorporating a view that the illness has few symptoms, a short duration, few consequences, and is curable (Hagger & Orbell, 2003). When such a criterion is placed on patient and parent illness representations, it is apparent that in regards to representation similarity in the dyad, four potential combinations can arise; two congruent – with the patient and the parent both being positive or both being negative, and two incongruent – patient positive/parent negative or patient negative/parent positive (Figueiras & Weinman, 2003; Sterba et al., 2008).

Following from this, the valence of both a patient’s or parent’s illness representations may be associated with particular coping strategies that impact on the occurrence of social constraints. As discussed in the previous chapter, Romero et al. (2008) and Hagger and Orbell (2003) suggested that negative illness representations lead to avoidant coping in cancer patients. Romero et al. further suggested that this may decrease a patient’s communication with their spouse, in turn decreasing the likelihood of shared understanding of illness within the dyad. Stemming from these findings, it may also be suggested that if both the patient and parent hold negative illness representation, both parties will be likely to engage in avoidant coping; again decreasing opportunities for patient-parent discussion. Conversely, if both parents and patients hold positive illness representations, fewer avoidant coping strategies would be predicted to be used within the dyad, making open communication more likely (Bodenmann, 2005).
Benyamini et al. (2007) reported that when heart disease patients hold more positive perceptions of illness than their partners, they may actively seek out social support. Given this finding, it may be suggested that CF patients who possess more positive illness perceptions than their parents may also actively seek social support. Yet, research discussed above noting the relationship between partner coping and partners’ availability for support also needs to be considered here. Quartana et al. (2005) suggested that social support provision may erode over time if a patient’s needs exceed their partner’s capabilities. It may, therefore, be suggested that the provision of social support and perceptions of social constraints when a patient has more positive illness representations than a significant other will also be impacted by the degree of discrepancy in the dyad. If there are only small differences between a patient’s and a partner’s illness representations, and the partner is coping well, then the patient’s perceptions of social constraints may be minimal. However, if there is a large difference in the perceptions of patients and their partners, with partners holding negative perceptions and not coping well, then patient perceptions of social constraints may be increased.

Thus, taken together, the literature appears to suggest that dyads with mutually positive illness perceptions are likely to have greater ease in communication and, hence, less experience of social constraints than dyads with either highly discrepant or mutually negative illness perceptions. In these dyads, the use of avoidant coping by either or both patients or parents may impede discussion of CF. These relationships are summarised in Figure 2.

![Figure 2. The relationship between patient and parent illness representations and experience of social constraints within the dyad.](image-url)
4.1.5.2 The Impact of Social Constraints on Sense of Coherence

As discussed earlier, SOC was originally conceptualised to be well-developed in an individual if they also developed strong internal resources (e.g., self-esteem) and were exposed to a stable environment across their life (e.g., had adequate access to basic physical and emotional resources) (Antonovsky, 1990). Baker (1998) further conceptualised that, for the adolescent CF population, while children with illness may experience life events which undermine SOC development, factors such as access to adequate health care and family support may buffer the effects of negative experiences on SOC development.

Regarding the stability of SOC in adulthood, while SOC was originally conceptualised to crystallise by adulthood and buffer against distress following stressful events, recent research indicates that experiencing a traumatic event can change one’s outlook on the world, thereby reducing their SOC (e.g., Roth & Ekblad, 2006). Further, recent research (e.g., Nilsson et al., 2000; Skarsater et al., 2005) also suggests that an emotionally supportive environment can assist in restoring an individual’s SOC after a traumatic event or illness. Thus, the interpretation of this research which has examined the relationship between emotionally supportive environments and SOC may be extended to suggest that a negative social network (i.e., a socially constrained environment) may have a detrimental effect on CF patients’ development of SOC during adolescence or young adulthood. It may also be suggested that parents’ levels of SOC may change following a traumatic illness-related event or other acutely stressful situation; hence, highlighting the importance of the examination of SOC and its relationship with other indicators of psychological adjustment for this population.

Reviewing and extending the discussion of cognitive information processing from Chapter 3, when events occur that are congruent with an individual’s beliefs and expectancies, they are easily integrated into their existing schemas and representations of the world (e.g., Kudler, 2000). The experience of a traumatic event can, however, shatter an individual’s fundamental beliefs about the world being a predictable, controllable and coherent place (Janoff-Bulman, 1992). Consistent with this proposition, as previously highlighted, traumatic events have been demonstrated to have the potential to reduce individuals’ perceptions of manageability, comprehensibility, and meaningfulness of life events (e.g., Roth & Ekblad, 2006; Schnyder et al., 2000). When distressing information is received, there is a discrepancy between the past schematic information and the new information received for cognitive processing.
Hence, extended information processing is required to integrate this information into one’s cognitive models of the world (Horowitz, 1997).

Relating these occurrences to the social environment, as reviewed previously, a less supportive social environment has been demonstrated to impede discussion of patients’ illness-related information. This reduces patients’ opportunity to both gain exposure to their thoughts and feelings in a supportive environment which may reduce associated negative emotional arousal, and obtain other individuals’ perspectives on the event and subsequent cognitive processing of their experiences. The obstruction of these processes can increase the likelihood of psychological distress (Clarke, 1993).

It is proposed that it is through these processes that social constraints will also exert an impact on CF patients’ SOC. It is suggested within the current research that when emotionally significant illness-related events occur (e.g., transitioning from paediatric to adult care or the occurrence of CF complications), negative thoughts and/or negative perceptions of these experiences may persist if an individual does not express these thoughts in their social environment, as this would increase cognitive avoidance and intrusions of the event-related information (Clarke, 1993). Thus, as negative thoughts about the incident may remain, this may lead to a weakening of the individual’s SOC. Conversely, for patients who can converse about their CF experiences with their parent, the traumatic events may be adequately processed, preserving their current SOC. While it is not the focus of the current study to examine the factors that lead to changes in parents’ SOC when they are caring for a child with CF, it is also proposed that the same process described here would impact parents’ processing of illness-related events.

Finally, one study (Lehto, 2007) has examined the relationship between illness coherence, emotional distress, and causal subscales of the IPQ-R in a sample of suspected lung cancer patients and found significant relationships between both illness coherence and emotional distress and illness coherence and causal attributions. While illness coherence focuses more specifically on understanding of illness and SOC is a more global construct examining cognitive adjustment and perception of the world; Lehto’s results suggest that, in addition to relationships between illness representations and social constraints, it is likely that relationships between SOC and the illness representations are also likely to be identified in the results of Study 1 (Chapter 5).
4.1.5.3 The Proposed Model

To summarise, a number of relationships were predicted to occur between the CSM, the SCP model, and patient outcomes. These are depicted graphically in Figure 3. As shown in this figure, negative illness representations within a dyad are predicted to increase either or both CF patients’ and parents’ use of avoidant coping, subsequently increasing social constraints. High social constraints are, in turn, suggested to increase the likelihood of decreased psychological adjustment and SOC by impeding cognitive processing of CF experiences and subsequent talking in the dyad. These relationships were tested in Study 1 (Chapter 5).

Figure 3. The proposed relationships between illness representations, coping style, SCP variables, and measures of CF patients’ psychological and cognitive adjustment.

4.1.6 Clarifying Methodological Issues in the Applied Models

4.1.6.1 Social Cognitive Processing Model – the Role of Intrusions and Avoidance

Although past research clearly demonstrates a relationship between social constraints and outcome measures, and it is known that cognitive intrusions and avoidance link these two constructs, debate remains in the literature regarding the exact nature of these relationships. The original studies of social constraints conducted by Lepore and colleagues (e.g., Lepore et al., 1996; Lepore & Helgeson, 1998) examined the relationship between the SCP variables and outcome measures using moderating analyses. Specifically, significant interactions were reported between social constraints and intrusive thoughts on both patient psychological adjustment and the degree to which patients discussed their cancer with their partner. More recent studies examining the SCP model (i.e., Cordova et al., 2001; Devine et al., 2003; DuHamel et al., 2004) have
examined the relationships between social constraints, intrusive thoughts, and psychological outcomes employing a mediator model. In these studies, intrusive thoughts were hypothesized to mediate the relationship between social constraints and psychological outcomes, and the predictions were supported on all occasions.

A number of authors have discussed that when conducting moderator analyses it is preferable for the predictor variable and the moderator variable to be independent of one another, as biased estimates of the interaction of the two factors are obtained when they are non-orthogonal (Baron & Kenny, 1986; Evans & Lepore, 1997; Lepore, 1997). In comparison, in mediation analyses it is a prerequisite that all variables have significant interrelations so that it can be demonstrated that the relationship between the criterion and the predictor becomes non-significant (or at least substantially reduced) when the mediator is entered into the analysis (Evans & Lepore; Lepore). From the current author’s review of the analyses conducted in both Lepore and colleagues’ earlier SCP studies and later investigations, moderate correlations (i.e., $r > 0.5$, significant at $p < .05$) have been found between social constraints and intrusive thoughts; suggesting non-orthogonality of these factors. Hence, although contrary to Lepore and colleagues’ (e.g., Lepore et al., 1996) original studies on social constraints and SCP, if these correlations were replicated in the current study, it was decided to take a mediational approach to the analyses concerning social constraints, intrusions, and outcomes.

The next issue to be examined in regards to relationships in the SCP model and outcomes pertains to the role of cognitive avoidance. As noted previously, the role of avoidance in the model is less clear. From the current author’s review of studies which examined the role of avoidance in the SCP model and the consideration of theoretical suggestions regarding the role of avoidance in trauma processing, it was suggested in Chapter 3 that the function of avoidance in the model would change over time.

Cross-sectional studies examining the adjustment of cancer patients post-treatment suggest that, at best, avoidance only partially mediates the relationship between social constraints and adjustment indicators; as studies report either partial (e.g., Lepore & Helgeson, 1998) or non-significant (e.g., Cordova et al., 2001) mediating effects. Longitudinal studies (i.e., DuHamel et al., 2004; Lutgendorf et al., 1999) have also reported that avoidance does not significantly predict patients’ psychological adjustment at diagnosis, and the authors of these studies have suggested that avoidance may buffer distress early after a traumatic experience. It has been further suggested that continued avoidance across treatment and remission may, however, increase distress as it prevents cognitive processing of trauma-related experiences. In
both 3-month (DuHamel et al.) and 6-month (Lutgendorf et al.) follow-up studies, avoidance reported at follow-up was associated with concurrent measures of distress.

As patients with CF have been facing their illness for a number of years and will continue to face it for the entirety of their lives, it is plausible that cognitive avoidance would be significantly associated with distress in this population. Regarding the analyses to be used to examine this relationship in Study 1, as significant relationships have been identified between both social constraints and avoidance (e.g., Lepore & Helgeson, 1998) and avoidance and distress (DuHamel et al., 2004; Lepore & Helgeson; Lutgendorf et al., 1999) it was expected that cognitive avoidance would mediate the relationship between social constraints and distress when the SCP model was applied to the CF population. Thus, it was decided to also adopt a meditational approach to examine these relationships.

### 4.1.6.2 The Social Cognitive Processing Model – Outcome Measures

The studies reviewed in Chapter 3 which examined relationships between SCP variables and the psychological adjustment of chronic illness patients primarily used measures of depression and anxiety as outcomes measures. Lepore and Kernan (2009) have also noted that no studies examining the effects of social constraints on patient outcomes have tested whether an environment with low constraints facilitates cognitive processing and promotes positive patient adjustment, such as personal growth, as SCP theory would suggest would occur. Thus, while it is beyond the scope of the current research to examine personal growth following illness-related challenges, a measure of positive affect was included as an outcome measure in Study 1. This inclusion of positive affect as an outcome measure is also in accordance with both current directions in illness perception research (Franks et al., 2002; Sterba et al., 2008) and with studies examining the adjustment of parents and children in families with children coping with chronic illness using other health psychology theoretical frameworks (e.g., Cameron, Young, & Wiebe, 2007; Currier, Hermes, & Phipps, 2009).

### 4.1.6.3 Statistical Approaches in Dyadic Illness Representations

In studies examining the effects of dyadic illness representations on various measures of patient adjustment, it is noted that the most common approach employed across this research is the mean differences approach. In this approach, quantitative measures of the partner’s illness representations are subtracted from that of the patient, with this difference score then correlated with various measures of patient adjustment (e.g., Benyamini et al., 2007; Heijmans et al., 1999). As noted in Chapter 3, a number of
alternative approaches to data analysis have also been utilised by some authors publishing in this field.

Two other approaches incorporating continuous variables into the analysis of patient-partner view discrepancy have been identified in the current literature. Firstly, Olsen et al. (2008) utilized the sums of squared differences approach. In this approach the squared difference between parent and child scores for each item on scales of interest were calculated and then added together to represent an overall dissimilarity score. Like the mean difference approach, this score can then be used in correlation or regression analyses. The second approach using continuous variables was that used by Dempster et al. (2011) who used the total scores of each IPQ-R scale for patients and their partners and examined whether partner representations moderated the relationship between the patient’s illness representations and patient adjustment indicators. It is noted, though, that this is technically not quantifying discrepancy scores, instead it is simply noting the impact of both patient and partner illness representations on patient adjustment.

One categorical approach to performing analyses using dyadic illness representation discrepancy analysis has also been identified in the current literature. This approach was first employed by Figueiras and Weinman (2003) who performed a median split for both patients’ and partners’ illness representation scores (separately for each illness representation domain), with those below the median being considered to have negative illness representations and those above the median to have positive illness representations. For each domain, dyads were categorised into four groups; both patient and partner positive, both patient and partner negative, patient-positive-partner-negative, patient-negative-partner-positive. Accordingly, these groupings of discrepancy scores lend themselves to use in ANOVA-based approaches to differences in patient adjustment based upon patient-partner view match.

Some arguments have supported the use of particular approaches to the analysis of the impact of dyadic illness representations on patient adjustment which highlight the specificity of particular approaches over others (i.e., Olsen et al., 2008). However, given that the current research proposes that both discrepant patient-parent illness perceptions and mutually negative dyadic illness perceptions will lead to increased social constraints and decreased adjustment in the dyad, continuous discrepancy measures were not considered to be appropriate for analyses in Study 1 (Chapter 5). Specifically, both the mean difference and sums of squares approach would denote both similar positive and similar negative dyads with the same score (i.e., on or around 0) and thus, predicted differences between mutually positive and mutually negative dyads would not be
directly testable with this approach. Thus, the categorical approach of Figueiras and Weinman (2003) was adopted for analyses incorporating dyadic illness perceptions in Study 1.

4.2 Cystic Fibrosis and the Social World – Application of Theory

From the review of the literature examining the psychosocial adjustment of individuals and families affected by CF in Chapter 2 it was established that there is a research gap in the development, implementation and evaluation of theoretically based interventions for older youth with CF who may be experiencing adjustment difficulties. Accordingly, it can be suggested that, in addition to examining the impact of family-based and intrapersonal factors on adjustment, an extended analysis of the social environment may also help to provide appropriate underpinnings for future intervention development. Specifically, obtaining an understanding of the attitudes of the peer group toward individuals with CF would be highly beneficial in shaping the content of future psychosocial interventions as this would provide an extra level of specificity in the understanding of social experiences, not only from the perspective of the individual with CF, but also from the perspective of other individuals involved in the interaction. Thus, another aim of the current research was to identify the characteristics of both peers and those of individuals with CF which lead peers to be accepting or rejecting of individuals with CF.

4.2.1 Stigma and Social Interactions

As reviewed in Chapter 2, the process of disclosing one’s illness status to peers can be challenging for individuals of all ages with CF (e.g., Christian & D’Auria, 1997; Lowton, 2004; Modi et al., 2010). Recent literature also suggests that coughing and its associated discharge of sputum, and frequent ingestion of enzyme tablets are characteristics of the illness that may lead to negative social reactions (e.g., G. Brown, personal communication, September 14, 2008; Foster et al., 2000; Harrop, 2007; P. E. Pfeffer et al., 2003; W. van Praag, personal communication, September 14, 2008). It has also been identified that when peers are given a medical explanation for such symptoms, this may also lead to negative interactions (La Greca et al., 2002). This may especially occur if CF is not well understood by the person receiving this information and it is confused with other, more contagious, illnesses (Christian & D’Auria, 1997; Dijker & Raeijmaekers, 1999). These personal accounts of social interactions from individuals with CF concur with social psychological research examining stigma.
Goffman (1963) defined stigma as a physical, mental or dispositional characteristic of a person which is socially discrediting. Identified in more recent research, the dimensions of stigma that appear to have the most impact on one’s perceptions of an individual and stigmatised individuals’ experiences are its visibility, controllability, and severity (Dovidio, Major, & Crocker, 2000). As previously discussed, La Greca et al. (2002) identified that an illness with noticeable physical symptoms, especially those that reduce one’s ability to engage socially with peers, may lead to negative reactions from the peer group. In addition to this, physical illness stigma research suggests that conditions which are considered to be under personal control and have strong detrimental effects for the affected individual and those around them are those most likely to lead to social rejection (e.g., Crandall & Moriarty, 1995; Swendeman, Rotheram-Borus, Comulada, Weiss, & Ramos, 2006; Zacks et al., 2006). Extending the concept of severity, in the domain of mental illness stigma research, Corrigan (2004) has noted that when individuals are perceived as potentially being ‘dangerous’ it is common that others may feel threatened and avoid social interactions with such individuals.

Applying these aspects of stigma to CF, while it is not anticipated that people with CF would be perceived as threatening, if an individual knows little about CF, they may perceive the illness to be contagious and, therefore, as a threat to their health. Yet, it is reasonable to suggest that if peers or colleagues are aware of the congenital (low controllability) and non-contagious (less severe) nature of the illness, they may be more likely to form favourable assessments of individuals with CF. If support is found for this proposition, it would suggest that education of peers and colleagues about CF may improve social interactions.

Other research has identified that, in addition to the psychological impact of the experience of negative reactions from peers to stigmatised characteristics, negative psychological effects can also occur when individuals concealing a stigmatised characteristic anticipate receiving negative reactions if their illness was ‘discovered’ by other individuals (Quinn & Chaudoir, 2009). These anticipated reactions can also lead to detriment for individuals with illness as they may avoid disclosing information and, thus, decrease their access to treatment and support (Kanter, Rusch, & Brondino, 2008; Romer & Bock, 2008). Specifically, in relation to individuals with chronic illnesses, studies in organisational psychology have also suggested that individuals may attend work even when feeling unwell to avoid negative consequences of absenteeism and other unfavourable reactions from employers (Edwards & Boxall, 2010; Munir, Yarker,
& Haslam, 2008). Hence, the results of these studies suggest that identifying ways for individuals to feel comfortable disclosing information about their illness to others may also be beneficial to the psychological adjustment of individuals with CF.

Two Australian educational resources can be identified which are aimed at the education of the peer group about CF. One of these resources is aimed at providing information about CF to teachers of children and adolescents with CF (Cystic Fibrosis Victoria [CFV], n.d), and the second is aimed at parents of classmates of individuals with CF (CFV, 2008). Similar resources have also been identified for use in schools in the United States (e.g., Ryan & Williams, 1996). Although there is a large amount of information given about the disease within these resources, there is no indication of how thoroughly this information is discussed with the classmates and their parents, and how the disclosure of this information affects the outcomes of individuals with CF. Likewise, no resources appear to be available that may inform employers about CF and how it may affect their employees’ work behaviours. However, guide books have been published (e.g., Peebles, Connett, Maddison, & Gavin, 2005) to assist parents and young adults in navigating school systems, employment, and the health care system. It is unlikely, though, that general members of the community would access these resources. Thus, given the few resources that appear to be freely available to educate the community about CF, it is reasonable to suggest that knowledge of CF in the general community may be low which would add to the potential of individuals with CF receiving negative reactions following disclosure of their illness.

4.2.2 Theoretical Approaches to the Examination of Social Interactions

As discussed in Chapter 3, research using CSM has begun to give further insight into perceptions of illness held in the general community. Specifically, Anagnostopoulos and Spanea (2005) investigated the perceptions of breast cancer in individuals with and without the disease and Vollman et al. (2010) compared perceptions of depression of individuals with and without a history of depression. In both studies, the healthy individual groups were found to have more negative perceptions of illness than individuals with illness. Holliday et al. (2005), however, reported the opposite effect when comparing illness representations of individuals with and without anorexia; reporting that healthy individuals had more positive perceptions of illness than those with a diagnosis of anorexia nervosa.

Given that these three illnesses are relatively well known in the community, and differences in perceptions were observed between individuals with and without the
illnesses, it can be assumed that differences in illness perceptions of the less well known CF would also be observed between the general community and individuals with CF.

Thus, considering the results of these studies of illness perceptions of healthy individuals in the context of both the stigma research reviewed, and studies examining the psychosocial experience of CF, it is suggested that if a healthy lay person did not have specific knowledge about CF and noticed the observable symptoms and treatments of CF (i.e., coughing, taking a number of medications) then unfavourable conclusions may be drawn. However, if a person was given specific and accurate information about CF, including that about its genetic basis, then more positive reactions may be observed.

This proposition is tested in Study 2 (Chapter 6) of the current research using a sample of university students enrolled in undergraduate non-health related subjects. In this study, an experimental design was taken with participants receiving one of six vignettes describing a person who coughs frequently and takes a number of medications. Participants then rated the likeability of the individual described in the vignette. The vignettes differed according to the diagnosis given to this person (CF or other); additionally, the conditions that stated the person has CF also varied as to the amount of information given to the reader about CF, and who discloses this information (the patient or another party). Study 2 also examined the illness perceptions of CF of this sample, and evaluated the similarity of illness perceptions between participants who were not given specific information about CF, those who were given specific CF information, and individuals with a diagnosis of CF (using patient data from Study 1).

4.3 Qualitative Investigation of the Psychosocial Experience of CF

Detailed in the previous sections of this chapter, the overall aim of the current research is to enhance the understanding of the psychosocial network of adolescents and young adults with CF. To achieve this aim, this investigation is grounded in well-tested psychological theory, which can be used as a basis for the development of psychological interventions for individuals who may be experiencing challenges in psychosocial adjustment. While the use of well-tested psychometric measures to obtain quantitative data to describe the experiences of the CF population and others in their social network within the chosen theoretical framework is necessary and justified, it is also acknowledged that qualitative investigations of these constructs can assist in obtaining a richer understanding of individuals’ experiences to complement that quantitative data obtained in the current research (Coyle, 2007; Lincoln & Guba, 1985; Ononeze, Murphy, MacFarlane, Byrne, & Bradley, 2009). Thus, in addition to the
quantitative studies of the psychosocial experiences of CF investigated in Studies 1 and 2 (Chapters 5 and 6), a qualitative investigation of these experiences was also incorporated in the current research in Study 3.

4.3.1 Qualitative Investigation of Patients’ and Parents’ Experience of Cystic Fibrosis – An Overview

In Study 3, the experiences of both patients with CF and their parents were investigated. The participants used in this sample were a subset of those utilised in Study 1 of the current research. Participants were given the opportunity to participate in either a semi-structured interview examining concepts presented in the Time 1 and Time 2 questionnaires from Study 1, or, alternatively, participants could provide written open-ended comments to their experiences of CF which relate to the concepts examined in the questionnaires completed in Study 1 and any other relevant experiences.

In the interviews, patients responded to topics examining the openness of their communication with their parent, and factors that influence this relationship; changes in parent-child communication associated with the transition from paediatric to adult care; challenges in coping with CF; ways of coping with challenges; and aspirations for the future; and experiences with disclosing CF to other individuals. Similarly, in the parent interviews, aspects of parent-child communication; experiences with the transition of care; positive and negative consequences of CF experienced by parents; and parental experiences of discussing CF in the community and assistance that they give their children with broaching this subject with individuals outside of the family were also examined.

4.3.2 Qualitative Frameworks for Health Psychology Research

A number of qualitative studies have previously been undertaken examining both the more global lived experience of CF (e.g., Huyard, 2008; Jessup & Parkinson, 2010; Williams et al., 2009) and more specific aspects of the CF experience such as ways of coping with the challenges of CF (children – Gjengedal et al., 2003; Pendleton et al., 2002; parents – Carpenter & Narsavage, 2004; Grossoehme et al., 2010; Hayes & Savage, 2008; Hodgkinson & Lester, 2002; M. Kharrazi & L. Kharrazi, 2005), navigating the social world (D’Auria et al., 2000; D’Auria et al., 1997; Lotwon, 2004; Lowton & Gabe, 2003), reflections of the transition from childhood to adulthood (children – Berge et al., 2007; George et al., 2010; Iles & Lowton, 2010; Lannon Palmer & Boisen, 2002; Miller, 2009; Tuchman et al., 2008; parents – Lowton, 2002) and family interactions (Coates et al., 2000; Foster et al., 2000). These studies were reviewed in Chapter 2.
Across these studies, a range of qualitative frameworks were used to analyse the data obtained, including grounded theory, thematic analysis, qualitative content analysis, framework analysis and computer-based analysis programs (e.g., NVivo, Textbase Alpha, ATLAS-ti). What is common to these approaches is that they all derive from the inductive naturalistic inquiry approach which allows themes to develop within the data throughout the analysis phase. These approaches differ to deductive qualitative approaches which categorise the data obtained into an expected framework based upon a particular theoretical approach (Lincoln & Guba, 1985; Patton, 2002).

While specific research questions were investigated in Study 3, a naturalistic inquiry approach was also undertaken in the current research. As the theoretical frameworks employed in the current research had only been applied minimally to the CF population prior to the current study, it was considered that an inductive approach would allow for the most comprehensive and accurate interpretation of the data. Additionally, it was also considered that this approach may allow themes to emerge which may explain any quantitative findings obtained which were not consistent with theoretical predictions.

As noted above, a number of different types of qualitative analysis were available for application in Study 3 that would have been consistent with the inductive approach adopted in the current research. When comparing a number of the abovementioned methods for qualitative analysis, Hsieh and Shannon (2005) note that the qualitative content approach is a more in depth approach than most others as it “goes beyond merely counting words to examine language intensely for the purpose of classifying large amounts of text into an efficient number of categories that represent similar meanings” (p. 1278). Specifically, qualitative content analysis focuses on both the manifest content and the latent content (contextual meaning) of the data (Graneheim & Lundman, 2004; Hsieh & Shannon). Given the depth of the understanding that can be obtained from this method, it was considered that this was the most appropriate for the exploratory nature of the current research.

In particular, a conventional content analysis approach was used for the analysis of the patient and parent semi-structured interviews in Study 3, as this approach allows for coding of the data directly from the text. A caveat of the conventional content analysis is noted, however, in that it can be difficult for the researcher to make relationships between categories if participants’ experiences are quite different given its grounding on content as opposed to theory (Hsieh & Shannon, 2005). Such concerns about this approach highlight Lincoln and Guba’s (1985) criteria for trustworthiness of
the data; being credibility, dependability, and transferability. Of these criteria, the concept of transferability of the data is questioned with this approach. To enhance the transferability of data, it is suggested that the research needs to give the reader a clear and distinct description of the sample utilised in the study (Graneheim & Lundman, 2004; Lincoln & Guba). These guidelines were followed in the current research. A more detailed discussion of each of Lincoln and Guba’s criteria for trustworthiness of the data and the steps taken to ensure the quality of the qualitative data obtained is explained in the methodology of Study 3.

However, in addition to following suggested guidelines for obtaining and analysing qualitative data, a directed content analysis was used for the analysis of the written data obtained from patients and parents in Study 3. A directed content analysis differs to a conventional content analysis as the approach is adopted to validate theory, as opposed to simply allowing the themes to emerge from the data as occurs in the conventional content approach (Elo & Kyngas, 2007; Hsieh & Shannon, 2005). Thus, for the analysis of the written data obtained in Study 3, the thematic framework obtained from the patient and parent interview data was tested. As a substantially larger number of participants from Study 1 elected to participate in the written component of the qualitative study, as opposed to the interview component, the transferability of the data to the wider CF family sample obtained in the current research was able to be tested.
CHAPTER 5 – STUDY 1

5.1 Aims and Predictions

The study presented in this chapter is a two-wave longitudinal study examining the individual adjustment of both patients with CF and their parents, using indices of psychological functioning and cognitive adjustment (i.e., sense of coherence [SOC]). In addition, the functioning of the patient-parent dyad is also examined using constructs from the common-sense model of illness (CSM) and the social cognitive processing (SCP) model.

The application and integration of the CSM, SCP model and SOC to parent-patient dyads in the CF population adds unique contributions to understanding the individual and dyadic functioning of this group as well as extending understanding of theoretical frameworks in health psychology research. To recap, the current study is the first to i. apply the SCP model to the CF population; ii. apply the SCP model with a parent-child dyad; iii. apply the CSM to an adolescent and young adult CF population to examine the psychological adaptation of this group; iv. apply the CSM to the study of parental perceptions of CF; v. examine dyadic illness representations in a CF population; vi. examine the relationship between SOC and other psychological outcome measures with a CF population, vii. apply SOC in the examination of parental adaptation in CF, viii. examine relationships between variables of the CSM, ix. predict relationships between the CSM and SCP models, and x. predict relationships between the SCP model and SOC.

In Chapters 3 and 4, the outcomes of a number of studies applying the CSM, SCP model and SOC to examination of the psychological adjustment of a range of chronic illness groups were discussed, together with the outcomes of studies examining the impact of illness perceptions and SOC on other aspects of patient adjustment (e.g., self care, quality of life) with the CF population. From this review and critique of the previous literature, a number of predictions were made. It was hypothesised that:

(1) Patient reports of social constraints would be negatively related to patient reports of frequency of discussions about CF with parents.

(2) Patient ratings of social constraints would be positively associated with the use of avoidant coping strategies by:
   a. Patients
   b. Parents.
(3) Negativity in illness perceptions would be positively associated with the use of avoidant coping strategies for:
   a. Patients
   b. Parents.

(4) Patient reports of social constraints would be positively related to patient reports of psychological distress and negatively related to patient reports of psychological well-being; that is patient reports of:
   a. Increased depression
   b. Increased anxiety
   c. Increased stress
   d. Decreased positive affect
   e. Decreased sense of coherence.

(5) Patient and parent reports of negativity in illness representations would be positively related to patient/parent reports of psychological distress and negatively related to patient/parent reports of psychological well-being; that is individuals’ reports of:
   a. Increased depression
   b. Increased anxiety
   c. Increased stress
   d. Decreased positive affect
   e. Decreased sense of coherence.

Greater use of avoidant coping strategies reported by patients and parents would be positively related to patient/parent reports of psychological distress and negatively related to patient/parent reports of psychological well-being; that is individuals’ reports of:
   a. Increased depression
   b. Increased anxiety
   c. Increased stress
   d. Decreased positive affect
   e. Decreased sense of coherence.
(9) Patients in dyads with mutually negative patient-parent illness representations would report greater social constraints (a), greater psychological distress (b-d) and reduced psychological well-being (e-f) than patients in dyads with mutually positive patient-parent illness perceptions.
   a. Greater social constraints
   b. Greater depression
   c. Greater anxiety
   d. Greater stress
   e. Lower positive affect
   f. Lower sense of coherence.

(10) Patients in dyads with discrepant patient-parent illness representations would report greater social constraints (a), greater psychological distress (b-d) and reduced psychological well-being (e-f) than patients in dyads with mutually positive patient-parent illness perceptions.
   a. Greater social constraints
   b. Greater depression
   c. Greater anxiety
   d. Greater stress
   e. Lower positive affect
   f. Lower sense of coherence.

(11) Patient and (12) parent ratings of sense of coherence would be negatively related to patient/parent reports of psychological distress and positively related to patient/parent reports of psychological well-being; that is individuals’ reports of:
   a. Decreased depression
   b. Decreased anxiety
   c. Decreased stress
   d. Increased positive affect.

These predictions were tested with both the data obtained at Time 1 (T1) and Time 2 (T2). In addition to these analyses, these predictions were also applied to test the relationships between T1 predictor variables and T2 outcomes variables. The latter analyses aimed to further extend current understanding of the CF population by examining the effect of illness perceptions and coping styles on SCP variables over time, as with SCP variables on psychological and cognitive adjustment over time.
5.2 Method

5.2.1 Participants

5.2.1.1 Recruitment

Participants were recruited through three state-based cystic fibrosis support organisations across Australia; Cystic Fibrosis Queensland, Cystic Fibrosis Victoria, and Cystic Fibrosis South Australia. Administration staff from the participating state organisations sent all households on their member registers with an adolescent or young adult with CF aged between 16 and 25 years, information about the study, contact details of the primary researcher and consent forms for both the young person and a nominated parent to complete. Reply-paid envelopes addressed to the primary researcher were also included in the package to assist participants in returning completed consent forms. In families with a young adult with CF over the age of 18 years, the recruitment package was addressed to the individual with CF. For younger persons with CF, the package was addressed to their parent. The consent form requested participants’ permission to be sent two questionnaires over a six month period and their mailing address for receipt of the questionnaires. For young persons aged 16 and 17 years, parental consent was also required for their participation.

Eligibility criteria for both the young person and their nominated parent were outlined on the study information sheet. Potential participants were informed that the concepts presented in the questionnaires may be difficult for individuals with an intellectual impairment or severe psychiatric difficulty to complete. It was also noted that participation may be burdensome for families coping with severe cystic fibrosis-related complications or adjunct illnesses. Regarding specific eligibility criteria for parents, it was requested that the person considered by the adolescent/young adult to be their primary caregiver be nominated as the person to complete the parent questionnaire (should this individual also choose to participate). Thus, biological and step-parents, as well as other family members or non-biologically related legal guardians were eligible for participation. While it was not essential for the adolescent/young adult and their caregiver to live together, it was essential that the parent and child pair be in regular physical or verbal contact to participate.

Participants were also informed on the study information sheet that if they completed the first questionnaire, they would be eligible to enter a draw for one of 30 prizes: 15 $20 Coles-Myer gift vouchers and 15 Birch Carol and Coyle cinema passes. These incentives were also offered to participants following the return of the second
questionnaire. Participants were also advised that they could withdraw from the study at any time without penalty. Further, they were also assured that no information regarding a particular individual’s participation would be forwarded to state organisations and that any results disseminated from the research would present participant data anonymously.

All ethical aspects of this study were approved by the Griffith University Human Research Ethics Committee (protocol number: PSY/G1/07/HREC).

5.2.1.2 Attrition Analyses

Eighty-six patients and 90 parents consented to participate in the current study. At T1, 56.97% of patients and 67.78% of parents who consented to participate returned the first questionnaire. At this time, 44 complete parent-patient dyads returned questionnaires, 17 parents responded without the return of a matching patient questionnaire, and five patients responded without the return of a matching parent questionnaire. Of the T1 sample of 49 patients and 61 parents, 32 patients (65.31%) and 37 parents (60.66%) were retained at T2. As discussed previously, participants consented to be sent both the T1 and T2 questionnaire during recruitment. Thus, some individuals who were sent a T2 questionnaire were those who did not return a questionnaire at T1. Accordingly, at T2, two new parent-patient dyads participated. Additionally, three patient questionnaires were returned without a matching parent questionnaire, and one parent questionnaire was returned without a matching patient questionnaire. Thus, in total, 37 patients and 40 parents participated at T2. All data obtained from patients and parents at T1 and T2 was included where possible in cross-sectional analyses not requiring predictor or control variables from the missing party in the dyad. Further, demographics obtained from both the T1 sample and new participants entering the study at T2 were included in analyses examining sample characteristics.

T-tests were conducted for both patient and parent samples which examined differences on all predictor and outcome measures between participants who participated at T1 only and those who were retained at T2. For patients, differences on indices of CF severity and impact on functioning were also examined. Given the number of analyses run, a more conservative p-value of .001 was used to evaluate group differences so that likelihood of Type 1 error would be reduced. Using this criterion, no differences were found between individuals who participated at T1 only and those who were retained at T2 on any measure completed at T1.
5.2.1.3 Sample Characteristics

Demographic characteristics. As previously mentioned, families were recruited from three states across Australia; 43.9% of participating families were recruited from Victoria, 34.8% were from Queensland, and the remaining 21.2% of families were recruited from South Australia. The majority of patients either identified their biological mother (80.30%) or father (13.10%) as their primary care-giver. Additionally, one step-mother, one grandfather and two extended family members were identified as primary care-givers. The majority of patients (71.40%) reported that they resided with their primary care-giver. Remaining patients reported living with a partner/spouse (n = 6), friend(s) (n = 5), with extended family (n = 1) or independently (n = 2). Key demographic characteristics of patients and parents are reported in Tables 1 and 2.

In the six-months between the first and second wave of the current study north Queensland experienced one severe, and a number of minor, tropical cyclones and a number of regions in Victoria and South Australia experienced severe bushfires. Given the large body of research demonstrating that the experience of trauma can have a negative effect on individuals’ psychological adjustment (e.g, Green, Krupnick, Rowland, Epstein, Stockton, Spertus, et al., 2000; Janoff-Bulman, 1992) participants were asked at T2 if they had been affected by a natural disaster so that variance in distress which may have been accounted for by the experience of such an event could be controlled for in later analyses. Accordingly, 8.30% (n = 3) of patients, and 15.00% (n = 6) of parents, reported being affected by a natural disaster.

At follow-up, it was also assessed whether participants had experienced any other distressing event since completing the first questionnaire. A number of patients and parents reported experiencing either the death or serious injury/illness of a loved one (n = 4 patients; n = 4 parents), a serious personal injury/illness or decrement in health status (n = 3 patients; n = 3 parents), or other (not specified by participants – n = 1 patients) distressing event. Yet overall, most participants (69.40% patients and 67.50% parents) did not report being affected by a natural disaster or other distressing event.
### Table 1

**Patient (n=49) and Parent (n=61) Demographic Characteristics**

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<td>61.20</td>
<td>51</td>
<td>83.60</td>
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<td><strong>Racial background</strong></td>
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<td>Caucasian</td>
<td>47</td>
<td>95.90</td>
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<td>98.40</td>
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<td>Other</td>
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<tr>
<td><strong>Relationship status</strong></td>
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<tr>
<td>Single</td>
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<tr>
<td>Partner</td>
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<td>20.40</td>
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<td>Divorced</td>
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<td>13.10</td>
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<tr>
<td>Work only</td>
<td>8</td>
<td>16.30</td>
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<tr>
<td>Study only</td>
<td>27</td>
<td>55.10</td>
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<tr>
<td>Work and study</td>
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<td>Other reasons</td>
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<tr>
<td><strong>Parent education attainment</strong></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Left before year 10</td>
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<td>3.30</td>
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<td>7</td>
<td>11.45</td>
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<td>-</td>
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<td>16.40</td>
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<tr>
<td>Post-graduate</td>
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<td>-</td>
<td>13</td>
<td>21.30</td>
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<tr>
<td><strong>Parent work status</strong></td>
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<td></td>
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<td></td>
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<tr>
<td>Work outside home</td>
<td>-</td>
<td>-</td>
<td>50</td>
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<td>Carer for patient</td>
<td>-</td>
<td>-</td>
<td>3</td>
<td>4.90</td>
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<tr>
<td>Home-maker</td>
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<td>-</td>
<td>6</td>
<td>9.80</td>
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<tr>
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<td></td>
<td></td>
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<tr>
<td>Seeking work</td>
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<td>-</td>
<td>1</td>
<td>1.65</td>
</tr>
<tr>
<td>Retired/other</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>1.65</td>
</tr>
<tr>
<td><strong>Age in years</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mean (SD)</td>
<td>19.81 (2.84)</td>
<td></td>
<td>49.83 (5.49)</td>
<td></td>
</tr>
<tr>
<td>range</td>
<td>16 – 25</td>
<td></td>
<td>39 – 77</td>
<td></td>
</tr>
</tbody>
</table>
Table 2

*Family Unit Attributes (n=61)*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family structure</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Both biological parents at home</td>
<td>44</td>
<td>72.20</td>
</tr>
<tr>
<td>Single parent home</td>
<td>10</td>
<td>16.40</td>
</tr>
<tr>
<td>Blended family</td>
<td>7</td>
<td>11.40</td>
</tr>
<tr>
<td><strong>Siblings of patient with CF</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One child with CF</td>
<td>19</td>
<td>31.20</td>
</tr>
<tr>
<td>Two children CF</td>
<td>7</td>
<td>11.40</td>
</tr>
<tr>
<td>No siblings with CF</td>
<td>35</td>
<td>57.40</td>
</tr>
<tr>
<td><strong>Family income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $25000</td>
<td>9</td>
<td>14.75</td>
</tr>
<tr>
<td>$25000 - $39999</td>
<td>5</td>
<td>8.15</td>
</tr>
<tr>
<td>$40000 - $54999</td>
<td>9</td>
<td>14.75</td>
</tr>
<tr>
<td>$55000 - $69999</td>
<td>6</td>
<td>9.85</td>
</tr>
<tr>
<td>$70000 - $84999</td>
<td>8</td>
<td>13.15</td>
</tr>
<tr>
<td>$85000 - $99999</td>
<td>8</td>
<td>13.15</td>
</tr>
<tr>
<td>More than $100000</td>
<td>16</td>
<td>26.20</td>
</tr>
</tbody>
</table>

*Illness severity.* For individuals with CF, lung function is most commonly assessed by comparing an individual’s current lung capacity to the average lung capacity of individuals in the general population of the same sex and of a similar age and body composition. This is known as the percentage of predicted forced expiratory volume (FEV1 %). A predicted FEV1 above 90% is considered to be indicative of normal lung function, with 70-90% indicative of mild impairment, 40-69% indicating moderate impairment and less than 40% indicating severe impairment (CFA, 2010; Modi et al., 2010). As shown in Table 3, while some differences are noted in the mild and moderate categories when comparing sample patient data to that reported in the Australian CF data registry in 2008 (CFA, 2010), it is acknowledged that CF severity generally increases in adulthood (Hegarty et al., 2009; Segal, 2008). Thus, given that the current patient sample is aged 16- to 25-years and the Australian CF registry data is representative of adults 18 years of age and beyond, it would be expected that there would be a higher percentage of individuals with less severe lung function impairment
in the current sample than that of the registry. Hence, overall, it appears that the current sample is representative of the wider CF population of Australia.

Further to this, patient evaluations of the difficulty of CF treatments, including their impact on daily life, and the impact of CF on role functioning (i.e., work/school, social, daily living, achievement of personal goals) were comparable to that of a larger American sample of adults with CF (Quittner, Schechter, Rasouliyan, Haselkorn, Pasta, & Wagner, 2010). These comparisons are presented in Table 4. The treatment burden and role functioning subscales were both measured on a scale with possible scores ranging from 0 to 100, with higher scores representing more adaptive functioning. Regarding hospital visits, a number of patients (51.00%) only attended their clinic for their tune-ups or one extra visit in the 12 months preceding the study. About one-third of patients (32.70%) attended hospital an extra two to three times outside of their tune-up and 16.3% attended more than four extra times in this period. Finally, no patients in the sample had received an organ transplant and only one patient was on a transplant wait-list.

Table 3

*Lung Function Impairment of the Current Patient Sample (n=49) Compared to Australian Adult CF Data Registry Sample (AACFDR, n=1027)*

<table>
<thead>
<tr>
<th>Lung functioning</th>
<th>Current sample</th>
<th>AACFDR sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Normal</td>
<td>13.90</td>
<td>15.10</td>
</tr>
<tr>
<td>% Mild impairment</td>
<td>47.20</td>
<td>29.40</td>
</tr>
<tr>
<td>% Moderate Impairment</td>
<td>25.00</td>
<td>41.00</td>
</tr>
<tr>
<td>% Severe Impairment</td>
<td>13.90</td>
<td>14.50</td>
</tr>
</tbody>
</table>

* CFA (2010)

Table 4

*Treatment Burden and Role Functioning of the Current Patient Sample (n=49) Compared to an American Adult CF Sample (n=420)*

<table>
<thead>
<tr>
<th>Sub-scale</th>
<th>Current sample</th>
<th>American sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment burden mean (SD)</td>
<td>61.68 (21.53)</td>
<td>59.90 (19.30)</td>
</tr>
<tr>
<td>Role functioning mean (SD)</td>
<td>75.68 (21.71)</td>
<td>76.10 (21.00)</td>
</tr>
</tbody>
</table>

* Quittner et al. (2010)
Treatment characteristics. At T1, 75% of patients were attending an adult CF clinic for their CF-related treatment. Of the remaining 25% of participants who were attending a paediatric facility at T1, two participants transitioned to adult care by follow-up. As expected, patients attending an adult clinic were significantly older ($m=20.91$, $sd=2.48$ years) than patients attending a paediatric clinic ($m=16.57$, $sd=0.89$ years), $t(44.81) = 8.65, p<.0001, d=1.29$. However, as noted by Anderson et al. (2002) with a large international sample of CF patients, variation also is observed in the current sample regarding the age of transition from paediatric to adult care. In the current sample the age range of individuals in paediatric care spanned from 16- to 19-years and that of individuals in adult-based care spanned from 16- to 25- years.

As demonstrated in Table 5, with the exception of finance management for CF-related care, across paediatric and adult hospital attendees at least two thirds of participants reported that they were responsible for their own care on each of the eight domains of CF-related self-care assessed in the current study. However, it is also noted that significant differences in four domains of self-care management were found between paediatric clinic attendees and adult clinic attendees; filling prescriptions ($\chi^2(1) = 20.20, p < .0001, \phi=.65$), monitoring diet ($\chi^2(1) = 6.59, p=.010, \phi=.37$), scheduling clinic appointments ($\chi^2(1) = 27.18, p < .0001, \phi=.75$), and managing CF-related medical finances ($\chi^2(1) = 13.54, p < .0001, \phi=.53$).

Odds ratios examining the likelihood of completing self-care management for adult clinic attendees compared to paediatric clinic attendees were calculated for filling prescriptions, monitoring diet and scheduling clinic appointments. As a zero cell count was obtained for paediatric clinic attendees managing CF-related finances, an odds ratio examining the likelihood of managing CF-related finances could not accurately be calculated. Instead, the likelihood of not managing CF-related finances for paediatric clinic attendees and adult clinic attendees were compared. The results of these analyses identified that adults clinic attendees were 5.18 times more likely to fill their own prescriptions, 1.93 times more likely to monitor their diet, and 10.70 times more likely to schedule clinic appointments than paediatric clinic attendees. Finally, paediatric clinic attendees were 2.57 times more likely to not be managing their CF-related finances than adult clinic attendees.

Again, these reports are consistent with those taken with other CF samples. Sampling an adult sample of CF patients from the United States, Hamlett et al. (1996) reported the mean age of assuming responsibility for taking medications, being responsible for CF care and completing chest physiotherapy ranged between 13- and
16-years of age, whereas the mean age of assuming responsibility for scheduling appointments, calling physicians, obtaining medication refills, monitoring diet and managing medical insurance ranged between 17- and 21 years.

Table 5

Percentages of Self-care Tasks Undertaken by Paediatric Clinic Attendees (n=12), Adult Clinic Attendees (n=38) and the Total Sample (n=49)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Paediatric</th>
<th>Adult</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chest physiotherapy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Completing independently</td>
<td>83.30</td>
<td>77.80</td>
<td>79.60</td>
</tr>
<tr>
<td>% Completing with assistance</td>
<td>16.70</td>
<td>22.20</td>
<td>20.40</td>
</tr>
<tr>
<td>Exercise therapy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Completing independently</td>
<td>83.30</td>
<td>100.00</td>
<td>95.90</td>
</tr>
<tr>
<td>% Completing with assistance</td>
<td>16.70</td>
<td>0.00</td>
<td>4.10</td>
</tr>
<tr>
<td>Taking antibiotics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Completing independently</td>
<td>83.30</td>
<td>91.70</td>
<td>89.80</td>
</tr>
<tr>
<td>% Completing with assistance</td>
<td>16.70</td>
<td>8.30</td>
<td>10.20</td>
</tr>
<tr>
<td>Taking enzymes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Completing independently</td>
<td>91.70</td>
<td>97.20</td>
<td>95.90</td>
</tr>
<tr>
<td>% Completing with assistance</td>
<td>8.30</td>
<td>2.80</td>
<td>4.10</td>
</tr>
<tr>
<td>Filling prescriptions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Completing independently</td>
<td>16.70</td>
<td>86.10**</td>
<td>69.40</td>
</tr>
<tr>
<td>% Completed with assistance</td>
<td>83.30</td>
<td>13.90</td>
<td>30.60</td>
</tr>
<tr>
<td>Monitoring diet</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Completing independently</td>
<td>41.70</td>
<td>80.60*</td>
<td>71.40</td>
</tr>
<tr>
<td>% Completing with assistance</td>
<td>58.30</td>
<td>19.40</td>
<td>28.60</td>
</tr>
<tr>
<td>Scheduling medical appointments</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Completing independently</td>
<td>8.30</td>
<td>88.90**</td>
<td>67.30</td>
</tr>
<tr>
<td>% Completing with assistance</td>
<td>91.70</td>
<td>11.10</td>
<td>32.70</td>
</tr>
<tr>
<td>Managing medical finances</td>
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<tr>
<td>% Completing independently</td>
<td>0.00</td>
<td>61.10**</td>
<td>55.10</td>
</tr>
<tr>
<td>% Completing with assistance</td>
<td>100.00</td>
<td>38.90</td>
<td>44.90</td>
</tr>
</tbody>
</table>

*difference between paediatric patients and adult patients significant at $p<.05$

*difference between paediatric patients and adult patients significant at $p<.0001$
5.2.2 Measures

5.2.2.1 Potential Control Variables

Demographics variables. On the patient and the parent questionnaires, the demographic information of age, gender, ethnicity, education level, work status, relationship status, and living arrangements was obtained. On the parents questionnaire information regarding annual household income, family structure, number of siblings with CF and relationship to patient was also collected.

On the T2 patient and parent questionnaires, information was also obtained examining whether individuals had experienced a natural disaster, death or significant injury of a loved one, experienced a personal injury or significant decrease in health status, or other kind of distressing event specified by the participant since the completion of the T1 questionnaire.

Illness severity indicators. On the patient questionnaire, illness severity was measured using two sub-scales from the Cystic Fibrosis Questionnaire-Revised – Teen/Adult Version (CFQ-R; Quittner, Modi, Watrous, & Davis, 2002) and with three additional items examining patients’ predicted FEV1 % at their last clinic appointment, whether patients had received an organ transplant or were on a transplant wait-list and how many times they had attended hospital in the last year (assessed at T1) and since completing the first questionnaire (assessed at T2). The treatment burden subscale of the CFQ-R was assessed at T1 only, and the role function subscale was assessed at both T1 and T2. The treatment burden subscale was not measured at T2 as it did not have a significant relationship (at p<.001) with key outcome variables, whereas role functioning was retained as a control measure at T2 (see section 5.3.1.5, p. 123).

The treatment burden subscale of the CFQ-R Teen/Adult version includes three items (two reverse scored) examining the extent to which CF treatments make life difficult, and how much time is spent completing treatments and how much time they take to complete. The role functioning subscale includes four items (one reverse scored) examining the extent to which CF impacts upon one’s ability to attend or keep up at work or school, as well as the impact of CF on general daily life activities (e.g., going to the bank) and meeting personal goals. Responses for these subscales are measured on a 4-point scale with ‘1’ indicating a high level of difficulty with CF treatment or a strong negative impact of CF on functioning and ‘4’ indicating few CF-related difficulties or restrictions. Total scores for each subscale are presented as scaled scores ranging from 0 to 100, with higher scores representing better quality of life.
The psychometric properties of the treatment burden and role functioning subscales of the CFQ-R have been reported in two studies (Henry, Aussage, Grosskopf, & Goehrs, 2003; Quittner, Buu, Messer, Modi, & Watrous, 2005). While Quittner et al. reported low internal reliability for the treatment burden scale and good internal reliability for the role functioning subscale, Henry et al. reported high internal consistency (e.g. Cronbach’s $\alpha > .70$) for both subscales. Satisfactory test-retest reliability has been reported by these authors with Pearson’s $r$ correlations ranging from .45 to .97 for the subscales over two weeks. Further, in both studies, good construct validity of these subscales was also reported, with significant differences on the treatment burden and role functioning subscales found between groups of individuals classed as having mild, moderate and severe CF. In these studies, patients with the most severe disease reported the lowest CF related quality of life.

In the current study, high internal consistency was found for both the treatment burden subscale at T1 (Cronbach’s $\alpha = .71$) and role functioning subscale at both assessments (see Table 6). Also shown in Table 6, poor test-retest reliability was found for the role functioning sub-scale over 6-months. However, given that CF symptoms are known to fluctuate at times (CFQ, 2001), this may be expected.

_Treatment characteristics._ On the patient questionnaires, hospital treatment status was examined, with participants indicating whether they were currently obtaining CF-related care from a paediatric or adult care facility. On the T1 questionnaire patient self-care status was also examined, with participants indicating whether they completed chest physiotherapy, exercise therapy, took antibiotics, took enzymes, filled prescriptions at pharmacist, monitored their diet for adequate nutrition, scheduled clinic and managed CF-related finances independently or required assistance for these tasks. The assessments of these eight domains of self-care were derived from those included in Hamlett et al.’s (1996) examination of developmental tasks of adulthood in CF and Australian guidelines for CF treatment (e.g., CFQ, 2001).

_Social support indicators._ Social support was measured using a modified version of the Significant Others Scale (SOS; Power, Champion, & Aris, 1988). The original version of the SOS requires participants to consider the quality of emotional and practical support provided to them by seven significant others (e.g., spouse, parent, sibling, child, friend etc). In this version, scoring of the SOS involves averaging the responses on each question across the seven significant others.

However, for the current study, it was considered that a number of participants may not be in a long-term romantic relationship or have children given the age of the
patient sample (i.e., 16- to 25- years) and the difficulties with fertility often observed in patients with CF. Thus, in the current study, to standardize the size and characteristics of the support group assessed between patients, participants were only required to assess the support they received from three individuals; the first being their caregiver. For the two additional support persons, patients were instructed to select the two persons from their support network (outside of their caregiver) with whom they conferred the most about CF in the previous month. Participants could select from a range of individuals (i.e., mother, father, sibling, romantic partner, extended family member, work colleague, friend who does not have CF, friend who has CF, neighbour, counsellor, doctor, nurse) or nominate another party not offered in the given selection.

For each of the three support providers assessed, patients were required to respond to two items examining emotional support, one assessing trust and one assessing reliability, and two items examining practical support, one assessing help received and one assessing social interaction. Items were responded to on a 7-point Likert-type scale (1- *never* to 7- *always*). The six items examining emotional support were summed together to give a total score, as with the six items examining practical support. Possible scores for the emotional support and instrumental support scales ranged from 6 to 42; with higher scores indicating the greater levels of support received by the patient. The original version of the SOS also requires participants to provide their ideal ratings of support from each individual in order to allow examination of support discrepancies. However, as only actual support was of interest in the current study, ideal ratings were not assessed.

Satisfactory psychometric properties have been reported for the SOS. Test-retest (Pearson’s *r*) reliability ranges from 0.73 to 0.83 for both emotional and practical subscales (Power et al., 1988); with both subscales found to predict psychological adjustment in non-clinical samples (Popovic, Milne, & Barrett, 2003; Power et al., 1988). Significant associations between the SOS and various psychological outcome measures have also been observed in cancer (e.g., Simmons & Lindsay, 2001) and rheumatoid arthritis (e.g., Minnock, Fitzgerald, & Brensihan, 2003) patient groups. As perceptions of support from different individuals are assessed, variability is observed in assessment between different individuals which, in turn, reduces the meaningfulness of measures of internal reliability. Thus, internal reliability was not tested in the current study. Further, as the current study allowed participants to elect the individuals they conferred with the most about CF at T1 and T2, some participants elected different individuals at these times; thus, test-retest reliability also could not be validly assessed in the current study.
Table 6

*Internal Reliability and Test-retest Reliability Data for Patients at T1 (n=49) and T2 (n=37) and Parents at T1 (n=61) and T2 (n=40)*

<table>
<thead>
<tr>
<th>Scale</th>
<th>T1 Cronbach’s α</th>
<th>T2 Cronbach’s α</th>
<th>r T1-T2 retest</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patients</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CFQ-R-role functioning</td>
<td>.75</td>
<td>.87</td>
<td>-.18</td>
</tr>
<tr>
<td>IPQ-R-consequences</td>
<td>.77</td>
<td>.82</td>
<td>.65***</td>
</tr>
<tr>
<td>IPQ-R-personal control</td>
<td>.76</td>
<td>.80</td>
<td>.54***</td>
</tr>
<tr>
<td>IPQ-R-treatment control</td>
<td>.66</td>
<td>.72</td>
<td>.54***</td>
</tr>
<tr>
<td>IPQ-R-illness coherence</td>
<td>.88</td>
<td>.85</td>
<td>.63***</td>
</tr>
<tr>
<td>IPQ-R-timeline cyclical</td>
<td>.87</td>
<td>.79</td>
<td>.72***</td>
</tr>
<tr>
<td>IPQ-R-emotional representations</td>
<td>.88</td>
<td>.87</td>
<td>.64***</td>
</tr>
<tr>
<td>Independent coping</td>
<td>.84</td>
<td>.80</td>
<td>.77***</td>
</tr>
<tr>
<td>Other-oriented coping</td>
<td>.78</td>
<td>.76</td>
<td>.61***</td>
</tr>
<tr>
<td>Social Constraints Scale</td>
<td>.91</td>
<td>.87</td>
<td>.72***</td>
</tr>
<tr>
<td>IES-intrusions</td>
<td>.79</td>
<td>.85</td>
<td>.63***</td>
</tr>
<tr>
<td>IES-avoidance</td>
<td>.74</td>
<td>.81</td>
<td>.58**</td>
</tr>
<tr>
<td>DASS-depression</td>
<td>.90</td>
<td>.90</td>
<td>-.01</td>
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<tr>
<td>DASS-anxiety</td>
<td>.79</td>
<td>.75</td>
<td>-.16</td>
</tr>
<tr>
<td>DASS-stress</td>
<td>.85</td>
<td>.88</td>
<td>.29</td>
</tr>
<tr>
<td>PANAS-positive affect scale</td>
<td>.92</td>
<td>.85</td>
<td>.36*</td>
</tr>
<tr>
<td>Sense of Coherence scale</td>
<td>.87</td>
<td>.86</td>
<td>.41*</td>
</tr>
<tr>
<td><strong>Parents</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IPQ-R-consequences</td>
<td>.77</td>
<td>.71</td>
<td>.64***</td>
</tr>
<tr>
<td>IPQ-R-personal control</td>
<td>.72</td>
<td>.76</td>
<td>.69***</td>
</tr>
<tr>
<td>IPQ-R-treatment control</td>
<td>.67</td>
<td>.64</td>
<td>.62***</td>
</tr>
<tr>
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<td>.88</td>
<td>.88</td>
<td>.52**</td>
</tr>
<tr>
<td>IPQ-R-timeline cyclical</td>
<td>.67</td>
<td>.46</td>
<td>.67***</td>
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<tr>
<td>IPQ-R-emotional representations</td>
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<td>.85</td>
<td>.73***</td>
</tr>
<tr>
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<td>.72***</td>
</tr>
<tr>
<td>Management-oriented coping</td>
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<td>.62</td>
<td>.48**</td>
</tr>
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<td>DASS-depression</td>
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<td>.87</td>
<td>.44**</td>
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<td>.95</td>
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<td>.68***</td>
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<tr>
<td>Sense of Coherence scale</td>
<td>.87</td>
<td>.83</td>
<td>.71***</td>
</tr>
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* p<.05  ** p<.01  ***p<.001
5.2.2.2 Predictor Variables

Illness representations. Patients’ and parents’ cognitive representations of CF were measured using the Illness Perception Questionnaire-Revised (IPQ-R; Moss-Morris et al., 2002). This measure examines individuals’ perceptions of illness symptomatology, timeline, cure/control, consequences, causality, illness understanding and emotional representations of illness. In the patient version, items were responded to in relation to the patients’ experience with CF. In the parent version items were slightly re-worded in order to examine parents’ perceptions of their child’s experience with CF.

The symptom subscale included a 14-item symptom checklist and required participants to indicate whether or not they have experienced a particular symptom (e.g., weight loss, fatigue) and whether they believe the symptom is related to their illness, measured with yes/no dichotomous response options. A total score was generated for the number of symptoms experienced and the number of symptoms attributed to CF. These scores were calculated by summing together the number of ‘yes’ responses on each symptom subscale.

In the original version of the IPQ-R, the causality subscale includes 18 possible causes of illness (e.g., heredity, poor medical care, chance/bad luck) and requires participants to endorse the extent to which they believe each cause contributed to their illness. However, as the genetic basis of CF is usually openly discussed with patients and their parents, it was considered that the full-version of this sub-scale may be unnecessary for participants to complete. Thus, in the current study, the assessment of causality consisted of an open-ended question where participants were asked to list all factors they believe caused their illness. This was assessed at T1 only.

Patient and parent beliefs regarding symptom management and curability of illness were measured on two subscales; one six-item scale (one reverse scored) examining person control of illness (e.g., “I have the power to influence my CF”) and one five-item subscale (two reverse scored) examining participants’ perceptions of the effectiveness of medical treatment (treatment control) for CF (e.g., “My treatment can control my CF”). Next, the consequences of illness subscale examined individuals’ anticipated outcomes and effects stemming from the illness (e.g., “My illness causes difficulties for those who are close to me”) with six items (one reverse scored).

Perceptions of the nature of CF over time were assessed with the four items on the timeline-cyclical subscale (e.g., “My CF is very unpredictable”). Discussed in section 5.2.3.1 (p. 112), the timeline-acute/chronic subscale of the IPQ-R was not included as a measure in the current study. Participants’ overall understanding of CF and its...
implications was measured with the five-item (four reverse scored) *illness coherence* subscale (e.g., “*CF is a mystery to me*”). Finally, participants’ *emotional representations* of illness were examined on a six-item subscale (one reverse scored) (e.g., “*When I think about my CF I become upset*”). These final six subscales of the IPQ-R required the participant to indicate the degree to which they endorsed each statement listed about CF on a 5-point Likert-type scale (1- *strongly disagree* to 5 - *strongly agree*).

Total scores for each of these subscales were calculated by summing each item in the subscale. The four-item scales had a possible score range of 4 to 16; for five-item scales the range was 5 to 25; and the range was 6 to 36 for the six-item scales. A high score on the consequences, emotional representations, and timeline-cyclical subscales indicated negative perceptions of these domains of CF; whereas high scores on the personal control, treatment control, and illness coherence subscales indicated more positive perceptions of CF.

Moss-Morris et al. (2002) reported excellent internal reliability for the IPQ-R, with Cronbach’s $\alpha$ reaching .79 and above for all subscales. Moss-Morris et al. have also reported good test-retest reliability, with Pearson’s $r$ correlations for each subscale across time ranging from .46 to .88. High reliability coefficients have also been reported in a range of chronic illness populations (e.g., Anagnostopoulos & Spanea, 2005; Horne & Weinman, 2002; Llewellyn, McGurk, & Weinman, 2006). Discriminant reliability with the Positive and Negative Affect Scale (Watson, Clark, & Tellegen, 1988) and predictive validity for the Sickness Impact Profile (Bergner, Bobbot, Cartner, & Gilson, 1981) were also demonstrated by Moss-Morris and colleagues.

As presented in Table 6 (p. 102) excellent test-retest reliabilities were observed for all IPQ-R subscales in the current study and reliability coefficients of .71 and above were observed for both patients’ and parents’ consequences, personal control, illness coherence, and emotional representation subscales at Times 1 and 2, indicating good to excellent reliability on these subscales. On both patients’ and parents’ treatment control subscales at Times 1 and 2, internal reliability coefficients were moderate to good. Finally, while excellent internal consistency was obtained on the timeline-cyclical subscale for patients, reliability was moderate for parents at T1, and poor at T2 (Robinson, Sharver, & Wrightsman, 1991). Thus, caution was taken when interpreting results with this measure. From a practical perspective, as parents are not experiencing the symptoms of CF first hand as their children are, it may be more difficult for them to evaluate the nature of CF over time and they may rely on their observations of severe
symptom fluctuation and child disclosure of their health status. Conversely, individuals living with CF would be more attuned to both minor and major symptom fluctuations over time and may be expected to give a more reliable assessment within this domain.

Coping style. The Brief COPE (Carver, 1997) was used to examine coping styles of patients and parents in the current study. This measure is a condensed version of Carver, Scheier, and Kumari’s (1989) COPE and incorporates only the two highest loading items from the original measure in each of the 14 coping subscales assessed. Each subscale examines a different form of coping: active coping, planning, positive reframing, acceptance, humour, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioural disengagement, and self-blame. Participants were required to indicate how much, on average, they engage in each type of coping behaviour when dealing with difficult events (both CF-related and more generally) using a 4-point Likert-type scale (1- I usually don’t do this at all to 4- I usually do this a lot). Examples include “I’ve been saying to myself “this isn’t real”’ (denial), “I’ve been using alcohol or other drugs to make myself feel better” (substance use), and, “I’ve been trying to come up with a strategy about what to do” (planning). A total score for each domain of coping was obtained by summing patient responses on the two constituent items.

Acceptable internal reliability has been reported for this measure, with Cronbach’s α statistics ranging from .60 to .90 for the majority of subscales (Carver, 1997; Kershaw, Northouse, Kritpracha, Schafenacker & Mood, 2004). Carver has also noted the ability of the scale to predict psychological and physiological outcomes in a variety of populations. Kershaw et al. (2004) conceptualized this scale as consisting of two higher-order factors of active and avoidant/dysfunctional styles of coping, and reported a factor structure supporting this proposition in a sample of advanced breast cancer patients and their partners.

Principal component analyses (PCA) were also conducted in the current study with patient and parent data from T1. Given that the coping literature suggests that individuals may use different coping strategies depending on the nature of a particular stressor at different points in time, or use similar strategies across contexts (Folkman & Moskowitz, 2004), non-independence of factors was predicted and, thus, oblique rotations were applied in all analyses. Additionally, given that at T1 only minimum sample size requirements for PCA were met, large violations of normality of the items to be included into the analyses could not be tolerated (Hair, Black, Babin, Anderson, & Tatham, 2006).
For the analysis of patient coping, only nine of the 14 Brief COPE subscales met normality requirements; being the active coping, self-distraction, planning, positive reframing, acceptance, humour, emotional support, instrumental support, and venting subscales. All other assumptions (i.e., sampling adequacy and sphericity) were met. In an initial PCA, the subscale of humour had low communality. Accordingly, this subscale was removed and a second PCA was run. In this analysis, a clear two-factor solution was obtained. The subscales of acceptance, active coping, positive reframing and planning loaded onto one factor, and instrumental support, emotional support, venting and self-distraction loaded onto the second factor.

After examining the relationships between the subscales loading onto each factor, it was considered that the first factor represented coping strategies which are primarily completed independently, whereas the second factor represented strategies usually requiring the input of others. Thus, these factors were labelled as independent coping and other-oriented coping and new variables were generated to represent these factors for patients at T1. While it would have been optimal to run confirmatory analyses with the data obtained at T2, minimal sample size requirements for this procedure were not met (Hair et al., 2006). Thus, the factor structure of the T1 PCA was also applied to the T2 data. Both patient coping scales had a possible total score range of 8 to 32, with a high score indicating frequent use of that particular coping style. As shown in Table 6 (p. 102) high internal consistency was obtained for both the independent and other-oriented scales at T1 and T2, as well as strong test-retest reliability.

For the analysis of parent coping, only seven of the 14 Brief COPE subscales met normality requirements; being the active coping, planning, positive reframing, acceptance, emotional support, instrumental support, and self-distraction subscales. All other assumptions for the PCA were met. In the initial parent analysis, a three-factor solution was generated. However, it was noted that one factor had only one loading subscale; self-distraction. As this factor was not robust, self-distraction was removed and a second PCA was run. In this analysis, a clear two-factor solution was obtained with active coping, planning, and positive reframing subscales loading onto the first factor and acceptance, instrumental support, and emotional support loading onto the second factor.

After examining the relationships between the subscales loading onto each factor, it was considered that the first factor includes scales that are aimed at changing a situation or one’s perception of it; whereas the second factor includes strategies aimed
at managing a current concern. These factors were labelled as *change-oriented coping* and *management-oriented coping* and were calculated for both the T1 and T2 parent data. Both parent coping scales had a possible total score range of 6 to 24, with a high score indicating frequent use of that particular coping style. Again, acceptable internal reliability was obtained for both the change-oriented and management-oriented scales at T1 and T2, as well as good test-retest reliability (see Table 6, p. 102).

**Social constraints.** Difficulties in parent-patient communication were measured using the Social Constraints Scale (SCS; Lepore & Ituarte, 1999). As patients’ comfort with disclosure to parents was the focus of the current study, the parent questionnaire did not include this measure. The SCS is a 15-item scale measuring the extent to which a patient perceives difficulty in expressing thoughts and feelings about their illness to a significant other. In the current study, patients reported perceived constraints from their nominated parent only. Responses were measured on a 4-point Likert-type scale (*1- never* to *4- often*), and patients were asked to rate how often in the past month their parent had partaken or omitted certain social behaviours (e.g., “*How often did your parent seem to be hiding their feelings?*” and “*How often did your parent tell you to not worry so much about your health?*”). The 15 items were summed to give a total scale score. Possible scores ranged from 15 to 60.

A number of studies have reported excellent internal consistency and reliability over time for the SCS, with Cronbach’s *α* statistics in excess of .85 and test-retest correlations approaching .70 and above (e.g., Cordova et al., 2001; Herzer et al., 2006; Lepore & Revenson, 2007). Lepore (2003) reported indices of convergent and predictive validity of the SCS with a sample of breast cancer patients. Lepore reported significant relationships between spouses’ ratings of their own behaviour and patients’ perceptions of social constraints. Further, both measures of constraints were inversely related to indices of mental health (e.g., Negative affect scale- PANAS [Watson et al., 1988]). In the current study, both internal reliability and test-retest reliability were excellent for this scale (see Table 6, p. 102).

**Cystic fibrosis discussion in the parent-child dyad and wider social network.** Similar to the methodology of Lepore et al. (1996) and Cordova et al. (2001), patients responded to three items regarding how much they have actually discussed their feelings about CF with parents, and two other significant support persons in the past month. These were measured on a 5-point Likert-type scale (*1- never* to *5- often*). For the questions examining discussions with two other significant support persons, participants were asked to rate the frequency of their discussions with the two support
persons they identified when completing the SOS scales (see p. 133). While the raw score generated from the item examining frequency of discussions with the patients’ parents was used in analyses of relationships in the SCP model, the two scores rating frequency of discussions with significant others were summed to give a score representing frequency of CF discussion outside of parent-child relationship (possible range of 2 to 10). This other-disclosure scale was tested as a potential control variable in the current study. For both the parent and significant other ratings, a higher score indicated a greater frequency of discussion.

**Cognitive intrusions and avoidance.** Horowitz (1987) conceptualised the Impact of Events Scale (IES) to measure the frequency of individuals’ experience of thoughts, images and feelings following the experience of a traumatic event and their intentional avoidance of these cognitions and emotions. In Horowitz’s original scale, seven items examined *intrusions* of thoughts, images and emotions and eight items examined individuals’ *avoidance*. In the current study, a modified version of the IES was used, with two items from the avoidance subscale and one item from the intrusions subscale removed to enhance the validity of the scale for the CF patient population. While it was recognised that a sudden decrement in health can lead to a traumatic stress response for some individuals, questions in the revised IES scale for the current study were targeting patients’ general experiences with CF related thoughts, images and emotions. Thus, original items examining symptoms commonly experienced in more severe traumatic responses to discreet events were removed.

The revised version of the IES included six items examining intrusions (e.g., ‘I had trouble falling asleep or staying asleep because I was worried about my health’) and six items examining avoidance (e.g., ‘I had unpleasant feelings about my CF, but I didn’t deal with them’) in the CF patient population. Patients rated how often each item was true in regards to their CF illness experience in the past seven days on a frequency scale ranging from 0 - *not at all* to 5 - *often*. Total scores were calculated by summing items on each subscale. Accordingly, possible total scores for both subscales ranged from 0 to 30.

Sundin and Horowitz (2002) reported high internal consistency of the IES subscales and also reported that both subscales demonstrated patient change across time after trauma in therapeutic settings. Other recent studies with various cancer patient and screening populations (i.e., Devine et al., 2003; Lepore & Helgeson, 1998; Taylor, Shelby, Gelmann & McGuire, 2004) have reported Cronbach’s *α* statistics ranging from .86 to .89 for the *intrusions* subscale and .77 to .87 for the *avoidance* subscale. Strong
internal and test-retest reliabilities were also obtained for the intrusion and avoidance subscales in the current study (see Table 6, p. 102).

5.2.2.3 Outcome Variables

Psychological adjustment. The brief version of the Depression Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995) was used to measure the psychological adjustment of both patients and parents. The DASS-21 consists of three subscales, each with seven items, assessing depression, anxiety, and stress levels. As well as in analyses examining correlates of parent adjustment, the adjustment scores of parents were also tested as a potential control measure in the current study as adjustment of close others has been demonstrated to impact patient adaptation to illness across much research (e.g., Holmberg, Scott, Alexy, & Fife 2001; Morse & Fife, 1998).

The depression subscale of the DASS-21 identifies individuals experiencing depressive symptoms such as disengagement, pessimism, and gloominess (e.g., “I felt that I had nothing to look forward to”). The anxiety and stress scales of the DASS-21 assess different features of anxious affect. The anxiety subscale examines autonomic arousal, and acute anxiety related experiences (e.g., “I was worried about situations in which I might panic and make a fool of myself”); whereas the stress subscale examines features of chronic, non-specific anxious affect (e.g., “I found it difficult to relax”). Participants responded to questions in relation to their experiences in the past week on a 4-point Likert-type scale (0- did not apply to me at all to 3- applied to me very much, or most of the time). Items within each subscale of the DASS-21 were summed to give a preliminary total score and then doubled to allow interpretation of scores using criteria set for the DASS-42. Thus, possible total scores ranged from 0 to 42, with higher scores indicating greater psychological maladjustment.

Strong psychometric properties have been reported for the DASS-21; comparable to that of the complete 42-item DASS scale (Antony, Bieling, Cox, Enns, & Swinson, 1998). Convergent and discriminant validity has been demonstrated using correlation analyses between the DASS subscales and those of the Hospital Anxiety and Depression Scales (Zigmond & Snaith, 1983) for non-clinical (i.e, Crawford & Henry, 2003) and acute physical illness (i.e., Sukantarar, Williamson, & Brett, 2007). Excellent internal consistency (Cronbach’s alpha .87 and above) has also been noted by Antony et al. on all DASS-21 subscales, and by Sarda, Nicholas, Pimenta, and Asghari (2008) who examined the use of the DASS-21 depression subscale with a chronic pain population. In the current study, comparable reliability coefficients were obtained (see
Table 6, p. 135). However, unlike most other measures included in the patient and parent scales, test-retest reliability was poor. This was interpreted as indicating that the DASS-21 is sensitive to changes in patients’ mood and, more generally, as demonstrating the variability in individuals’ mood and psychological functioning over time (APA, 1994).

Adaptive adjustment of both the patients and parents was also examined using the positive affect scale of the Positive and Negative Affect Schedule (PANAS; Watson et al., 1988). Like the DASS, the positive affect scores of parents were also tested as a control measure for analyses of patient outcomes in the current study. The PANAS was selected in accordance with the recent acknowledgement (e.g., Lepore & Kernan, 2009) of the importance of documenting not only increases in patient distress, but also decreases in patient well-being, when assessing the impact of social constraints on patient outcomes. The positive affect subscale of the PANAS included 10 items (e.g., interest, excitement, enthusiasm) and patients were required to indicate the extent they have experienced each emotional state in the past week on a 5-point Likert-type scale (1-very slightly/not at all to 5-extremely). Items were summed to give a total score. Thus, possible scores for this scale ranged between 5 and 50, with higher scores indicating the experience of a high level of positive affect.

Watson et al. (1988) reported the strong psychometric properties of the PANAS; Cronbach’s α for the positive affect were .86 and .85, for a student and psychiatric sample, respectively. Watson and colleagues also reported significant associations in the expected directions between the PANAS and various other well-noted measures of psychological distress (e.g., the Beck Depression Inventory [Beck, Rush, Shaw, & Emery, 1979]). More recent studies recruiting various chronic illness samples (e.g., Hansdottir, Malcarne, Furst, Weisman & Clements, 2004; Lepore & Ituarte, 1999; Manne & Schnoll, 2001) have also found internal consistency of the PANAS scales to equal or exceed Watson et al.’s early reports. Excellent internal consistency was also noted for this scale in the current study. Yet, as with the DASS-21 subscale scores, low test-retest reliability was obtained for patients’ scores over time, however, parents’ scores were more consistent (see Table 6, p. 102). It is again suggested that this indicates true and expected variation in individuals’ mood and affect over time.

Cognitive adjustment. Patients’ belief in the predictability of the world and their ability to face health-related crises was examined using the 13-item Sense of Coherence Questionnaire (SOC-13; Antonovsky, 1987). This measure includes three underlying domains which examine individuals’ perceptions of comprehensibility (five items),
manageability (four items) and meaningfulness (four items) of their life at the current time. All items are measured on a 7-point Likert-type scale, however, each of the items has a different anchor description which corresponds with the item’s content. Examples include “When you face a difficult problem the choice of solution is:” (1- always confusing and hard to find to 7- always completely clear), “Do you have the feeling that you’re being treated unfairly?” (1- very often to 7- very seldom or never) and “Until now your life has had:” (1- no clear goals or purpose at all to 7- very clear goals or purpose), respectively. Although there are three underlying domains in the SOC-13, Antonovsky suggests that only the total score should be interpreted. Hence, the total score for this scale was generated by summing responses to each item. Possible scores for this scale ranged between 13 and 91, with higher scores indicating a stronger sense of coherence.

Antonovsky (1993) reported that, across a wide range of non-clinical samples, Cronbach’s α statistics were .84 and above, with test-retest reliability at $r = .80$ and above for both the SOC-13 and the original SOC-29 scale (Antonovsky, 1979). It was also noted by Antonovsky (1993) that both scales can discriminate between known-group samples, such as Israeli army officer trainees (who are in superb health and motivated to succeed in the face of adversity) and the general Israeli population; with the officers obtaining significantly higher SOC scores than members of the general community. The SOC-29 (Antonovsky, 1979) has been successfully applied in research with adolescents with CF (Baker, 1998). Baker also reported high internal consistency for this measure (Cronbach’s α = .92). More recently, Olsson, Gassne, and Hansson (2009) reported that the SOC-29 and the SOC-13 have comparable internal reliability (Cronbach’s α = .93 and .89, respectively) and a high inter-correlation ($r = .96$) when tested with parents of children with a disability. Likewise, both strong internal consistency and test-retest reliability statistics were obtained for both patients and parents in the current study (see Table 6, p. 102). Like the DASS and PANAS, it was decided to test parent scores as a control measure to be included in patient outcome analyses.

5.2.3 Procedure

5.2.3.1 Peer Review of Measures

The patients’ and parents’ questionnaires were first produced by the current author in conjunction with an experienced researcher in health psychology and a clinical psychologist. All investigators agreed that short versions of outcomes measures should
be used where possible to reduce burden to participants. The decision to utilise a short-
version was based upon the psychometric data for the measure compared to its original
version and its previous application to the CF population or other chronic illness
populations. Accordingly, the Brief COPE (Carver, 1997), DASS-21 (Lovibond &
Lovibond, 1995) and SOC-13 (Antonovsky, 1987) were selected for use over the COPE
(Carver et al., 1989), DASS-42 (Lovibond & Lovibond) and SOC-29 (Antonovsky,
1979), and only the positive affect scale of the PANAS (Watson et al., 1988) was
utilised given the significant associations reported between the content of the negative
affect scale and all DASS-21 subscales (Henry & Crawford, 2005).

The proposed questionnaires were then reviewed by two social workers and a
clinical psychologist from the Prince Charles Hospital (Brisbane, QLD), all having a
number of years experience working with the CF population. A suggestion was made by
the reviewers that little variation would be expected on the IPQ-R acute-chronic
timeline subscale and that inclusion of these items may appear to be insensitive to the
population given the chronic and terminal nature of the illness. Thus, a decision was
made to remove this subscale from the final measure. In Sawicki et al.’s (2011) recent
examination of the impact of illness representations on health-related quality of life for
adult CF patients this subscale was also omitted.

5.2.3.2 Participant Review of Measures

Following peer review, the readability and clarity of the revised questionnaires
were then assessed by two young adults with CF and their parents. These individuals
were contacted by a social worker at Cystic Fibrosis Queensland (CFQ) who informed
them of the nature of the study and intentions for the use of their feedback. During a
scheduled visit to the Brisbane CFQ office, each participant completed a questionnaire
and a questionnaire feedback form and was also given a reply paid envelope to return
these materials to the primary researcher. The return of these questionnaires to the social
worker was considered as implicit consent to participate. As with the main sample,
these participants were also eligible to enter the T1 prize draw.

The feedback form asked pilot participants to comment on how easily the
questionnaire instructions were understood and how comfortable they felt completing
the questionnaire. Additionally, any general comments on the questionnaire were also
requested. The feedback from this suggested that the questionnaire was easy to
understand and was not overly emotionally-arousing for the participants to complete.
Thus, all scales included in this version of the questionnaire were retained in the final
patients’ and parents’ versions of the questionnaires. Finally, at this time, questionnaire completion time was also noted; being approximately 30 minutes.

5.2.3.3 Time 1 Testing

As noted previously, participants were first contacted through their respective state CF organisations, each being sent a study information and consent package, as well as a reply paid envelope addressed to the primary researcher to return their completed consent form. Upon the primary investigator's receipt of completed consent forms, participants were sent a T1 questionnaire, a prize draw entry form, and a reply paid envelope to return these materials. The questionnaire instructions requested that participants complete the questionnaire in an area away from their parent/child. This was outlined as it was considered that individuals may feel uncomfortable reporting either dissatisfaction within their family relationships or high personal distress levels if either factor was a concern for them. To assist in facilitating independent reporting, each member of the dyad was sent their questionnaires in separate packages even if they lived at the same residence.

Three months after the T1 questionnaires were distributed, the study was closed and the prizes were drawn. Subsequently, prize winners were contacted via telephone or email. Prize draw entry forms with participants’ names and contact details were stored separately to the questionnaires to protect participants’ anonymity. Also at this time, participants were sent a thank-you letter for their participation in the first wave of the study.

Finally, also following the cessation of data collections patients’ and parents’ questionnaires were matched. To facilitate this process, on the coversheet of the T1 questionnaires, participants were instructed to mark a code that would be common between both persons in a dyad, but distinct from other dyads. Thus, a 6-character code consisting of the patient’s birth date and month, and the last two letters of their parent’s surname was used.

5.2.3.4 Time 2 Testing

Six months after T1 questionnaires were distributed, participants were sent a follow-up questionnaire package. This consisted of the T2 questionnaire, a prize draw entry form and a reply paid envelope for return of the package. As with the completion of the first questionnaire, participants were again requested to complete the questionnaire in a space away from their parent/child. The prizes for T2 were drawn three months after the distribution of the follow-up questionnaire packages. Again,
winners were contacted via telephone or email. Participants were also sent a thank-you letter for their participation in the second wave of the study.

On the T2 questionnaire coversheets, participants were instructed to produce the unique code generated at T1. Instructions on how to create this code were again detailed for participants. Following the conclusion of the follow-up data collection, parents’ follow-up questionnaires were matched to patients’ follow-up questionnaires. Subsequently, follow-up questionnaires were also matched to the T1 questionnaires.

Approximately six months after the cessation of follow-up data collection, all participants were sent a summary of the key findings and implications generated from the data. Participants were also given another copy of the contact details of the primary investigator so that any questions or concerns arising from their participation in the study could be attended to. No participants requested assistance.

5.3 Results

5.3.1 Preliminary Analyses

5.3.1.1 Missing Data

At both T1 and T2, no variable had more than 5.00% missing data, suggesting that data was omitted by participants completely at random (Munro, 2005); accordingly, an imputation approach was considered to be appropriate to replace missing values on selected scales (Hair et al., 2006). Where particular imputation approaches were suggested by scale authors, their suggestions were followed. When suggestions for treatment of missing data were not made by original scale authors, approaches adopted in recent research for the particular scales were followed.

For missing data on the IPQ-R (Moss-Morris et al., 2002) Moss-Morris et al. recommend that a maximum of two items on the six-item subscales (consequences, personal control, emotional representations), and a maximum of one item from five- and four-item subscales (treatment control, illness coherence, timeline cyclical) can be replaced with each participant’s individual mean of their responses from the remaining subscale items. Thus, when an individual had more than the suggested number of missing items for a particular subscale, a total subscale score was not calculated.

For missing data on scales from the CFQ-R (Quittner et al., 2002) Quittner et al.’s procedures for missing data were also followed. Similar to the IPQ-R substitution procedures, imputations were also based upon the individual’s responses to other items on a particular subscale. However, Quittner et al. suggested substitution with the
median, as opposed to the mean, of the other subscale items. Quittner et al. also advised that if more than half of the answers are missing for a particular subscale, a subscale total should not be calculated. Thus, for the treatment burden subscale (three items), only one missing data point could be substituted, and for the role functioning subscale (four items) a maximum of two data points could be substituted.

Following scale authors’ recommendations (i.e., Lovibond & Lovibond, 1995), and procedures adopted in recent studies (i.e., Agustsdottir et al., 2010; Drageset, Nygaard, Eide, Bondevik, Nortvedt, & Natvig, 2008; Post, 2010) for subscales from the DASS-21, PANAS, SCS and SOC-13, the individual mean substitution approach was adopted, similar to that adopted for the IPQ-R subscales. In this instance, for subscales with eight or more items (i.e., PANAS-Negative Affect, SCS), missing data was substituted when a maximum of two data points were missing. For subscales with four to seven items (DASS-21 subscales and underlying SOC-13 domains), missing data substituted when a maximum of one data point was missing. Given that subscales in the Brief COPE and SOS subscales only included two items on each subscale, no data imputation was applied for each of these subscales.

5.3.1.2 Descriptive Statistics

Examination of the distributions of the key measures obtained at T1 and T2 revealed that the majority of the distributions were normally distributed. Of the variables which did have significant skew (i.e., standardised skew statistic > 2.58 [Field, 2000]), all but one variable was skewed in a direction which suggested that the majority of the sample were coping relatively well. Specifically, at T1 and T2, measures of social constraints for patients, and measures of depression, anxiety and stress for both patients and parents suggested that few patients perceived high levels of social constraints from their parents and that few patients and parents experienced high levels of distress. Also, at T1, few parents reported low levels of understanding of CF as indicated by responses on the illness coherence subscale of the IPQ-R. It is noted, however, that for parents at T1 and T2, the consequences subscale of the IPQ-R was skewed in a direction which indicated that the majority of parents perceived CF as having a large impact on their children’s lives. Yet, given the chronic and ultimately fatal nature of CF, this may be expected.

A summary of the descriptive statistics from all predictor and outcome variables for patients and parents at T1 and T2 of the current study is presented in Tables 7 to 9. Table 7 displays the descriptive statistics for the quantitative IPQ-R domains for both
patients and parents. Regarding the causal subscale of the IPQ-R, this subscale was modified in the current study, using an open-ended question to assess participants’ perceived causes of CF instead of the original 18-item quantitative scale and was assessed at T1 only (see section 5.2.2.2, p. 105). The participant responses indicated that 97.50% of patients and 98.20% identified genetics as the cause of CF. One patient reported ‘not keeping up with medications’ as a cause of CF. Finally, one parent identified ‘stress’ as a cause of CF.

Table 7

IPQ-R Domains Patient (T1 n=49, T2 n=36) and Parent (T1 n=61, T2 n=40) Descriptive Statistics

<table>
<thead>
<tr>
<th>Domain</th>
<th>Time 1</th>
<th></th>
<th>Time 2</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>SE</td>
<td>Range</td>
</tr>
<tr>
<td>Patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptoms Experienced</td>
<td>9.53</td>
<td>3.01</td>
<td>0.43</td>
<td>2 – 16</td>
</tr>
<tr>
<td>Symptoms Related to CF</td>
<td>6.40</td>
<td>3.40</td>
<td>0.49</td>
<td>0 – 14</td>
</tr>
<tr>
<td>Consequences</td>
<td>21.47</td>
<td>4.47</td>
<td>0.63</td>
<td>12 – 30</td>
</tr>
<tr>
<td>Personal Control</td>
<td>24.40</td>
<td>3.49</td>
<td>0.50</td>
<td>14 – 30</td>
</tr>
<tr>
<td>Treatment Control</td>
<td>16.76</td>
<td>3.26</td>
<td>0.47</td>
<td>11 – 25</td>
</tr>
<tr>
<td>Illness Coherence</td>
<td>21.10</td>
<td>3.32</td>
<td>0.47</td>
<td>11 – 25</td>
</tr>
<tr>
<td>Timeline Cyclicical</td>
<td>11.92</td>
<td>3.85</td>
<td>0.55</td>
<td>4 – 20</td>
</tr>
<tr>
<td>Emotional Representations</td>
<td>16.16</td>
<td>5.28</td>
<td>0.75</td>
<td>6 – 27</td>
</tr>
<tr>
<td>Parents</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom Experienced</td>
<td>8.50</td>
<td>3.52</td>
<td>0.45</td>
<td>0 – 14</td>
</tr>
<tr>
<td>Symptom Related to CF</td>
<td>7.57</td>
<td>4.09</td>
<td>0.52</td>
<td>0 – 14</td>
</tr>
<tr>
<td>Consequences</td>
<td>24.87</td>
<td>3.81</td>
<td>0.49</td>
<td>13 – 30</td>
</tr>
<tr>
<td>Personal Control</td>
<td>22.15</td>
<td>3.66</td>
<td>0.47</td>
<td>14 – 30</td>
</tr>
<tr>
<td>Treatment Control</td>
<td>15.23</td>
<td>3.34</td>
<td>0.43</td>
<td>6 – 23</td>
</tr>
<tr>
<td>Illness Coherence</td>
<td>21.49</td>
<td>3.30</td>
<td>0.42</td>
<td>10 – 25</td>
</tr>
<tr>
<td>Timeline Cyclicical</td>
<td>12.33</td>
<td>2.89</td>
<td>0.37</td>
<td>5 – 19</td>
</tr>
<tr>
<td>Emotional Representations</td>
<td>19.98</td>
<td>5.18</td>
<td>0.66</td>
<td>6 – 30</td>
</tr>
</tbody>
</table>
As seen in Table 8, only the coping scales for patients and parents derived from principal component analyses were included as coping measures in the current study. These were independent coping and other-oriented coping for patients, and change-oriented coping and management oriented coping for parents. Thus, overall, these coping styles were derived from more active and engaged styles of coping than avoidant styles. While a measure of avoidant coping was desired for the current study to replicate analyses which suggest that greater use of avoidant coping is associated with having more negative illness representations (e.g., Hagger & Orbell, 2003), a similar pattern of results was also reported in a recent study examining the coping styles of parents of primary school aged children with CF. Wong and Heriot (2008) discussed that parents reported engaging in active styles of coping more frequently than avoidant coping styles.

Table 8

*Coping and Adjustment Indicators Patient (T1 n=49, T2 n=36) and Parent (T1 n=61, T2 n=40)*

**Descriptive Statistics**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Time 1</th>
<th></th>
<th></th>
<th></th>
<th>Time 2</th>
<th></th>
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<tbody>
<tr>
<td></td>
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<td>SD</td>
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<td>Mean</td>
<td>SD</td>
<td>SE</td>
<td>Range</td>
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<tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual-oriented Coping</td>
<td>21.67</td>
<td>5.78</td>
<td>0.83</td>
<td>12 – 32</td>
<td>20.81</td>
<td>5.93</td>
<td>0.99</td>
<td>9 – 31</td>
</tr>
<tr>
<td>Other-oriented Coping</td>
<td>16.55</td>
<td>5.64</td>
<td>0.81</td>
<td>8 – 29</td>
<td>17.19</td>
<td>5.32</td>
<td>0.89</td>
<td>8 – 30</td>
</tr>
<tr>
<td>DASS – Depression</td>
<td>7.32</td>
<td>8.14</td>
<td>1.18</td>
<td>0 – 34</td>
<td>6.28</td>
<td>7.27</td>
<td>1.21</td>
<td>0 – 30</td>
</tr>
<tr>
<td>DASS – Anxiety</td>
<td>5.29</td>
<td>6.41</td>
<td>0.93</td>
<td>0 – 32</td>
<td>4.94</td>
<td>5.31</td>
<td>0.89</td>
<td>0 – 24</td>
</tr>
<tr>
<td>DASS – Stress</td>
<td>8.92</td>
<td>8.22</td>
<td>1.19</td>
<td>0 – 30</td>
<td>9.39</td>
<td>8.46</td>
<td>1.41</td>
<td>0 – 38</td>
</tr>
<tr>
<td>PANAS – Positive Affect</td>
<td>32.62</td>
<td>8.12</td>
<td>1.18</td>
<td>15 – 50</td>
<td>31.56</td>
<td>6.20</td>
<td>1.03</td>
<td>16 – 49</td>
</tr>
<tr>
<td>Sense of Coherence</td>
<td>59.41</td>
<td>11.59</td>
<td>1.66</td>
<td>22 – 82</td>
<td>64.08</td>
<td>11.81</td>
<td>1.97</td>
<td>35 – 87</td>
</tr>
<tr>
<td><strong>Parents</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Change-oriented Coping</td>
<td>16.45</td>
<td>4.67</td>
<td>0.62</td>
<td>7 - 24</td>
<td>16.88</td>
<td>3.49</td>
<td>0.55</td>
<td>11 – 23</td>
</tr>
<tr>
<td>Management-oriented Coping</td>
<td>14.44</td>
<td>3.42</td>
<td>0.45</td>
<td>7 - 24</td>
<td>15.28</td>
<td>3.05</td>
<td>0.48</td>
<td>9 – 24</td>
</tr>
<tr>
<td>DASS – Depression</td>
<td>6.43</td>
<td>7.41</td>
<td>0.96</td>
<td>0 – 36</td>
<td>7.25</td>
<td>9.31</td>
<td>1.47</td>
<td>0 – 42</td>
</tr>
<tr>
<td>DASS – Anxiety</td>
<td>3.83</td>
<td>6.19</td>
<td>0.80</td>
<td>0 – 28</td>
<td>4.65</td>
<td>5.88</td>
<td>0.93</td>
<td>0 – 24</td>
</tr>
<tr>
<td>DASS – Stress</td>
<td>8.90</td>
<td>7.89</td>
<td>1.02</td>
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<td>10.10</td>
<td>8.71</td>
<td>1.38</td>
<td>0 – 38</td>
</tr>
<tr>
<td>PANAS – Positive Affect</td>
<td>34.05</td>
<td>8.40</td>
<td>1.08</td>
<td>13 – 50</td>
<td>34.02</td>
<td>7.80</td>
<td>1.23</td>
<td>16 – 50</td>
</tr>
<tr>
<td>Sense of Coherence</td>
<td>57.73</td>
<td>11.75</td>
<td>1.50</td>
<td>24 – 84</td>
<td>62.60</td>
<td>11.32</td>
<td>1.79</td>
<td>41 – 90</td>
</tr>
</tbody>
</table>
Table 9

*Patients’ Social Cognitive Processing Variables Descriptive Statistics at T1 (n=49) and T2 (n=36)*

<table>
<thead>
<tr>
<th>Scale</th>
<th>Time 1</th>
<th></th>
<th></th>
<th></th>
<th>Time 2</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>SE</td>
<td>Range</td>
<td>Mean</td>
<td>SD</td>
<td>SE</td>
</tr>
<tr>
<td>Social Constraints</td>
<td>21.83</td>
<td>7.52</td>
<td>1.07</td>
<td>15 – 54</td>
<td>21.03</td>
<td>6.04</td>
<td>1.01</td>
</tr>
<tr>
<td>Parent-child Discussion</td>
<td>2.41</td>
<td>1.10</td>
<td>0.16</td>
<td>1 – 5</td>
<td>2.72</td>
<td>1.23</td>
<td>0.21</td>
</tr>
<tr>
<td>IES – Intrusions</td>
<td>5.20</td>
<td>5.03</td>
<td>0.72</td>
<td>0 – 22</td>
<td>5.28</td>
<td>5.54</td>
<td>0.92</td>
</tr>
<tr>
<td>IES – Avoidance</td>
<td>9.51</td>
<td>6.73</td>
<td>0.96</td>
<td>0 – 26</td>
<td>10.56</td>
<td>7.92</td>
<td>1.31</td>
</tr>
</tbody>
</table>

While descriptive data for patients’ and parents’ DASS-21 subscale scores are presented in Table 8, Lovibond and Lovibond (1995) also outline recommended cut-off scores to allow DASS subscale scores to be interpreted within categorical clinical severity ratings. However, Lovibond and Lovibond caution that these ratings do not have direct implications for the diagnosis of a psychological disorder and should only be used as a general guide to the interpretation of the psychological functioning of the current sample. As displayed in Figures 4 to 7, the DASS severity scores suggest that the majority of the patients and parents were not experiencing more symptoms of psychological distress than the general population at both T1 and T2. Yet, the data also demonstrates that for most DASS subscales for both patients and parents, all severity domains (i.e., normal, mild-, moderate-, severe- and extremely-severe) are represented. This suggests that while the current sample was functioning relatively well, variations and range in psychological distress scores were still observed for both patients and parents.
Figure 4. Percentage of patients in DASS severity rating categories at T1 (n=49).

Figure 5. Percentage of patients in DASS severity rating categories at T2 (n=36).
Figure 6. Percentage of parents in DASS severity rating categories at T1 (n=61).

Figure 7. Percentage of parents in DASS severity rating categories at T2 (n=40).
5.3.1.3 Data Transformations for Skewed Variables

As noted in the previous section, moderate skew was noted in the distributions of some IPQ-R variables and outcome measures obtained for patients and parents within both the T1 and T2 data. For the ANOVA and regression-based procedures, the normality of the distributions for all groups at each level of the dependent variable, and normality of the residuals, respectively, are more vital assumptions to be met for these types of analyses (Hair et al., 2006). Thus, all variables in their original form were retained for use in these analyses. The specific assumptions of these analyses were evaluated in turn and actions to reduce the impact of violations of assumptions were taken where required.

However, it was noted that moderate and severe skew can reduce power in correlational analyses and to limit the impact of skew, data transformations are recommended by some authors (e.g., Dunlap, Burke, & Greer, 1995; Hair et al., 2006). In the data obtained in the current study, the magnitude of the skew for all variables with significant skew was in the moderate range. To improve the distributions of variables with this magnitude of skew, square-root transformations are recommended (Hair et al.). Thus, for all variables in the current study with positive skew (i.e., all patient and parent DASS subscales, all patient social constraints data, and illness coherence data for parents at T1) these variables were reproduced with a square-root transformation applied. For the consequence subscale of the IPQ-R for parents at T1 and T2, negative skew was noted, and thus, the data was first reflected, and a square-root transformation then applied. The results of correlational analyses using the transformed version of the variables noted above were then compared to those obtained using the original data obtained. As negligible differences were noted in correlation coefficients before and after data transformation for all analyses conducted, the results incorporating all original data are those reported throughout the remainder of this study.

5.3.1.4 Calculation of Illness Perception Discrepancy Variables

At T1 and T2, categorical patient-parent illness perception discrepancy variables were calculated for each subscale of the IPQ-R. The approach utilised by Figueiras and Weinman (2003) and Sterba et al. (2009) was also adopted in the current study. First, median splits were performed for both patients’ and partners’ illness representation scores. For the treatment control, personal control, and illness coherence IPQ-R subscales, participants scoring below the median were considered to have negative illness representations and those scoring above the median were considered to have
positive illness representations. Conversely, for the consequences, emotional representations, timeline, symptoms experiences and symptoms related to CF IPQ-R subscales, participants scoring above the median were considered to have negative illness representations and those scoring below the median were considered to have positive illness representations. For each illness representation domain, dyads were then categorised into four groups: both patient and parent positive, both patient and parent negative, patient-positive-parent-negative, patient-negative-parent-positive. Frequency data for these variables is presented in Table 10.

Table 10

_Frequency (%) of Participant Dyads Across the Four Categorical Domains of Illness_

_Perception Similarity at T1 (n=44) and T2 (n=30)_

<table>
<thead>
<tr>
<th>Scale</th>
<th>Similar +*</th>
<th>Similar –*</th>
<th>Patient + Parent –</th>
<th>Patient – Parent +</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Time 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptoms Experienced</td>
<td>19 (43.20)</td>
<td>14 (31.80)</td>
<td>5 (11.40)</td>
<td>6 (13.60)</td>
</tr>
<tr>
<td>Symptoms Related to CF</td>
<td>20 (45.40)</td>
<td>16 (36.40)</td>
<td>4 (9.10)</td>
<td>4 (9.10)</td>
</tr>
<tr>
<td>Consequences</td>
<td>12 (27.25)</td>
<td>12 (27.25)</td>
<td>9 (20.50)</td>
<td>11 (25.00)</td>
</tr>
<tr>
<td>Personal Control</td>
<td>16 (36.40)</td>
<td>15 (34.10)</td>
<td>7 (15.90)</td>
<td>6 (13.60)</td>
</tr>
<tr>
<td>Treatment Control</td>
<td>9 (20.50)</td>
<td>17 (38.60)</td>
<td>10 (22.70)</td>
<td>8 (18.20)</td>
</tr>
<tr>
<td>Illness Coherence</td>
<td>12 (27.25)</td>
<td>12 (27.25)</td>
<td>9 (20.50)</td>
<td>11 (25.00)</td>
</tr>
<tr>
<td>Timeline Cyclical</td>
<td>8 (18.20)</td>
<td>16 (36.40)</td>
<td>9 (20.50)</td>
<td>11 (25.00)</td>
</tr>
<tr>
<td>Emotional Representations</td>
<td>12 (27.25)</td>
<td>12 (27.25)</td>
<td>12 (27.30)</td>
<td>8 (18.20)</td>
</tr>
<tr>
<td><strong>Time 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptoms Experienced</td>
<td>11 (36.70)</td>
<td>6 (20.70)</td>
<td>5 (17.20)</td>
<td>7 (23.30)</td>
</tr>
<tr>
<td>Symptoms Related to CF</td>
<td>10 (33.30)</td>
<td>9 (30.00)</td>
<td>6 (20.00)</td>
<td>5 (16.70)</td>
</tr>
<tr>
<td>Consequences</td>
<td>9 (30.00)</td>
<td>10 (33.33)</td>
<td>4 (13.33)</td>
<td>7 (23.33)</td>
</tr>
<tr>
<td>Personal Control</td>
<td>6 (20.00)</td>
<td>12 (40.00)</td>
<td>7 (23.30)</td>
<td>5 (16.70)</td>
</tr>
<tr>
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<td>12 (40.00)</td>
<td>3 (10.00)</td>
<td>6 (20.00)</td>
</tr>
<tr>
<td>Illness Coherence</td>
<td>4 (13.35)</td>
<td>6 (20.00)</td>
<td>9 (30.00)</td>
<td>11 (36.65)</td>
</tr>
<tr>
<td>Timeline Cyclical</td>
<td>6 (20.00)</td>
<td>11 (36.66)</td>
<td>8 (26.66)</td>
<td>5 (16.70)</td>
</tr>
<tr>
<td>Emotional Representations</td>
<td>9 (30.00)</td>
<td>11 (36.66)</td>
<td>4 (13.33)</td>
<td>6 (20.00)</td>
</tr>
</tbody>
</table>

* (+) = positive perception; (-) = negative perception
5.3.1.5 Examination of Potential Control Variables

In preliminary analyses, the relationships between potential control variables (i.e., demographic variables, illness severity indicators, treatment characteristics, social support indicators, and parent adjustment) and all key outcome measures (psychological adjustment variables, cognitive adjustment variables) in the patient data were tested at T1 and T2. As social constraints was used in the current study as both a predictor of patient adjustment and as a dependent measure in analyses examining predictors of social constraints, the effect of potential control variables on this measure was also tested. Further, given that longitudinal analyses were also conducted examining the effect of T1 predictors on T2 outcomes, the effect of T1 control measures on T2 outcome variables was also tested. Similar analyses examining the effect of potential control variables on psychological and cognitive adjustment indicators were also conducted for parents at T1 and T2. However, in these analyses, only demographic variables and children’s illness severity indicators were tested as potential covariates.

As all outcome measures for both patients and parents were continuous variables, when examining the impact of control variables, correlational analyses were run with continuous controls and either ANOVA or t-test analyses were run with categorical controls. Considering the large number of analyses to be run, the alpha level was set at .001 to reduce Type 1 error.

At T1, only one potential control variable was found to have a significant relationship with patient outcomes. Further, no significant relationships were observed between T1 and T2 potential controls and T2 patient outcome measures. At T1, role functioning was significantly correlated with social constraints, $r(47) = -0.47, p = .001$. As patients’ role functioning improved, patients’ perceptions of social constraints also improved. Thus, role functioning was included in analyses predicting social constraints at T1.

This finding is similar to that of Lepore and Helgeson (1998) who found a positive relationship between time since diagnosis of prostate cancer and patients’ perceptions of social constraints. They subsequently utilised this measure as a control in their analysis of social constraints and patient outcomes. Lepore and Helgeson also found a significant relationship between education and patient outcomes which was not replicated in the current study. However in other studies examining both social constraints (i.e., Lepore et al., 1996; Lutgendorf et al., 1999) and illness representations (i.e., Sawicki et al., 2011) and patient outcomes, no significant relationships were
observed between patient outcomes and demographics variables (e.g., age and education).

Regarding potential control variables for inclusion in analyses examining parent adjustment, one control variable at T1, and two control variables at T2 were found to have significant relationships with parent adjustment. At both T1 ($t(59) = 3.80, p<.0001, d = 1.02$) and T2 ($t(35) = 3.66, p=.001, d = 1.24$), parent work status was found to be significantly related to parents’ SOC. Further, work status was also significantly related to parents’ level of stress at T2 ($t(35) = 4.39, p<.0001, d = 1.48$). In all cases, parents who were working full-time reported more positive adjustment than parents who were not working full-time. In addition to work status, the experience of a traumatic event was also related to parent stress ratings at T2, $t(38) = 4.20, p<.0001, d = 1.36$. Parents who had experienced a traumatic event reported significantly higher stress levels than parents who had not experienced a traumatic event. Descriptive statistics for all significant parent control measures are presented in Table 11. Accordingly, work status was included in analyses examining parent stress levels at T1 and T2, and in analyses examining parents’ SOC at T2. Trauma status was also included as a predictor of parent stress at T2.

These findings are similar to Driscoll et al. (2010) who reported that not having employment outside of the family home was associated with increased distress for parents of children with chronic illness. A number of previous studies have also reported a strong relationship between the experience of trauma and decreases psychological functioning (e.g., Green et al., 2000; Janoff-Bulman, 1992), which was replicated in the current study. Yet, it was also expected that child illness severity indicators would also be related to parental adjustment, as previous research with families with children with CF have demonstrated that parents with children with more severe illness have greater levels of anxiety than children with less severe illness (Thompson et al., 1992b). However, given that the current sample of CF patients were older than those involved in Thompson et al.’s sample, it is possible that parents’ coping abilities and their resilience to distress stemming from their children’s illness may increase over time given the chronic nature of CF.
Table 11

*Descriptive Statistics for Significant Control Measures from Analyses of Parent Adjustment at T1 and T2*

<table>
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<th></th>
<th>Time 1</th>
<th></th>
<th>Time 2</th>
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<tr>
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<td>Working Less Than Full-time</td>
<td>Working Full-time</td>
<td>Working Less Than Full-time</td>
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<td>64.64 (9.21) 1.65 31</td>
<td>49.50 (9.66) 3.95 6</td>
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<td>Traumatic Event Experienced</td>
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<td></td>
<td>6.74 (6.21) 1.19 27</td>
<td>17.08 (9.22) 2.56 13</td>
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</table>

5.3.2 **Main Analyses**

5.3.2.1 **Relationships Between Patient Perceptions of Social Constraints, Frequency of Parent-Child Discussions and Patient and Parent Coping**

Hypotheses 1 and 2 of the current study predicted significant associations between patient perceptions of social constraints with their parent and the frequency of parent-child discussions, and between patient perceptions of social constraints and patient and parent coping styles. Regarding patient and parent coping, it was predicted that when patients perceived a high level of social constraints with their parent, both patients and parents would use avoidant coping strategies. However, as discussed in sections 5.2.2.2 and 5.3.1.2, the principal components analysis of the patient and parent Brief COPE subscales did not identify a factor for either patients or parents which resembled an avoidant style of coping. Alternatively, the two predominant coping styles utilised by patients were independent and other-oriented coping styles, with independent coping incorporating the Brief COPE subscales of acceptance, active coping, positive reframing and planning, and other-oriented coping incorporating the instrumental support, emotional support, venting and self-distraction subscales. For parents, two coping styles were also identified: a management-oriented and a change-oriented coping style. Management-oriented coping incorporated the acceptance, instrumental support,
and emotional support subscales from the Brief COPE and change-oriented coping incorporated the active coping, planning, and positive reframing subscales.

Thus, while the relationship between avoidant coping and social constraints could not be tested, exploratory correlational analyses were conducted between social constraints and the four coping styles generated from the patient and parent PCA of the Brief COPE. Correlational analyses were also run to examine whether social constraints were significantly associated with the frequency of parent-child discussions. All effect sizes reported in this section and those for all other results presented in this chapter were interpreted using Cohen’s (1988) conventions.

Cross-sectional results. The results of the correlational analyses between social constraints and frequency of parent-child discussions, and those between social constraints and patient and parent coping styles at T1 are presented in Table 12. The results from T2 are presented in Table 13. These relationships are highlighted in bold in these tables. Relationships pertinent to specific hypotheses for all other analyses in the current study are also highlighted in bold in other tables throughout this chapter. As shown in Tables 12 and 13, at both T1 and T2 social constraints showed no significant relationships with frequency of parent-child discussions, or with either patient or parent coping styles.

Longitudinal results. The results of the correlational analyses between patients’ perceptions of social constraints at T1 and frequency of parent-child discussions at T2, and those between social constraints at T1 and patient and parent coping styles at T2 are presented in Table 14. Again, no significant relationships were identified between social constraints and frequency of parent-child discussions, patient coping styles, or parent coping styles.
Table 12

Pearson’s r Correlations Between Patients’ Perceptions of Social Constraints with Their Parent, Frequency of Parent-Child Discussions and Patient⁹ and Parentᵇ Coping Variables at T1 (n=49)

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* p<.05  ** p<.01  ***p<.001

Table 13

Pearson’s r Correlations Between Patients’ Perceptions of Social Constraints with Their Parent, and Frequency of Parent-Child Discussions and Patientᵃ and Parentᵇ Coping Variables at T2 (n=36)

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* p<.05  ** p<.01  ***p<.001
Table 14

Pearson’s r Correlations Between Patients’ Perceptions of Social Constraints with Their Parent at T1 and Frequency of Parent-Child Discussions and Patient a and Parent b Coping Variables at T2 (n=31)

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* p<.05  ** p<.01  *** p<.001

5.3.2.2 Relationships Between Illness Representations and Coping Styles for Patients and Parents

Hypothesis 3 of the current study predicted positive associations between the negativity in illness perceptions and the frequency of the use of avoidant coping strategies for both patients and parents. As noted in the previous section, a measure of avoidant coping was not obtained in preliminary analysis of the patient and parent Brief COPE data. Thus, exploratory correlational analyses were instead conducted to examine the relationships between patient illness perceptions and patient independent and other-oriented coping styles, and those between parent illness perceptions and parent management and change-oriented coping styles.

Cross-sectional results. The results of the correlational analyses between illness perceptions and coping styles at T1 and T2 for patients are presented in Tables 15 and 16, respectively. The results of these analyses for parents are presented in Tables 17 (T1) and 18 (T2). As displayed in Table 15, for patients at T1, two IPQ-R domains were significantly related to independent coping, and two IPQ-R domains were significantly related to other-oriented coping. The results indicated that as patients’ perceptions of personal and medical treatment control over CF became more positive, patients’ use of an independent coping style was more frequent. Regarding the significant associations
between illness perceptions and other-oriented coping, as patients’ perceived CF to be more cyclical in nature and reported greater emotional distress related to CF, other-oriented coping was engaged in more frequently.

As shown in Table 16, at T2, significant relationships were again identified between independent coping and perceptions of personal and treatment control for patients. Further, a significant relationship was also identified between independent coping and illness coherence such that greater perceived understanding of CF was associated with more frequent use of an independent coping style. Contrary to the results obtained at T1 between patients’ illness perceptions and other-oriented coping, only one significant relationship was identified, incorporating the IPQ-R domain of symptoms related to CF. As the number of perceived symptoms related to CF increased for patients, their reported use of other-oriented coping also increased. All significant relationships between illness perceptions and coping styles for patients at T1 and T2 were moderate to strong relationships.

For parents, the relationships between illness perceptions and coping styles also differed from T1 to T2. As shown in Table 18, at T1, timeline-cyclical and change-oriented coping had a moderately strong negative relationship, with no significant relationships between illness perceptions and management oriented coping. As parents perceived CF to be more cyclical in nature, change-oriented coping was used less frequently. Yet at T2, two significant relationships were identified between parents’ illness perceptions and their use of change-oriented coping and one relationship was identified between illness perceptions and management-oriented coping. As shown in Table 19, all significant relationships between illness perceptions and coping styles for parents at T2 were moderately strong. The results indicated that as parents perceptions of personal and medical treatment control over CF became more positive, parents’ used change-oriented coping more frequently. Regarding management-oriented coping, as parents’ perceptions of their child’s ability to control their CF was enhanced, parents engaged in change-oriented coping more frequently.

**Longitudinal results.** The results of the correlation analyses between illness perceptions at T1 and coping styles at T2 are displayed in Tables 17 and 20 for the patient and parent data, respectively. For patients, only one significant relationship was identified between illness perceptions and coping, being a moderately strong positive relationship between emotional representations and other-oriented coping. Similar to the results at T1, as patients reported experiencing more emotional distress related to CF at T1, the more frequently patients reported using other-focussed coping strategies at T2.
Regarding relationship between illness perceptions and coping for parents over time, the results most closely resembled the parent cross-sectional results obtained at T2. Two significant relationships were identified between change-oriented coping and illness perceptions, and one significant relationship was identified between illness perceptions and management oriented coping. Interestingly, perceptions of personal control over CF were related to both change-oriented and management-oriented coping. Additionally, perceptions of CF being cyclical were also related to change-oriented coping. Regarding effect sizes, all significant relationships were moderately strong. The results indicated that the more control parents perceived their children to have over their CF at T1 and the less parents perceived CF to be cyclical in nature at T1, the more frequently parents’ reported using change-oriented coping at T2; also, as parents perceived their child to have more personal control over CF at T1, parents reported engaging in management-oriented coping more frequently at T2.
Table 15

*Pearson’s r Correlations Between Patients’ IPQ-R Subscales and Coping Variables at T1 (n=49)*

<table>
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*p < .05  ** p < .01  *** p < .001
Table 16

Pearson’s r Correlations Between Patients’ IPQ-R Subscales and Coping Variables at T2 (n=36)

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* $p<.05$  ** $p<.01$  *** $p<.001$
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* p<.05  ** p<.01  *** p<.001
Table 18

*Pearson’s r Correlations Between Parents’ IPQ-R Subscales and Coping Variables at T1 (n=61)*

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* * p<.05  ** * p<.01  *** * p<.001
### Table 19

*Pearson’s r Correlations Between Parents’ IPQ-R Subscales and Coping Variables at T2 (n=40)*

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* *p<.05  ** p<.01  *** p<.001*
Table 20

*Pearson’s r Correlations Between Parents’ IPQ-R Subscales at T1 and Coping Variables at T2 (n=36)*

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* p<.05  ** p<.01  *** p<.001
5.3.2.3 Relationships Between Patients’ Reports of Social Constraints with Their Parent and Patient Psychological Adjustment

Hypothesis 4 of the current study predicted that patient reports of social constraints with their parent would be associated with increased psychological distress and decreased psychological well-being. To evaluate this hypothesis, correlational analyses were conducted.

Cross-sectional results. The results of the correlational analyses between social constraints and patient adjustment indicators are shown in Table 21 (T1 results) and Table 22 (T2 results). At both T1 and T2, moderate to strong positive relationships were identified between social constraints and psychological distress indicators. As patient perceptions of social constraints with parents increased, patients’ reports of depression, anxiety and stress symptoms also increased. Further, at T1 social constraints were also found to be negatively related to patient measures of psychological well-being; again these were moderate to strong effects. These results indicated that when patient perceptions of social constraints increased, patients’ reports of sense of coherence and experience of positive affect decreased. At T2, however, these relationships were not significant.

Longitudinal results. Table 23 presents the results of the correlational analyses between social constraints and patients’ psychological outcomes over time. These analyses indicated that only 2 of the 5 significant relationships observed between the social constraints and patient outcomes observed at T1 were sustained over time. As stronger perceptions of social constraints were reported by patients at T1, the greater the patient distress reported at T2 on the anxiety and stress outcome measures. These were moderately strong relationships.
Table 21

Pearson’s r Correlations Between Patients’ Perceptions of Social Constraints with Their Parent and Patient Psychological Adjustment and Coping Measures at T1 (n=49)

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* p<.05   ** p<.01   *** p<.001

Table 22

Pearson’s r Correlations Between Patients’ Perceptions of Social Constraints with Their Parent and Patient Psychological Adjustment and Coping Measures at T2 (n=36)

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* p<.05   ** p<.01   *** p<.001
Table 23

*Pearson’s r Correlations Between Patients’ Perceptions of Social Constraints with Their Parent at T1 and Patient Psychological Adjustment at T2 and Coping Measures at T1 (n=31)*

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* p<.05   ** p<.01   *** p<.001

5.3.2.4 Relationships Between Illness Representations and Psychological Adjustment for Patients and Parents

In addition to social constraints being predicted to correlate with patient outcomes, patients’ cognitive representations of their illness were also predicted in Hypothesis 5 to be related to their psychological adjustment. Additionally, Hypothesis 6 also predicted that parents’ illness representations of CF would be related to their psychological adjustment. Again, correlational analyses were conducted to test these hypotheses.

*Cross-sectional results.* The results of the correlational analyses between patients’ illness perceptions and adjustment indicators are shown in Tables 25 (T1 results) and 26 (T2 results) and the results of these analyses for parents are reported in Tables 28 (T1 results) and 29 (T2 results). At T1, no significant relationships were obtained between illness perceptions and depression, however, at T2, three domains of IPQ-R were significantly related to patient reports of depression. As patients perceived more physical symptoms both related to CF and those experienced generally, patients reported more symptoms of depression. Additionally, the more distress related to CF reported by patients, the greater their reports of depressive symptoms.
Regarding patient reports of anxiety, at both T1 and T2, significant relationships were noted in the IPQ-R domains of general symptoms experienced and emotional representations of CF. As patients perceived more general physical symptoms and reported more distress related to CF, patient reports of anxiety also increased. Additionally, significant relationships between anxiety and both consequences of CF and illness coherence were noted for patients at T1, where more symptoms of anxiety were reported when more consequences of CF were perceived and CF was less well understood. Further, a significant relationship between symptoms related to CF and anxiety was noted for patients at T2, where more symptoms of anxiety were reported when more symptoms related to CF were perceived.

Regarding the final DASS subscale, stress, significant relationships were noted for the domains of general symptoms perceived and emotional representations for patients at both T1 and T2. Additionally, patients’ perceptions of symptoms of CF were found to be related to stress symptoms at T2. These results for the stress subscale of the DASS indicated that as more symptoms were perceived by patients, generally or specifically related to CF, and more distress stemming from CF was reported, patients’ reports of the experience of symptoms of stress also increased. Regarding the effect sizes of the relationships between stress and significant illness perception correlates, and those for depression and anxiety, all relationships observed were in the moderately strong range.

Significant relationships between illness perceptions and measures of psychological well-being were also noted at T1 and T2 for patients. At both T1 and T2, patient reports of general symptoms experienced, experience of symptoms related to CF and emotional representations of CF had significant negative associations with patient reports of positive affect. As patients reported more symptoms, both general and those specifically related to CF, and greater distress related to CF, patients’ reported experience of positive affect decreased. In addition to these relationships, at T1 only, a significant positive relationship was obtained between patients’ reports of illness coherence and patients’ reported positive affect. This relationship demonstrated that as patients’ reported understanding of CF increased, the experience of positive affect also increased. All significant relationships including positive affect were in the moderately strong range.

The final measure of patient adjustment, sense of coherence, was also found to have a number of significant relationships with illness perceptions. Resembling the results obtained for patients’ reported positive affect, at T1, as patients reported more symptoms, both general and those specifically related to CF, and greater distress related
to CF, patients’ reported experiences of sense of coherence decreased. At T2, however, only one of these relationships was found to be significant; that being the negative association between emotional representations and sense of coherence. All significant relationships obtained were in the moderately-strong range. No other significant associations between patients’ sense of coherence and illness perceptions were obtained at T2.

For parents, fewer significant relationships between illness perceptions and adjustment were obtained at T1 and T2 than were obtained for patients. One consistent finding, however, was that parents’ emotional representations of CF were significantly related to all parent outcome measures at both T1 and T2. As parents’ reported distress related to CF increased, parents reported more symptoms of depression, anxiety, and stress, and less positive affect and a weaker sense of coherence. Illness coherence was also found to have three significant relationships with parent measures of adjustment, but these were only obtained at T1. At this time, as parents reported greater understanding of CF, their reports of stress symptoms decreased and reported sense of coherence increased.

As shown in Table 28, at T1, two other significant relationships between illness perceptions and adjustment were found, both pertaining to parents’ sense of coherence. As parents perceived their child experiencing fewer symptoms, both generally and specifically related to CF, parents’ reported sense of coherence strengthened. At T2 (Table 29), four other significant relationships were also obtained between illness perceptions and parents’ adjustment in addition to those observed between emotional representations and illness coherence and outcomes. At this time, positive relationships were obtained between perceived consequences of CF and stress and personal control of CF and sense of coherence. Additionally, the perceived cyclical nature of CF was found to be negatively related to parent reports of positive affect and sense of coherence. Regarding the interpretation of these relationships, as parents perceived more consequences stemming from their child’s CF, they also reported a high number of stress symptoms. Secondly, as parents perceived their child having a high level of control over their CF, stronger sense of coherence was also reported. Finally, as parents perceived CF to be less cyclical in nature, parents reported more positive affect and a strong sense of coherence. For all the significant cross-sectional relationships between illness perceptions and adjustment for parents, moderate sized effects were obtained.

**Impact of control variables on parents’ cross-sectional results.** As discussed in section 5.3.1.5, parents’ work status at T1 was found to be significantly correlated to
parents’ sense of coherence at both T1 and T2 and parents’ stress ratings at T2. Additionally, parents’ trauma status was found to impact parents’ stress ratings at T2 only. Thus, for significant relationships between illness perception domain and sense of coherence at both T1 and T2, multiple regression analyses were conducted with work status and the illness perception domain added as predictors in a single step and sense of coherence entered as the criterion variable. Multiple regression analyses were also conducted to control for the effects of trauma status and work status on parents’ stress ratings at T2. In these analyses, both control measures and illness perception domain were entered in a single step as predictor variables, and stress entered as the criterion variable. As work status and trauma status were categorical variables, these variables were dummy coded before being included in analyses.

For all regression analyses conducted, the assumptions of linearity and homoscedasticity were evaluated, and distance, leverage, and Cook’s distance values were examined for extreme scores. In all regressions, all assumptions and values, excluding distance, were met or in the acceptable range. For stress, two patients had very high distress scores and for sense of coherence, one patient had a very low score. These scores were identified at both T1 and T2. Further, when analyses were run without these scores, significant changes were noted in variance accounted for by the regression model. As the majority of the patients were well functioning, it was considered that these patients with extreme scores represented a different population and, thus, the results from the analyses with these patients excluded are reported here.

Regarding the impact of work status on the relationship between parents’ perceptions of their child’s experience of general symptoms and sense of coherence at T1, the overall regression model accounted for a large and significant portion of variance in sense of coherence ($R^2 = .32$ ($R^2_{adj} = .30$), $F(2,57) = 13.69, p < .0001$). In this model, both perceived symptoms ($\beta = -.27, p = .017$) and work status ($\beta = -.50, p < .0001$) accounted for significant variance in parents’ ratings of sense of coherence. Similarly, regarding the impact of work status on the relationship between parents’ perceptions of their child’s experience of CF-related symptoms and sense of coherence at T1, the overall regression model accounted for a large, significant portion of variance in sense of coherence ($R^2 = .30$ ($R^2_{adj} = .28$), $F(2,57) = 12.16, p < .0001$). In this model, perceived CF-related symptoms ($\beta = -.21, p = .059$) accounted for a marginally significant percentage of variance in sense of coherence. Again, work status ($\beta = -.50, p < .0001$) accounted for significant variance in parents’ ratings of sense of coherence.
In the analysis of the impact of work status on the relationship between parents’ perceptions of CF being cyclical and sense of coherence at T1, the overall regression model accounted for a large and significant percentage of the variance in sense of coherence ($R^2 = .30$ ($R^2_{adj} = .27$), $F(2,57) = 11.94, p < .0001$). However, while the control measure of work status ($\beta = -.46, p < .0001$) significantly contributed to the variance accounted for, perceptions of CF being cyclical ($\beta = -.21, p = .07$) did not. Similar to these results, when the impact of work status on the relationships between parents’ understanding of CF and sense of coherence at T1 was tested, the overall model accounted for a large and significant percentage of variance in sense of coherence ($R^2 = .25$ ($R^2_{adj} = .22$), $F(2,56) = 9.28, p < .0001$). Yet only work status ($\beta = -.47, p < .0001$) significantly accounted for variance independently, unlike illness coherence ($\beta = .18, p = .119$). Regarding the impact of work status on the relationship between parents’ emotional representations and sense of coherence at T1, the overall regression model accounted for a large and significant portion of variance in sense of coherence ($R^2 = .40$ ($R^2_{adj} = .38$), $F(2,57) = 11.94, p < .0001$). In this model, both emotional representations ($\beta = -.39, p = .001$) and work status ($\beta = -.41, p < .0001$) accounted for significant variance in parents’ ratings of sense of coherence.

Regarding the analyses conducted to examine the impact of work status on the relationships between the three illness perception domains and parents’ sense of coherence at T2, all models tested accounted for a large and significant percentage of variance in sense of coherence. Further, all individual predictors within these models individually accounted for significant variance in parents’ sense of coherence ratings. The regression coefficients and significance values for these analyses are presented in Table 24.

Regarding the examination of the impact of work status and trauma status on the relationship between parents’ perceived consequences of CF and stress at T2; while the overall variance in stress accounted for by the model was large and significant ($R^2 = .53$ ($R^2_{adj} = .48$); $F(3,31) = 11.74, p < .0001$); perceived consequences ($\beta = .24, p = .07$) did not significantly contribute to the variance accounted for when entered with work status ($\beta = .42, p = .003$) and trauma status ($\beta = .40, p = .004$), which were both significant predictors. In the analysis of the impact of work status and trauma status on the relationship between parents’ emotional representations of CF and stress at T2, the overall model also accounted for significant variance in stress ($R^2 = .57$ ($R^2_{adj} = .52$); $F(3,31) = 13.45, p < .0001$), being a large effect. In this model, both the control measures (work status, $\beta = .41, p = .002$, and trauma status, $\beta = .42, p = .002$), and
emotional representations ($\beta = .30, p = .018$) significantly contributed to the variance accounted for in stress.

Table 24

Regression Coefficients for the Analyses of the Impact of Parents’ Work Status on Relationships Between Illness Perception Domains and Sense of Coherence at T2

<table>
<thead>
<tr>
<th>Analysis</th>
<th>$R^2$ ($R^2_{adj}$)</th>
<th>$F$</th>
<th>$\beta$</th>
<th>$p$</th>
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<tr>
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<td>.51 (.47)</td>
<td>$F(2,32) = 16.29, p &lt; .0001$</td>
<td>.37</td>
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<td>Personal control</td>
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<td>Work Status</td>
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<td></td>
<td>-.64</td>
<td>&lt;.0001</td>
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<tr>
<td>Analysis 2</td>
<td>.47 (.43)</td>
<td>$F(2,33) = 14.40, p &lt; .0001$</td>
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<td>.003</td>
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<td></td>
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<tr>
<td>Work Status</td>
<td></td>
<td></td>
<td>-.42</td>
<td>.002</td>
</tr>
<tr>
<td>Analysis 3</td>
<td>.44 (.41)</td>
<td>$F(2,32) = 13.03, p &lt; .0001$</td>
<td>-.37</td>
<td>.010</td>
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<td>Emotional representations</td>
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<td></td>
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<tr>
<td>Work Status</td>
<td></td>
<td></td>
<td>-.45</td>
<td>.002</td>
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</table>

Longitudinal results. The relationships between illness perceptions and adjustment indicators for patients and parents are presented in Tables 27 and 30. For patients, two IPQ-R domains were found to have a significant relationship with outcomes from T2. Firstly, the number of general symptoms experienced at T1 was associated with 4 of the 5 outcome measures at T2; with all relationships obtained being moderately-strong. As patients perceived more symptoms at the first wave of data collection, more symptoms of depression, anxiety and stress, and a weakened sense of coherence was reported at follow-up. Additionally, patients’ perceived control over CF at T1 was positively related to patients’ sense of coherence at T2; where perceiving a greater degree of personal control over CF was associated with greater sense of coherence over time.

For parents, three significant relationships between illness perceptions and adjustment were obtained within the longitudinal analyses. Firstly, parents’ emotional representations of CF were related to reports of depressive and stress symptoms; with greater levels of distress related to their child’s CF at T1 being associated with parents
reporting an increased number of depressive and stress symptoms at T2. Additionally, parent reports of their child’s personal control over CF at T1 was positively related to parents’ sense of coherence at T2; where perceiving that their child had a greater degree of control over CF was associated with greater sense of coherence over time. Again, all significant relationships obtained were moderate sized effects.

As reviewed earlier in this section, the examination of control variables for parent analyses in section 5.3.1.5 identified that both work status from T1 and trauma status from T2 were significant correlates of parents’ stress levels at T2, and that work status from T1 was also a significant correlate of sense of coherence at T2. Thus, two regression analyses were run to examine the impact of these control variables on the longitudinal relationships between parents’ emotional representations of CF and stress ratings and parents’ perceptions of the child’s personal control over CF and sense of coherence ratings. Again, evaluation of the assumptions of regression identified two participants, one for each criterion variable, who reported extremely high distress/low well-being and were considered to represent a different population and removed from analyses. All other assumptions of the longitudinal regression analyses were met.

In the analysis of the impact of work status and trauma status on the relationship between parents’ emotional representations of CF at T1 and stress ratings at T2, the overall model also accounted for significant variance in stress ($R^2 = .52$ ($R^2_{adj} = .47$); $F(3,32) = 11.53, p < .0001$), being a large effect. Within the regression, both the control measures (work status at T1, $\beta = .35, p = .01$, and trauma status at T2, $\beta = .32, p = .02$), and emotional representations ($\beta = .35, p = .013$) significantly contributed to the variance accounted for in stress. Finally, in the analysis of the impact of work status on the relationship between parents’ perceptions of their child’s personal control over CF at T1 and stress at T2, the overall model also accounted for significant variance in stress ($R^2 = .47$ ($R^2_{adj} = .44$); $F(3,33) = 14.48, p < .0001$), being a large effect. In this model, both work status ($\beta = -.60, p < .0001$) and perceptions of child’s personal control over CF ($\beta = .39, p = .004$) significantly contributed to the variance accounted for in stress.
Table 25

Pearson’s $r$ Correlations Between Patients’ IPQ-R Subscales and Psychological Adjustment Measures at T1 (n=49)

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* $p<.05$  ** $p<.01$  *** $p<.001$
Table 26

Pearson’s r Correlations Between Patients’ IPQ-R Subscales and Psychological Adjustment Measures at T2 (n=36)

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* p<.05  ** p<.01  *** p<.001
Table 27

*Pearson’s r Correlations Between Patients’ IPQ-R Subscales at T1 and Psychological Adjustment Measures at T2 (n=31)*

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*p<.05   **p<.01   ***p<.001
Table 28

**Pearson’s r Correlations Between Parents’ IPQ-R Subscales and Psychological Adjustment Measures at T1 (n=61)**

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*p<.05   **p<.01   ***p<.001
Table 29

*Pearson’s r Correlations Between Parents’ IPQ-R Subscales and Psychological Adjustment Measures at T2 (n=40)*

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*p<.05  **p<.01  ***p<.001*
Table 30

*Pearson’s r Correlations Between Parents’ IPQ-R Subscales at T1 and Psychological Adjustment Measures at T2 (n=36)*

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*p<.05   **p<.01   ***p<.001
5.3.2.5  Relationships Between Coping Strategies and Psychological Adjustment for Patients and Parents

Hypothesis 7 of the current study predicted that patients’ use of avoidant coping would be associated with increased distress and decreased psychological well-being. As stated in Hypothesis 8, these relationships were also predicted for parents. As discussed previously, a measure of avoidant coping was not obtained from reduction analyses using patient and parent Brief COPE data. Thus, exploratory correlational analyses were conducted between patients’ adjustment measures and the independent and other-oriented coping measures obtained for patients, and between parent adjustment measures and the change-oriented and management-oriented coping measures obtained for parents.

*Cross-sectional results.* The results of the correlational analyses conducted between patient outcomes, independent coping and other-oriented coping are presented in Table 21 (T1 results) and Table 22 (T2 results). At both T1 and T2, reports of independent and other-oriented coping were each related to only one domain of patient adjustment. Accordingly, at both T1 and T2, patients’ experience of greater number of stress symptoms was associated with more frequent use of an other-oriented coping style. Additionally, patients’ experience of a high level of positive affect was associated with more frequent use of an independent coping style. These relationships represented moderately-strong sized effects. Contrary to the results obtained for patients, cross-sectional analyses examining the relationships between parents’ coping style and psychological functioning at T1 and T2 did not obtain any significant results. These results are displayed in Tables 31 and 32.

*Longitudinal results.* The results of the longitudinal analysis of the relationships between coping style and psychological adjustment for patients and parents are displayed in Tables 23 and 33, respectively. The pattern of results obtained for both the patient and parent data replicated those obtained in the cross-sectional analyses. For patients, more frequent use of an independent coping style at T1 was associated with greater positive affect being reported at T2. Secondly, patients’ use of other-oriented coping at T1 was associated with a greater number of stress symptoms being reported at T2. The effect sizes for significant relationships between both coping styles and outcomes were in the moderately-strong range. For parents, no significant relationships between coping style at T1 and adjustment at T2 were obtained.
Table 31

*Pearson’s r* Correlations Between Parents’ Psychological Adjustment and Coping

*Measures at T1 (n=61)*

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* p<.05  ** p<.01  *** p<.001

Table 32

*Pearson’s r* Correlations Between Parents’ Psychological Adjustment and Coping

*Measures at T2 (n=40)*

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<td>7. Management-oriented Coping</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

* p<.05  ** p<.01  *** p<.001
Table 33

Pearson’s r Correlations Between Parents’ Psychological Adjustment at T2 and Coping Measures at TI (n=36)

<table>
<thead>
<tr>
<th></th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>6.</th>
<th>7.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. DASS-Depression T2</td>
<td>1.00</td>
<td>.77***</td>
<td>.79***</td>
<td>-.59***</td>
<td>-.64***</td>
<td>.13</td>
<td>.24</td>
</tr>
<tr>
<td>2. DASS-Anxiety T2</td>
<td>1.00</td>
<td>.79***</td>
<td>-.50**</td>
<td>-.57***</td>
<td>.09</td>
<td>.16</td>
<td></td>
</tr>
<tr>
<td>3. DASS-Stress T2</td>
<td>1.00</td>
<td>.50**</td>
<td>.55**</td>
<td>-.06</td>
<td>.14</td>
<td>.15</td>
<td></td>
</tr>
<tr>
<td>4. PANAS-Positive Affect T2</td>
<td>1.00</td>
<td>.67***</td>
<td>.18</td>
<td>-.02</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Sense of Coherence T2</td>
<td>1.00</td>
<td>-.06</td>
<td>-.14</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Change-oriented Coping T1</td>
<td>1.00</td>
<td>.45**</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>7. Management-oriented Coping T1</td>
<td>1.00</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

* p<.05  ** p<.01  *** p<.001

5.3.2.6 Differences Between Patient-Parent Dyads with Mutually Positive, Mutually Negative, and Discrepant Illness Perceptions of CF on Measures of Patient Reports of Social Constraints and Psychological Adjustment

Hypotheses 9 and 10 of the current study predicted that patients in parent-child dyads with mutually negative perceptions of CF and patients in dyads with discrepant illness perceptions of CF, respectively, would report greater social constraints, increased psychological distress, and reduced psychological well-being than patients in dyads with mutually positive illness perceptions of CF. Analyses of variance using the categorical dyadic illness representations variable as an independent variable (discussed in section 5.3.1.4) and patient adjustment measures as dependent variables were used to evaluate parts b. to f. (patient adjustment measures) of the hypotheses at T1 and T2, and for part a. (social constraints) at T2 (see p. 90). For analyses examining the effect of dyadic illness representations group on social constraints, role functioning needed to be included as a control measure for analyses with the T1 data (as per discussion in 5.3.1.5). Thus, ANCOVA was used for these analyses with role functioning included as a covariate.

In the evaluation of the assumptions of the ANOVAs and ANCOVAs, it was noted that two patients reported extreme distress on a number of the outcome measures
at both T1 and T2, and, accordingly, this increased the skew scores observed for the dyadic illness representation groups they belonged to. As the vast majority of the patients in the current sample were functioning relatively well, it was considered that the individuals with extreme scores represented a different population and were removed from analyses where relevant. This action substantially improved normality for all affected groups. Additionally, violations of the homogeneity of variance assumption were noted for a small percentage of the analyses run. To reduce the impact of the inconsistent variance across dyad illness representation groups in affected analyses, a more conservative $p$-value of .025 was used to evaluate the significance of effects (Keppel, 1991). Specific to ANCOVA, the assumptions of linearity and homogeneity of the regression slopes were met in all cases.

**Cross-sectional results.** At both T1 and T2, the impact of group on all six patient outcomes (i.e., social constraints, depression, anxiety, stress, positive affect, and sense of coherence) was examined for each IPQ-R domain. Regarding the effect of group on social constraints, a significant effect was only identified for one domain of illness perceptions at T1; that domain being symptoms experienced, $F(3,37) = 3.53, p = .024, \omega^2 = .20$, with a large effect of group on social constraints obtained. Role functioning was also a significant covariate in this model, $F(3,37) = 7.09, p = .01, \omega^2 = .07$, having a moderate sized effect on social constraints. Thus, group descriptive statistics are reported with adjustments for effect of role functioning at $M = 75.79$.

Patients in the group with mutually negative patient-parent perceptions of general symptoms experienced by the patient ($M = 24.70, SD = 1.89, SE = 1.26$) reported significantly higher social constraints than patients in the group with mutually positive perceptions of patients’ experience of symptoms ($M = 18.60, SD = 8.80, SE = 1.51$), $p = .034, d = .95$, being a large difference of nearly one standard deviation unit between groups; yet the mutually negative group did not differ to the patient-positive-parent-negative group ($M = 18.12, SD = 4.55, SE = 2.26$) or the patient-negative-parent-positive group ($M = 19.42, SD = 3.27, SE = 2.06$). No other significant group differences were obtained. Additionally, no significant effects of group on social constraints were found for any illness perception domain at T2.

Regarding the effect of group on patients’ depression rating at T1, no significant effects were found for any illness representation domain. At T2, a significant effect was only identified for one domain of illness perceptions; being symptoms experienced, $F(3,23) = 4.01, p = .02, \omega^2 = .28$, with a large effect of group on depression obtained. Patients in the group with mutually negative patient-parent perceptions of general
symptoms experienced by the patient \((M = 10.00, SD = 2.75, SE = 1.36)\) reported
significantly more symptoms of depression than patients in the group with mutually
positive perceptions of patients’ experience of symptoms \((M = 2.18, SD = 2.75, SE =
1.36)\), \(p = .023, d = 1.21\), being a large difference of over one standard deviation unit
between groups; yet the mutually negative group did not differ to the patient-positive-
parent-negative group \((M = 3.00, SD = 2.58, SE = 2.26)\) or the patient-negative-parent-
positive group \((M = 6.57, SD = 3.41, SE = 1.71)\). No other significant group differences
were obtained.

Examining the results for the effects of group on patients’ anxiety ratings at T1,
a significant effect was only identified for two domains of illness perceptions;
symptoms experienced \((F(3,37) = 7.16, p = .001, \omega^2 = .33)\) and illness coherence
\((F(3,37) = 6.04, p = .002, \omega^2 = .26)\). Both effects of group on anxiety were large.
Regarding the results for the symptoms experienced domain, patients in the group with
mutually negative perceptions of general symptoms experienced by the patient \((M =
7.83, SD = 2.65, SE = 0.82)\) reported significantly more symptoms of anxiety than the
mutually positive group \((M = 2.22, SD = 5.01, SE = 1.00)\) \((p = .001, d = 1.40)\) and the
patient-negative-parent-positive group \((M = 2.33, SD = 2.34, SE = 1.41)\) \((p = .012, d =
1.41)\), but not the patient-positive-parent-negative group \((M = 2.80, SD = 2.28, SE =
1.55)\). The effect sizes of the two significant effects were large, approaching differences
of nearly one and a half standard deviation units between groups. No other significant
group differences were identified. Similarly, the group differences for the illness
coherence domain indicated that patients in the group with mutually negative illness
coherence perceptions of CF \((M = 7.50, SD = 5.27, SE = 1.03)\) reported significantly
more symptoms of anxiety than the mutually positive group \((M = 1.64, SD = 2.50, SE =
1.08)\) \((p = .002, d = 1.42)\) and the patient-negative-parent-positive group \((M = 2.60, SD =
2.50, SE = 1.26)\) \((p = .016, d = 1.19)\), but not the patient-positive-parent-negative
group \((M = 3.50, SD = 2.56, SE = 1.13)\). The effect sizes of the two significant effects
were large, both representing differences of over one standard deviation unit between
groups. Contrary to the results obtained at T1, no significant effects of group on anxiety
were found for any illness perception domain at T2.

Converse to the results obtained for anxiety, in the analysis of the effect of group
on patients’ stress ratings, no significant effects for any illness perceptions domain were
obtained at T1, and only one significant effect was obtained at T2. At this time, a large
significant effect of group on stress was obtained in the symptoms experienced illness
perception domain, \((F(3,23) = 4.35, p = .014, \omega^2 = .30)\). Patients in the group with
mutually negative patient-parent perceptions of general symptoms experienced by the patient (\(M = 16.80, SD = 5.40, SE = 2.68\)) reported significantly more symptoms of stress than patients in the group with mutually positive perceptions of patients’ experience of symptoms (\(M = 5.27, SD = 5.08, SE = 1.81\), \(p = .010, d = 2.20\)), being a large difference of over two standard deviation units between groups; yet the mutually negative group did not differ to the patient-positive-parent-negative group (\(M = 7.00, SD = 10.13, SE = 3.00\)) or the patient-negative-parent-positive group (\(M = 8.86, SD = 4.88, SE = 2.27\)). No other significant group differences were obtained.

Regarding the effect of group on patients’ reports of positive affect, significant effects were found in three illness perception domains at T1 and one illness perception domain at T2. At T1, large significant effects of group on positive affect were found within the symptoms experienced (\(F(3,39) = 6.93, p = .001, \omega^2 = .31\)), illness coherence (\(F(3,39) = 4.21, p = .011, \omega^2 = .20\)) and emotional representation (\(F(3,39) = 4.62, p = .007, \omega^2 = .22\)) domains. At T2, a large significant effect of group on positive affect was also found in the emotional representation domain (\(F(3,26) = 7.22, p = .001, \omega^2 = .40\)).

In both the symptoms experienced (\(p = .002, d = 1.41\)) and illness coherence domains (\(p = .008, d = 1.46\)) at T1, patients in the mutually positive groups reported more positive affect than patients in the mutually negative groups. Additionally, in the symptoms experienced domain, patients in the patient-positive parent-negative group reported more positive affect than patients in the mutually negative groups (\(p = .006, d = 1.78\)). Further, in the emotional representations domain, patients in the patient-positive-parent-negative group reported more positive affect than patients in the mutually negative group (\(p = .06, d = 1.02\)). Descriptive statistics for these analyses are displayed in Table 34. No other significant group differences were obtained at T1.

Finally, in the emotional representations domain at T2, patients in the patient-positive-parent-negative group (\(M = 39.75, SD = 6.29, SE = 2.43\)) reported more positive affect than patients in the mutually negative (\(M = 27.82, SD = 6.37, SE = 1.47\)) (\(p = .014, d = 2.12\)) and mutually positive (\(M = 29.89, SD = 1.96, SE = 1.62\)) groups (\(p = .002, d = 1.88\)), but not the patient-negative-parent-positive group (\(M = 34.83, SD = 3.43, SE = 1.98\)). No other significant differences were obtained. It is noted that all significant group differences in positive affect ratings at T1 and T2 were large effects of over one standard deviation unit differences between groups.
Table 34

Descriptive Statistics for Illness Perception Discrepancy Groups for IPQ-R Domains

Obtaining Significant Effects of Group on Patients' Reports of Positive Affect at T1

<table>
<thead>
<tr>
<th>IPQ-R domain</th>
<th>Similar +*</th>
<th>Similar –*</th>
<th>Patient + Parent –</th>
<th>Patient – Parent +</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><em>M</em>   <em>SD</em> <em>SE</em></td>
<td><em>M</em>   <em>SD</em> <em>SE</em></td>
<td><em>M</em>   <em>SD</em> <em>SE</em></td>
<td><em>M</em>   <em>SD</em> <em>SE</em></td>
</tr>
<tr>
<td>Symptoms Experienced:</td>
<td>36.28    7.37  1.67</td>
<td>26.14    6.97  1.89</td>
<td>39.20    7.66  3.17</td>
<td>32.67    5.75  2.89</td>
</tr>
<tr>
<td>Illness Coherence:</td>
<td>37.82    6.98  2.30</td>
<td>26.75    8.10  2.20</td>
<td>33.89    5.95  2.54</td>
<td>33.55    8.79  2.30</td>
</tr>
<tr>
<td>Emotional Representations:</td>
<td>34.58    8.30  2.17</td>
<td>26.25    7.40  2.17</td>
<td>34.36    7.35  2.27</td>
<td>37.88    8.45  2.66</td>
</tr>
</tbody>
</table>

* (+) = positive perception; (-) = negative perception

Examining the effect of group on patients’ sense of coherence ratings at T1, large significant effects were obtained in both the symptoms experienced ($F(3,40) = 6.03, p = .002, \omega^2 = .27$) and emotional representation ($F(3,40) = 4.50, p = .008, \omega^2 = .21$) domains. Additionally, at T2, a large significant effect of group on sense of coherence was also obtained in the emotional representation domain ($F(3,26) = 4.19, p = .015, \omega^2 = .26$). For both the symptoms experienced and emotional representation domains at T1, patients in the mutually negative group reported significantly lower sense of coherence than patients in the mutually positive ($p = .003, d = 1.43^a$ and $p = .044, d = 1.34^b$), patient-positive-parent-negative ($p = .042, d = 1.17^a$ and $p = .022, d = 1.21^b$), and patient-negative-patient-positive groups ($p = .035, d = 1.40^a$ and $p = .035, d = 1.41^b$). No other significant group differences were found in either domain. Finally, for the emotional representations domain at T2, only one group difference approached significance; where patients in the mutually positive group reported a stronger sense of coherence than patients in the patient-negative-parent-positive group ($p = .085, d = 1.36$). All significant group differences in positive affect ratings at T1 and T2 were large effects of over one standard deviation unit differences between groups. Descriptive statistics for these effects are reported in Table 35.
Table 35

Descriptive Statistics for Illness Perception Discrepancy Groups for IPQ-R Domains

Obtaining Significant Effects of Group on Patients’ Reports of Sense of Coherence at T1 and T2

<table>
<thead>
<tr>
<th>IPQ-R domain</th>
<th>Similar +*</th>
<th>Similar –*</th>
<th>Patient + Parent –</th>
<th>Patient – Parent +</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>SE</td>
<td>M</td>
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<tr>
<td>Time 1</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptoms Experienced</td>
<td>64.00</td>
<td>9.10</td>
<td>2.09</td>
<td>51.93</td>
</tr>
<tr>
<td>Emotional Representations</td>
<td>62.83</td>
<td>9.15</td>
<td>2.73</td>
<td>51.92</td>
</tr>
<tr>
<td>Time 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional Representations</td>
<td>71.33</td>
<td>10.39</td>
<td>3.61</td>
<td>59.73</td>
</tr>
</tbody>
</table>

* (+) = positive perception; (-) = negative perception

Revision of cross-sectional analyses. After completion of these cross-sectional analyses it was noted that it was only within a few illness perception domains that the patient-parent discrepancy group had a significant effect on each of the patient outcome measures. Thus, it was considered that illness perception similarity between patients and parents may have a more cumulative effect on patient outcomes, whereby patients who shared mutually positive illness perceptions with their parent across a number of illness perception domains may report significantly better adjustment than patients in dyads who shared mutually negative illness perceptions with their parent and those who had discrepant patient-parent illness perceptions across a number of domains.

Accordingly, patients’ illness perception discrepancy data was recoded where patients were assigned to one group which represented their similarity to their parent’s perceptions across a number of domains. The criteria set for recoding was that patients needed to have the same illness discrepancy group assignment across at least 4 of the 8 illness perception domains to be assigned to their predominant group. For example if a patient held mutually positive illness perceptions with their parents in four or more illness perception domains then they would be assigned to the ‘overall similar positive’
patient-parent illness perception group. The same procedure was followed when assigning participants to the ‘overall similar negative’, ‘overall patient-positive-parent-negative’, and ‘overall patient-negative-parent-positive’ groups. For patients who did not have a consistent discrepancy group affiliation over the eight illness perception domains, they were assigned to the ‘overall mixed’ group.

When assigning participants to one of the five overall illness perception discrepancy groups, it was noted that few patients were consistently affiliated with the patient-positive-parent-negative group or the patient-negative-parent-positive group across the eight illness perception domains at either T1 or T2. Further, few patients were assigned to the overall mixed group at either time. Thus, the overall patient-positive-parent-negative, overall patient-negative-parent-positive, and overall mixed groups were collapsed into a ‘discrepant/mixed’ group.

At the end of the recoding procedure for the T1 data, 12 patients were assigned to each of the overall similar positive and overall similar negative patient-parent illness perception groups, and 16 patients were assigned to the discrepant/mixed patient-parent illness perception group. For the patients retained at T2, 10 were assigned to each of the three patient-parent illness perception groups. To evaluate group differences on each of the six patient outcomes, ANOVA was again utilised for all analyses expect for the analysis of the effect of group on social constraints at T1. Again, as role functioning needed to be included as a control variable in this analysis, ANCOVA was utilised. Regarding the assumptions for these analyses, as noted earlier, patients with extreme distress scores were excluded from analyses, and in analyses where homogeneity of variance was violated, an adjusted $p$-value of .025 was utilised. Finally, all assumptions specific to ANCOVA were met.

Examining the effect of cumulative patient-parent illness perceptions group on patients’ social constraints ratings at T1, group was found to have a large significant effect, $F(2,36) = 6.19 = p = .005$, $\omega^2 = .16$. Role functioning was also a significant covariate in this model, $F(1,36) = 4.94$, $p = .033$, $\omega^2 = .04$, having a small sized effect on social constraints. Thus, group descriptive statistics are reported with adjustments for effect of role functioning at $M = 75.63$. Patients in the mutually negative dyadic representations group ($M = 26.68$, $SD = 9.68$, $SE = 1.75$) reported significantly more social constraints than the mutually positive ($M = 18.75$, $SD = 3.38$, $SE = 1.69$) ($p = .011$, $d = 1.09$) and the discrepant/mixed dyadic representations group ($M = 19.37$, $SD = 3.19$, $SE = 1.42$) ($p = .009$, $d = 1.01$), who did not significantly differ. The effect sizes obtained for the group differences were large, being just over a one standard deviation
unit difference between the groups for each effect. Regarding the effect of group on patients’ social constraints ratings at T2, group did not have a significant effect, $F(2,27) = .27, p = .766$.

Regarding the effect of cumulative patient-parent illness perceptions group on patients’ depressive symptoms ratings at T1 ($F(2,35) = 2.54, p = .094$) and T2 ($F(2,27) = 2.25, p = .125$), and that on patients’ stress symptoms ratings T1 ($F(2,36) = 1.27, p = .294$) and T2 ($F(2,27) = 2.97, p = .068$), group did not have a significant effect on either outcome at either time. However, regarding the effect of cumulative patient-parent illness perceptions group on patients’ anxiety ratings, a large significant effect was found at T1, $F(2,36) = 7.53, p = .002, \omega^2 = .25$. Patients in the mutually negative group ($M = 8.18, SD = 5.17, SE = 1.18$) reported significantly more symptoms of anxiety than patients in the mutually positive ($M = 3.33, SD = 4.54, SE = 1.13$) ($p = .015, d = 1.00$) and the discrepant/mixed dyadic representations group ($M = 2.50, SD = 1.86, SE = .94$) ($p = .002, d = 1.46$), who did not significantly differ. The effect sizes obtained for the group differences were large, being a one standard deviation unit between the mutually positive and mutually negative groups, and nearly a one and a half standard deviation unit difference between the mutually negative and the discrepant/mixed groups. Yet, at T2, the effect of group on patients’ anxiety ratings was not significant, $F(2,27) = 2.08, p = .144$.

Examinining the effect of cumulative patient-parent illness perceptions group on patients’ ratings of positive affect, a large significant effect was found at T1, $F(2,36) = 4.94, p = .013, \omega^2 = .17$. Patients in the mutually negative group ($M = 27.08, SD = 8.45, SE = 2.27$) reported significantly less positive affect than patients in the mutually positive ($M = 36.46, SD = 7.54, SE = 2.37$) ($p = .021, d = 1.17$) and the discrepant/mixed dyadic representations group ($M = 34.94, SD = 7.63, SE = 1.97$) ($p = .039, d = 0.98$), who did not significantly differ. The effect sizes obtained for the group differences were large, being around a one standard deviation unit difference between the groups for each effect. At T2, however, the effect of group on patients’ anxiety ratings was not significant, $F(2,27) = 1.51, p = .10$.

Contrary to the results obtained in the other patient outcome domains, cumulative patient-parent illness perceptions group was found to have a significant effect on patients’ ratings of sense of coherence at both T1 ($F(2,37) = 6.48, p = .004, \omega^2 = .22$) and T2 ($F(2,27) = 3.29, p = .053, \omega^2 = .13$). At T1, the effect size indicated this was a large effect of group on outcomes, whereas at T2, this effect was only moderately sized. The paired group differences at T1 indicated that patients in the mutually negative group ($M = 52.50, SD = 10.00, SE = 2.72$) reported a significantly lower sense of
coherence rating than patients in the mutually positive group \((M = 62.17, SD = 8.19, SE = 2.72)\) \((p = .05, d = 1.06)\) and those in the discrepant/mixed dyadic representations group \((M = 65.19, SD = 9.85, SE = 2.36)\) \((p = .003, d = 1.28)\), who did not significantly differ. At T2, patients in the mutually negative group \((M = 57.80, SD = 9.36, SE = 3.67)\) reported a significantly lower sense of coherence rating than patients in the mutually positive group \((M = 71.10, SD = 10.69, SE = 3.67)\) \((p = .049, d = 1.32)\), being a large effect of over one standard deviation unit difference between the groups. Patient ratings of sense of coherence in the discrepant/mixed group \((M = 64.60, SD = 14.19, SE = 3.67)\), however, did not significantly differ to patient ratings in either the mutually positive or mutually negative groups.

**Longitudinal results.** The impact of patient-parent illness discrepancy group assignment at T1 on all six patient outcomes from T2 (i.e., social constraints, depression, anxiety, stress, positive affect, and sense of coherence) was examined for each IPQ-R domain. In one illness perception domain, symptoms experienced, group at T1 was found to have a large significant effect on patients’ ratings of social constraints with their parent at T2, \(F(3,26) = 3.73, p = .023, \omega^2 = .24\). Patients in the group with mutually negative patient-parent perceptions of general symptoms experienced by the patient \((M = 25.60, SD = 7.44, SE = 1.73)\) reported significantly more symptoms of depression than patients in the group with mutually positive perceptions of patients’ experience of symptoms \((M = 18.36, SD = 4.03, SE = 1.51)\), \(p = .025, d = 1.39\), being a large difference approaching one and a half standard deviation units between groups; yet the mutually negative group did not differ to the patient-positive-parent-negative group \((M = 18.33, SD = 2.89, SE = 1.51)\) or the patient-negative-parent-positive group \((M = 19.25, SD = 4.65, SE = 2.73)\). No other significant group differences were obtained.

Regarding the effect of group at T1 on patients’ reported symptoms of depression at T2, in two illness perceptions domains, symptoms experienced \((F(3,23) = 5.34, p = .006, \omega^2 = .35)\) and symptoms related to CF \((F(3,23) = 3.90, p = .022, \omega^2 = .29)\), group was found to have a large significant effect on adjustment. Regarding the results for the symptoms experienced domain, patients in the group with mutually negative patient-parent perceptions of general symptoms experienced by the patient \((M = 8.44, SD = 4.67, SE = 1.22)\) reported significantly more symptoms of depression than patients in the group with mutually positive perceptions of patients’ experience of symptoms \((M = 3.00, SD = 3.36, SE = 1.06)\) \((p = .016, d = 1.61)\) and those in the patient-positive-parent-negative group \((M = 1.33, SD = 1.15, SE = 2.12)\) \((p = .047, d =
1.22), but not those in the patient-negative-parent-positive group \((M = 2.00, SD = 2.00, SE = 2.12)\). No other significant differences were obtained. All significant group differences represented large effects of over one standard deviation unit between groups.

Regarding the results for the symptoms related to CF domain, patients in the group with mutually negative patient-parent perceptions of symptoms experienced by the patient related to CF \((M = 7.60, SD = 5.15, SE = 1.23)\) reported significantly more symptoms of depression than patients in the group with mutually positive perceptions of patients’ experience of symptoms \((M = 2.00, SD = 2.68, SE = 1.17)\), \(p = .019, d = 1.36\), being a large difference approaching one and a half standard deviation units between groups. Yet the mutually negative group did not differ to the patient-positive-parent-negative group \((M = 5.33, SD = 4.16, SE = 2.25)\) or the patient-negative-parent-positive group \((M = 2.67, SD = 1.15, SE = 2.25)\). No other significant group differences were obtained. Finally, regarding the results of the effect of group from T1 on the remaining patient outcomes at T2 (i.e., anxiety, stress, positive affect, and sense of coherence) no significant effects were identified across any of the illness perception domains.

**Revision of longitudinal analyses.** Similar to the cross-sectional results, this set of longitudinal results also indicated that it was only within a few illness perception domains that patient-parent discrepancy grouping had a significant effect on each of the patient outcome measures. Thus, analyses examining the cumulative effect of patient-parent illness perception discrepancy grouping at T1 on patient outcomes at T2 were also conducted for the longitudinal patient data. Again, ANOVA was utilised for all analyses, and patients (two identified) with extreme distress scores were removed, as it was considered that they represented a different population. All other assumptions of ANOVA were met.

Examining the effect of cumulative patient-parent illness perceptions group at T1 on patients’ social constraints ratings at T2, group was found to have a large significant effect, \(F(2,23) = 4.49, p = .023, \omega^2 = .21\). Patients in the mutually negative dyadic representations group \((M = 26.11, SD = 7.83, SE = 1.85)\) reported significantly more social constraints than patients in the mutually positive group \((M = 18.57, SD = 4.58, SE = 2.10)\) \((p = .039, d = 1.17)\), being a large effect of over one standard deviation unit between the groups. Patient ratings of social constraints in the discrepant/mixed group \((M = 19.90, SD = 3.18, SE = 1.75)\), however, did not significantly differ to patient ratings in either the mutually positive or mutually negative groups.
Regarding the effect of cumulative patient-parent illness perceptions group at T1 on patients’ ratings of depressive symptoms at T2, group was found to have a large significant effect, $F(2,23) = 3.42, p = .05, \omega^2 = .16$. Patients in the mutually negative dyadic representations group ($M = 10.44, SD = 6.98, SE = 2.07$) reported significantly more symptoms of depression than patients in the discrepant/mixed group ($M = 3.00, SD = 6.79, SE = 2.00$) ($p = .047, d = 1.08$), being a large effect of just over one standard deviation unit between the groups. Patient ratings of depression symptoms in the mutually positive group ($M = 6.00, SD = 8.49, SE = 2.35$), however, did not significantly differ to patient ratings in either the mutually negative or discrepant/mixed groups.

Examining the effect of cumulative patient-parent illness perceptions group at T1 on patients’ ratings of anxiety symptoms at T2, group was found to have a large significant effect, $F(2,23) = 4.02, p = .032, \omega^2 = .19$. Patients in the mutually negative group ($M = 7.78, SD = 6.59, SE = 1.40$) reported significantly more anxiety symptoms than patients in the mutually positive group ($M = 2.00, SD = 1.63, SE = 1.58$) ($p = .035, d = 1.20$), being a large effect of over one standard deviation unit between the groups. Patient ratings of anxiety symptoms in the discrepant/mixed group ($M = 4.00, SD = 2.11, SE = 1.33$), however, did not significantly differ to patient ratings in either the mutually positive or mutually negative groups.

Contrary to the significant effect of group obtained on patients’ depression and anxiety ratings, the cumulative patient-parent illness perceptions group at T1 was not found to have a significant effect on patients’ ratings of stress at T2, $F(2,23) = 1.75, p = .196$. Further, regarding the effect of cumulative patient-parent illness perceptions group at T1 on measures of patient well-being, no significant effect of group on patient sense of coherence ratings was obtained, $F(2,23) = 2.62, p = .095$. Also, while a large significant effect of group on patient ratings of positive affect was observed, $F(2,23) = 3.60, p = .044, \omega^2 = .17$, the paired group differences indicated that none of the cumulative patient-parent illness perceptions groups differed at $p < .05$. The group difference which was closest to statistical significance was that between the mutually positive and mutually negative group at $p = .08$.

5.3.2.7 Relationships Between Sense of Coherence and Other Psychological Adjustment Measures for Patients and Parents

Hypotheses 11 and 12 of the current study pertain to the relationships between sense of coherence and measures of psychological distress and well-being, for patients and parents, respectively. It was predicted that negative relationships would be observed.
between sense of coherence and psychological distress, and positive relationships would be observed between sense of coherence and other measures of psychological well-being. To evaluate these hypotheses, correlational analyses were undertaken.

**Cross-sectional results.** The results of the correlational analyses between sense of coherence and other adjustment measures are presented in Tables 21 (T1 results) and 22 (T2 results) for the patient data, and Tables 31 (T1 results) and 32 (T2 results) for the parent data. All cross-sectional analyses for patients and parents indicated that sense of coherence was significantly associated with measures of both psychological distress and well-being, where reports of an individual experiencing few symptoms of depression, anxiety and stress, and frequently experiencing positive affect were associated with reports of a strong sense of coherence. The effect sizes indicated that the relationships obtained were in the moderate to strong range.

**Longitudinal results.** The results of the longitudinal analyses of the relationships between sense of coherence and other adjustment measures are presented in Table 36 for patients, and Table 37 for parents. As with the cross-sectional results, significant relationships were obtained between all parent adjustment measures obtained at T1 and parent reports of sense of coherence at T2. However, for patients, sense of coherence at T2 was only related to one outcome measure, stress, at T1. For both patients and parents, reporting few stress symptoms at T1 was associated with reports of a strong sense of coherence at T2. Additionally, as parents reported experiencing few symptoms of depression and anxiety and frequently experiencing positive affect at T1, parents reported strong sense of coherence at T2. The effect sizes indicated that the relationships obtained were in the moderate to strong range.

As parents’ sense of coherence rating at T2 was identified as a DV in the longitudinal analyses, and was found to be significantly correlated with all other parent adjustment measures from T1, a regression analysis with parents’ work status from T1 was conducted to examine the effect of this variable on these relationships. As discussed previously, work status from T1 was identified as a significant control measure to be included in parent analyses with sense of coherence ratings at T2. Evaluation of the assumptions of regression identified two participants who reported extremely low sense of coherence ratings and were considered to represent a different population and removed from analyses. All other assumptions for the longitudinal regression analyses were met (i.e., linearity, homoscedasticity, leverage evaluations, and Cook’s distance evaluations).
When parent ratings of depression, anxiety, stress, positivity and work status were entered in one step, overall, a large and significant percentage of variance in parents’ sense of coherence rating at T2 was accounted for, $R^2 = .60$ ($R^2_{adj} = .53$), $F(5,29) = 8.73, p < .0001$. Yet, of the predictor variables entered, only depression at T1 ($\beta = -.66, p = .032$) and positivity at T1 ($\beta = .32, p = .039$) independently accounted for significant variance in stress; anxiety ($\beta = -.05, p = .827$), stress, ($\beta = .15, p = .659$) and work status ($\beta = -.07, p = .663$) from T1 did not.

Table 36

Pearson’s r Correlations Between Patients’ Sense of Coherence at T2 and Other Psychological Adjustment Measures at T1 (n=31)

<table>
<thead>
<tr>
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<th>1.</th>
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</tr>
</thead>
<tbody>
<tr>
<td>1. DASS-Depression T1</td>
<td>1.00</td>
<td>.60***</td>
<td>.54**</td>
<td>-.70***</td>
<td>-.21</td>
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<tr>
<td>2. DASS-Anxiety T1</td>
<td>1.00</td>
<td>.66**</td>
<td>-.51**</td>
<td>-.33</td>
<td></td>
</tr>
<tr>
<td>3. DASS-Stress T1</td>
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<td>-.38*</td>
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<td></td>
</tr>
<tr>
<td>4. PANAS-Positive Affect T1</td>
<td>1.00</td>
<td>.15</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>5. Sense of Coherence T2</td>
<td>1.00</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

* $p<.05$  ** $p<.01$  *** $p<.001$

Table 37

Pearson’s r Correlations Between Parents’ Sense of Coherence at T2 and Other Psychological Adjustment Measures at T1 (n=36)

<table>
<thead>
<tr>
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<td>.78***</td>
<td>-.56***</td>
<td>-.59***</td>
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<td>2. DASS-Anxiety T1</td>
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<td>-.50**</td>
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<td>3. DASS-Stress T1</td>
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<td>-.61***</td>
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<td>4. PANAS-Positive Affect T1</td>
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<td>.50**</td>
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<tr>
<td>5. Sense of Coherence T2</td>
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</table>

* $p<.05$  ** $p<.01$  *** $p<.001$
5.3.2.8 Relationships within the Social Cognitive Processing Model – the Role of Intrusions and Avoidance

While no specific hypotheses were derived regarding the role of cognitive intrusions and avoidance in the social cognitive processing model for the adolescent and young adult CF population, it was a broader aim of the current study to investigate the role of these variables in the model both cross-sectionally and longitudinally, as discrepant analysis methods and results were identified in previous research. As discussed in Chapter 4, if the conditions for mediation analysis were met, hierarchical regression analyses would be utilised to examine whether patients’ experience of intrusions and avoidance mediate the relationships between patients’ perceptions of social constraints and patients’ psychological outcome measures. According to Baron and Kenny (1986), for a mediating relationship to be identified there must be significant relationships between i) the independent variable and mediating variable; ii) the mediating variable and the dependent variable, and; iii) the independent and dependent variable. The cross-sectional relationships for the patient data are presented in Tables 38 (T1) and 39 (T2), and the longitudinal data (i.e., social constraints, intrusions and avoidance at T1; outcome measures at T2) is presented in Table 40.

Table 38
Pearson’s r Correlations Between Patient Perceptions of Social Constrains, Experience of Cognitive Intrusions and Avoidance and Psychological Adjustment Measures at T1 (n = 46)

<table>
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<tr>
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<td>.41**</td>
<td>.45**</td>
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<td>-.37**</td>
<td>-.59***</td>
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<tr>
<td>2. Intrusions</td>
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<td>.58***</td>
<td>.47**</td>
<td>.61**</td>
<td>.62**</td>
<td>-.41**</td>
<td>-.58**</td>
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<tr>
<td>3. Avoidance</td>
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<td>.51**</td>
<td>-.35**</td>
<td>-.65**</td>
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<td>4. Depression</td>
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<td>.72***</td>
<td>-.64***</td>
<td>-.65**</td>
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<td>-.62***</td>
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<td>-.66***</td>
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<td>7. Positive affect</td>
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<td>.49***</td>
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<td>8. Sense of coherence</td>
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<td>1.00</td>
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</table>

* independent and mediator variable b mediator and dependent variable c independent and dependent variable
* p<.05 ** p<.01 *** p<.001
**Table 39**

Pearson’s r Correlations Between Patient Perceptions of Social Constraints, Experience of Cognitive Intrusions and Avoidance and Psychological Adjustment Measures at T2 (n = 32)

<table>
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<td>.49c**</td>
<td>-.13c</td>
<td>-.26c</td>
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<tr>
<td>2. Intrusions</td>
<td>1.00</td>
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<td>.58b***</td>
<td>.67b***</td>
<td>.70b***</td>
<td>-.25b</td>
<td>-.49b**</td>
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<tr>
<td>3. Avoidance</td>
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<td>.45b*</td>
<td>.45b**</td>
<td>-.21b</td>
<td>-.45b**</td>
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<tr>
<td>4. Depression</td>
<td>1.00</td>
<td>.72***</td>
<td>.66***</td>
<td>-.36*</td>
<td>-.79***</td>
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<td>5. Anxiety</td>
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<td>-.32</td>
<td>-.47***</td>
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<td>6. Stress</td>
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<td>-.58***</td>
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<tr>
<td>7. Positive affect</td>
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<tr>
<td>8. Sense of coherence</td>
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* independent and mediator variable  
** mediator and dependent variable  
*** independent and dependent variable  
* p<.05  ** p<.01  *** p<.001

**Table 40**

Pearson’s r Correlations Between Patient Perceptions of Social Constraints at T1, Experience of Cognitive Intrusions and Avoidance at T1 and Psychological Adjustment Measures at T2 (n = 30)

<table>
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<th>5.</th>
<th>6.</th>
<th>7.</th>
<th>8.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Social constraints</td>
<td>1.00</td>
<td>.65***</td>
<td>.41***</td>
<td>.22c</td>
<td>.41c*</td>
<td>.48c***</td>
<td>-.13c</td>
<td>-.28c</td>
</tr>
<tr>
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<td>.35b</td>
<td>.28b</td>
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<td>.04b</td>
<td>.11b</td>
<td>-.26b</td>
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</tr>
<tr>
<td>4. Depression</td>
<td>1.00</td>
<td>.72***</td>
<td>.66***</td>
<td>-.36**</td>
<td>-.79***</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Anxiety</td>
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<td>.74**</td>
<td>-.32</td>
<td>-.47**</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>6. Stress</td>
<td>1.00</td>
<td>-.33*</td>
<td>-.58***</td>
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<tr>
<td>7. Positive affect</td>
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<td>.34*</td>
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</table>

* independent and mediator variable  
** mediator and dependent variable  
*** independent and dependent variable  
* p<.05  ** p<.01  *** p<.001
The relationships presented in these tables are interpreted within the cross-sectional and longitudinal results sections below. For all models which met criteria to be tested as a mediating relationship, hierarchical regression analyses were conducted. In these analyses, the bivariate relationship between the social constraints (independent variable – IV) and patient psychological outcome variables (dependent variables – DV) were tested by entering only social constraints in Step 1 of the regression analysis. At Step 2, social constraints and the mediator variable (intrusions or avoidance) were both entered. The presence of a mediating relationship was then evaluated by examining whether a significant relationship between the mediator and patient outcomes was observed at Step 2, and whether the relationship between social constraints and patient outcomes became non-significant (full mediation) or reduced in strength (partial mediation). For partial mediators, the Sobel test was conducted to further investigate the strength of the mediator in the model (Baron & Kenny, 1986).

For all regression analyses, the assumptions of linearity and homoscedasticity were examined, and distance, leverage, and Cook’s distance values evaluated. For each of the patient distress variables (i.e., depression, anxiety and stress) two patients were identified on each variable as having a high distance value in all analyses conducted, indicating that these patients were experiencing high levels of distress. Further, when these patients were removed from analyses, significant changes in variance accounted for within the mediation models were noted. Thus, these patients were removed from the analyses reported here as they appeared to represent a more distressed population than the predominately well-functioning patient sample obtained. All other assumptions were met.

**Cross-sectional results.** As displayed in Table 38, at T1, social constraints was significantly correlated with all patient outcome measures; all outcomes measures were significantly related to both intrusions and avoidance; and both intrusions and avoidance were significantly correlated with social constraints. Thus, both intrusions and avoidance were tested as mediators of the relationships between social constraints and all patient outcome measures.

In the models which tested intrusions and avoidance as mediators of the relationship between social constraints and depression at T1, at Step 1, social constraints significantly accounted for 20.88% of variance in patient distress, $F(1,44) = 11.63, p = .001$. In the model which included intrusions as a mediator, the addition of intrusions at Step 2 accounted for an additional 9.40% of the variance in depression, $F_{\text{change}}(1,43) = 5.78, p = .021$. At this step, intrusions accounted for significant variance in depression ($sr^2 = .09, p = .021$), whereas social constraints did not ($sr^2 = .02, p =$
The change in the significance of social constraints as a predictor of depression at Step 2 indicated that intrusions significantly mediated the relationship between social constraints and depression at T1. In the model which tested avoidance as a mediator of this relationship, the addition of avoidance at Step 2 accounted for an additional 8.50% of the variance in depression, $F_{\text{change}}(1,43) = 5.16, p = .028$. At this step, both avoidance ($sr^2 = .09, p = .028$) and social constraints ($sr^2 = .10, p = .02$) accounted for significant variance in depression. As some reduction in the strength of the relationship between social constraints and depression was noted, the Sobel test was calculated. This analysis indicated that avoidance was not a significant mediator of the relationship between social constraints and stress at T1, $z = 1.80, p = .072$.

In the models which tested intrusions and avoidance as mediators of the relationship between social constraints and anxiety at T1, at Step 1, social constraints significantly accounted for 45.29% of variance in patient distress, $F(1,45) = 37.18, p < .0001$. In the model which included intrusions as a mediator, the addition of intrusions at Step 2 accounted for an additional 9.00% of the variance in anxiety, $F_{\text{change}}(1,44) = 8.65, p = .005$. At this step, both intrusions ($sr^2 = .09, p = .005$) and social constraints ($sr^2 = .10, p = .004$) accounted for significant variance in anxiety. Again, as some reduction in the strength of the relationship between social constraints and anxiety was noted, the Sobel test was calculated. This analysis indicated that intrusions was a significant partial mediator of the relationship between social constraints and anxiety at T1, $z = 2.61, p = .009$. In the model which tested avoidance as a mediator of social constraints and anxiety, while the model accounted for significant variance overall, when avoidance was added at Step 2 ($F(2,44) = 19.31, p < .0001$) no significant change in variance accounted for was obtained ($F_{\text{change}}(1,44) = 1.24, p = .272$). Accordingly, social constraints ($sr^2 = .32, p < .0001$) was the only significant predictor of anxiety at Step 2. Thus, avoidance ($sr^2 = .02, p = .272$) did not add to the explanation of anxiety in this model.

Regarding the impact of intrusions and avoidance on the relationship between stress, the final indicator of patient distress, and social constraints, at Step 1 of these analyses, social constraints significantly accounted for 35.80% of variance in patient distress, $F(1,46) = 25.62, p < .0001$. In the model which included intrusions as a mediator, the addition of intrusions at Step 2 accounted for an additional 9.20% of the variance in stress, $F_{\text{change}}(1,45) = 7.52, p = .005$. At this step, both intrusions ($sr^2 = .09, p = .009$) and social constraints ($sr^2 = .06, p = .028$) accounted for significant variance in stress. Given the reduction in the strength of the relationship between social constraints and stress, the Sobel test was calculated. This analysis indicated that
intrusions was a significant partial mediator of the relationship between social constraints and stress at T1, \( z = 2.48, p = .013 \). In the model which tested avoidance as a mediator of this relationship, the addition of avoidance at Step 2 accounted for an additional 8.80% of the variance in stress, \( F_{\text{change}}(1,45) = 7.11, p = .011 \). At this step, both avoidance (\( sr^2 = .09, p = .011 \)) and social constraints (\( sr^2 = .19, p < .0001 \)) accounted for significant variance in stress. Again, as some reduction in the strength of the relationship between social constraints and stress was noted, the Sobel test was calculated. This analysis indicated that avoidance was a significant partial mediator of the relationship between social constraints and anxiety at T1, \( z = 1.99, p = .013 \).

In the models which tested intrusions and avoidance as mediators of the relationship between social constraints and positive affect at T1, at Step 1, social constraints significantly accounted for 18.70% of variance in patient well-being, \( F(1,46) = 7.39, p = .009 \). However, neither intrusions (\( sr^2 = .05, F_{\text{change}}(1,45) = 2.68, p = .109 \)), nor avoidance (\( sr^2 = .05, F_{\text{change}}(1,45) = 2.61, p = .113 \)) accounted for significant variance in positive affect when they were added at Step 2 of their respective models. Further, social constraints did not account for significant variance at Step 2 in either analysis (i.e., with intrusions, \( sr^2 = .02, p = .295 \); with avoidance, \( sr^2 = .06, p = .064 \)).

In the final analysis for the T1 patient data, in the models which tested intrusions and avoidance as mediators of the relationship between social constraints and sense of coherence, at Step 1, social constraints significantly accounted for 41.10% of variance in sense of coherence, \( F(1,46) = 32.11, p < .0001 \). In the model which included intrusions as a mediator, the addition of intrusions at Step 2 accounted for an additional 8.20% of the variance in sense of coherence, \( F_{\text{change}}(1,45) = 7.29, p = .01 \). At this step, both intrusions (\( sr^2 = .08, p = .01 \)) and social constraints (\( sr^2 = .10, p = .006 \)) accounted for significant variance in sense of coherence. Again, as some reduction in the strength of the relationship between social constraints and sense of coherence was noted, the Sobel test was calculated. This analysis indicated that intrusions was a significant partial mediator of the relationship between social constraints and sense of coherence at T1, \( z = 2.44, p = .015 \). In the model which tested avoidance as a mediator of this relationship, the addition of avoidance at Step 2 accounted for an additional 22.20% of the variance in sense of coherence, \( F_{\text{change}}(1,45) = 27.27, p < .0001 \). At this step, both avoidance (\( sr^2 = .22, p < .0001 \)) and social constraints (\( sr^2 = .16, p < .0001 \)) accounted for significant variance in sense of coherence. Given the reduction in the strength of the relationship between social constraints and sense of coherence, the Sobel test was calculated. This
analysis indicated that intrusions was a significant partial mediator of the relationship between social constraints and stress at T1, \( z = 2.57, p = .01 \).

Regarding the mediation analyses conducted with social cognitive processing model variables at T2, as shown in Table 39, only one of the proposed mediators, intrusions, was significantly correlated with social constraints. Further, significant relationships were only identified between social constraints and 3 of the 5 patient outcome measures, depression, anxiety, and stress. These measures were also significantly correlated with intrusions. Thus, three mediating models were tested at T2 with social constraints as the IV and intrusions as the mediator and depression, anxiety, and stress as DVs.

When depression was the outcome measure, at Step 1, social constraints significantly accounted for 43.30% of the variance in patient distress, \( F(1,32) = 24.47, p < .0001 \). However, when intrusions were added to the model at Step 2, while the model accounted for significant variance overall \( (F(2,31) = 14.40, p < .0001) \), no significant change in variance accounted for was obtained \( (F_{\text{change}}(1,31) = 2.84, p = .102) \). Thus, social constraints \( (sr^2 = .12, p = .011) \) was the only significant predictor of depression as intrusions \( (sr^2 = .05, p = .290) \) did not add to the explanation of variance.

In the analysis of the impact of intrusions on the relationship between social constraints and anxiety at T2, at Step 1, social constraints significantly accounted for 40.70% of the variance in patient distress, \( F(1,32) = 21.95, p < .0001 \). When intrusions was added at Step 2, an additional 8.60% of the variance in anxiety was accounted for overall, \( F_{\text{change}}(1,31) = 5.28, p = .028 \). At this Step, both social constraints \( (sr^2 = .10, p = .017) \) and intrusions \( (sr^2 = .09, p = .028) \) accounted for significant unique variance in anxiety. As some reduction in the strength of the relationships between social constraints and anxiety was noted, the Sobel test was calculated. This analysis indicated that intrusions was a significant partial mediator of the relationship between social constraints and anxiety, \( z = 2.04, p = .042 \).

In the analysis of the impact of intrusions on the relationship between social constraints and stress at T2, at Step 1, social constraints significantly accounted for 41.47% of the variance in patient distress, \( F(1,32) = 22.62, p < .0001 \). When intrusions was added at Step 2, an additional 9.60% of the variance in stress was accounted for overall, \( F_{\text{change}}(1,31) = 6.07, p = .020 \). At this Step, both social constraints \( (sr^2 = .10, p = .017) \) and intrusions \( (sr^2 = .10, p = .20) \) accounted for significant unique variance in stress. Again, calculation of the Sobel test indicated that intrusions was a significant partial mediator of the relationship between social constraints and stress at T2, \( z = 2.21, p = .027 \). All cross-sectional mediating relationships are summarised in Figure 8.
Longitudinal results. As shown in Table 40, only one of the proposed mediators from the patient data at T1, intrusions, was significantly correlated with any of the T2 outcome measures and social constraints. Specifically, intrusions was positively correlated with both stress and social constraints, which were also positively correlated. Thus, from the longitudinal data only one mediating relationship was tested.

At Step 1, social constraints at T1 significantly accounted for 39.19% of the variance in patients’ reports of stress at T2, $F(1,27) = 17.43, p < .0001$. However, when intrusions at T1 were added to the model at Step 2, while the model accounted for significant variance overall ($F(2,26) = 9.40, p = .001$), no significant change in variance accounted for was obtained ($F_{change}(1,26) = 1.23, p = .278$). Accordingly, social constraints ($r^2 = .14, p = .018$) was the only significant predictor of stress at Step 2. Thus, intrusions ($r^2 = .03, p = .278$) did not add to the explanation of stress at T2 in this model.
5.4 Discussion

The two central aims of the current study were to examine the psychological adjustment of adolescents and young adults with CF and their parents and to examine how communication within the dyad contributes to patients’ adjustment. Along with these aims, the theoretical frameworks used to examine these aspects of communication and psychological adjustment were extended to identify factors which impact communication in the patient-parent dyad and to identify processes within these model which lead to patient and parent outcomes. Specifically, the current study utilised the social cognitive processing model to examine potential problems in parent-child communication termed ‘social constraints’. The psychological adjustment indicators of depression, anxiety, stress, and positive affect were utilised to examine how social constraints may impact patients’ adjustment. Additionally, sense of coherence, which examines individuals’ beliefs of predictability in their world and their ability to cope with challenges, was also used as a measure of adjustment. Finally, the illness representation domains from the common sense model of illness were used to examine how patients and parent cognitively conceptualise CF and how differences between patients’ and parents’ representations of CF may impact the development of social constraints in the dyad. These constructs were examined at two points, 6 months apart, to allow both cross-sectional and longitudinal data to be obtained for the evaluation of these applied and theoretical research questions.

5.4.1 Social Constraints, Parent-Child Discussions, and Patients’ and Parents’ Coping

5.4.1.1 Hypothesis 1

Hypothesis 1 predicted that discussions about CF-related emotional concerns would be less frequent between patients and parents when social constraints were high, as reported by the patients. However, both the cross-sectional data from Times 1 and 2, and the longitudinal prediction of parent-child discussion at T2 from social constraints reported at T1 did not support this hypothesis. No significant relationships were revealed in the three analyses conducted. These findings differ to those of Lepore and colleagues (i.e., Lepore et al., 1996; Lepore, 2001) which identified a significant inverse relationship between social constraints and talking within patient-spouse dyads. Yet, suggestions can be made regarding the reasons for the discrepant results obtained in the current study.

While in the current study patients were asked to rate how much they actually discussed their feelings about CF with their parent, it is possible that participants
responded to this question regarding their general frequency of discussion of CF-related topics with their parent. Given that patients, especially if still attending paediatric services, frequently discuss treatment-related aspects of CF with their parents, as well as regularly discussing symptoms experienced, it is likely that responses to the parent-child discussion question would indicate frequent discussion if it was responded to in a more general manner. Thus, this interpretation of the measure may not correlate with reports of social constraints. From this, it is suggested that two discussion items should be included, one evaluating the frequency of discussion of CF symptoms and treatment-related topics, and one evaluating the frequency of discussions of feelings about CF, and CF-related emotional distress with parents. This would assist in differentiating particular aspects of CF-related discussions and may provide a more specific measure for analyses with social constraints.

5.4.1.2 Hypothesis 2

The second hypothesis of the current study predicted that social constraints would be positively associated with the use of avoidant coping strategies for patients and parents. As discussed previously, reduction analyses conducted on the patient and parent Brief COPE data did not identify a factor resembling avoidant coping for either group. Alternatively, the two predominant coping factors identified in the reduction analysis for patients were titled ‘independent’ coping (including the acceptance, active coping, positive reframing, and planning coping strategies) and ‘other-oriented’ coping (including the coping strategies of instrumental support, emotional support, venting, and self-distraction). In both cases these predominant styles resembled more active coping approaches. This more active approach was also identified for parents, but the factors differed somewhat. For parents, a ‘management-oriented’ coping style incorporating acceptance, instrumental support, and emotional support was identified as well as a ‘change-oriented’ style incorporating active coping, planning, and positive reframing. While this was unexpected from the review of theoretical literature for this study, a similar pattern of results was also reported in a recent study examining the coping styles of parents of primary school aged children with CF. Wong and Heriot (2008) discussed that parents reported engaging in active styles of coping more frequently than avoidant coping styles.

Given Wong and Heriot’s (2008) findings and those of the current study, it is suggested that an active coping style may be common among parents of children with CF. From a practical perspective, it is likely that, since having a child with CF, parents
have needed to be diligent with their child’s treatment regimes and attendance at clinic appointments, as well as managing more general duties (e.g., other children, personal relationships, house-work, possible external employment). Thus, it is understandable that parents may adopt a more active, rather than avoidant approach to coping with life events, as avoidance may have negative consequences (e.g., child becoming sicker, relationship problems occurring). As most children with CF would also need to learn to monitor and manage their illness from a young age, as well as learn more general developmental skills (e.g., academic skills, social skills) it would also make sense that children with CF may develop a more active style of coping over time. However, it is also possible that individuals who are likely to volunteer to participate in research projects are those who are coping more effectively and, therefore are less likely to use avoidant coping strategies. Thus, replications of these findings are needed to confirm these interpretations of the current results.

Thus, while hypothesis 2 could not be directly tested in the current study, exploratory correlational analyses between the patient and parent coping styles obtained and social constraints were conducted. However, for both patients and parents, no significant relationships between coping style and social constraints were obtained either cross-sectionally or longitudinally. While it is surprising that no significant relationships were identified, as suggested above, if an active coping style is engaged in to assist parents and children to cope with CF and other life occurrences then it may be unlikely that coping style may differ in the presence of one problematic factor.

5.4.2 The Social Cognitive Processing Model and Patient Outcomes

5.4.2.1 Hypothesis 4

Hypothesis 4 predicted that patients’ perceptions of social constraints with their parents would be positively related to patient reports of psychological distress and negatively related to patient reports of well-being. From the data collected for patients at T1, this hypothesis was fully supported. As patients’ perceptions of social constraints increased, patients’ reports of depression, anxiety, and stress increased, reports of positive affect decreased, and sense of coherence weakened. At T2, the relationships between social constraints and patient distress were maintained, yet, those between positive affect and sense of coherence and social constraints were not. It is noted, however, that given the smaller sample size of patients at T2, all correlations between social constraints and outcome measures reduced in strength. Thus, it would appear that the non-significant correlations between social constraints and positive affect and sense
of coherence obtained at T2 are more a product of reduced power in analyses than inconsistencies in results. Longitudinally, social constraints at T1 were related to patient reports of anxiety and stress 6 months later.

The significant relationships obtained between social constraints and psychological distress indicators are consistent with a number of other studies conducted utilising the social cognitive processing model (e.g., Cordova et al., 2001; Lepore et al., 1996; Lepore & Helgeson, 1998) and again supports the notion that problems in communication and the provision of support in close partnerships, if unresolved, can lead to patient distress (e.g., Clarke, 1993; Devine et al., 2003; Lepore, 1997; Lepore et al., 2000; Lepore, 2001; Lutgendorf & Ulrich, 2002). Further, the results of the current study also demonstrate that social constraints not only have a short-term detrimental effect, but can also have longer lasting impacts on patients’ ratings of anxiety and stress over time. While Lepore et al. (1996) demonstrated that social constraints moderated the relationships between intrusive thoughts and depression over 18 months with a sample of bereaved mothers, the current study is the first to examine longitudinal relationships between social constraints and patient psychological adjustment in a chronic illness sample. Thus, this appears to be a promising application of the social cognitive processing model and would benefit from replication within both the CF population and other chronic illness groups to provide further evidence of these effects.

Additionally, recent applications of the social cognitive processing model have also identified that social constraints reported by adults with diabetes are related to both patient distress and self-care behaviour (Braitman, 2008). Thus, future research with this model with the adolescent and young adult CF population may also assist in identifying factors for intervention to improve both patients’ psychological health and self-care behaviour. Given the detrimental impact of treatment non-adherence on personal health and family functioning within families coping with CF (e.g., De Lambo et al., 2004; Iles & Lowton, 2010; Miller, 2009), this may be a particularly promising area in which to extend the current research findings.

A new finding identified in the current study is the significant negative relationships between social constraints and indicators of patient well-being. It was theoretically plausible that if social constraints increased patients’ distress, then social constraints should also be associated with decreases in patient well-being. Yet, Lepore and Kernan (2009), who discussed these other applications of the social cognitive processing model, identified that no previous studies had tested this prediction. Thus, the findings of the current study support Lepore and Kernan’s suggestions and also
provide a basis for future applications of the social cognitive processing model with other indicators of patient adjustment beyond those of patient distress indices.

5.4.2.2 The Role of Intrusions and Avoidance in the Social Cognitive Processing Model

While the results of the current study, and that of past research, have presented strong evidence that social constraints within a dyad impact individual adjustment, the processes within the social cognitive processing model which lead to these outcomes are less clear. As reviewed in Chapter 3, the theory suggests that when social constraints are perceived in a close relationship, individuals experiencing distress are less likely to feel comfortable discussing their concerns with their significant other, which is proposed to lead to cognitive avoidance of the topic. Additionally, suppression of distressing thoughts is also proposed to promote the occurrence of cognitive intrusions as the distressing stimulus is not being processed and, thus, cannot be integrated into the individuals’ pre-existing cognitive schemas. Instead, the thoughts cycle in and out of conscious awareness (Clarke, 1993; Lepore, 1997; 2001). In past research with the social cognitive processing model, however, both mediating (e.g., Cordova et al., 2001) and moderating models (e.g., Lepore et al., 1996) have been used to explain the relationships between social constraints, intrusions, avoidance and patient outcomes. Additionally, within each paradigm, some results are supportive of the model presented and others are not. Thus, it was an aim of the current study to attempt to clarify the role of intrusions and avoidance in the social cognitive processing model.

Regarding the prerequisites for moderating and mediating analyses, the central factors to be considered when choosing which model is best for the data at hand is the relationship between the independent variable and the potential moderator/mediator. It is preferable in moderation analyses that the independent variable and the moderator be independent of one another, as non-independence can lead to biased estimates of the interaction term. In mediation, however, it is a criterion of the analyses that all variables included (i.e., independent, mediator, and dependent) be correlated to one another (Baron & Kenny, 1986; Evans & Lepore, 1997; Lepore, 1997). As significant relationships were identified between social constraints, intrusions, avoidance and all outcome measures at T1, a mediation approach was considered the most appropriate for analyses in the current study. It was noted that, at T2, not all significant relationships identified at T1 were significant at this time. However, it was again considered that this
pattern of results was most likely a product of a reduction in power obtained from a smaller sample size at T2 as opposed to being an indication of inconsistent effects.

Across all of the analyses conducted at T1 which tested the role of intrusions and avoidance as mediators of the relationship between depression, anxiety, stress, positive affect, and social constraints, only one full-mediation effect and five partial mediation effects were identified. Specifically, intrusions were found to fully mediate the relationship between social constraints and depression, and to partially mediate the relationships between social constraints and anxiety, stress and sense of coherence. Additionally, avoidance was found to partially mediate the relationships between social constraints and stress and social constraints and sense of coherence. At T2, only the partial mediation effect of intrusions on the relationships between social constraints and anxiety, and social constraints and stress were maintained.

The results for the mediation models of intrusions are consistent with those of Cordova et al. (2001) and Devine et al. (2003) who also identified intrusions as a partial mediator between indices of social constraints/interpersonal functioning and patient outcomes in couples where one spouse had a cancer diagnosis. Thus, it appears to be a robust finding that cognitive intrusions about one’s illness are detrimental to a patient’s psychological adjustment, which also supports the key propositions of the social cognitive processing model discussed above (e.g., Clarke, 1993; Lepore, 1997; 2001).

Additionally, the role of avoidance as a partial mediator between social constraints and two of the patient outcomes identified in the current study is consistent with the research of Lepore and Helgeson (1998) who also reported that avoidance partially mediated the relationship between social constraints and patient adjustment in a sample of male cancer patients. Further, the finding that avoidance played a mediating role in fewer relationships than intrusions is also consistent with the propositions of DuHamel et al. (2004) and Lutgendorf et al. (1999) who suggested that avoidance may buffer individuals from distress when it first occurs. These authors also suggested that avoidance will have a greater impact on individuals’ adjustment over time, as sustained avoidance is predicted to impede the processing of the distressing event.

However, while the conditions were met to test avoidance and intrusions at T1 as mediators of the relationship between social constraints at T1 and stress at T2, no significant mediation relationships were identified. Again, it is proposed that these results may be the product of reduced power in analyses following attrition at T2. Thus, future research with larger samples of CF patients and other chronic patient groups is
recommended to further clarify the longitudinal relationships between social constraints, avoidance, intrusions and patient outcomes.

5.4.3 Illness Perceptions of CF, Coping Style and Patients’ and Parents’ Outcomes

5.4.3.1 Hypothesis 3

The third hypothesis predicted a positive relationship between negativity in illness representations of CF and avoidant coping. Again, as this hypothesis could not be directly tested, exploratory correlational analyses between illness perceptions and the coping styles obtained from the reduction analysis of patients’ and parents’ coping data were conducted.

As patients’ perceptions of personal and medical control over CF became more positive, patients’ use of an independent coping style was more frequent. These relationships were identified at T1 and T2. Additionally, independent coping was also related to illness coherence at T2 where having a greater understanding of CF was associated with more frequent use of independent coping. Yet, when illness perceptions at T1 were correlated with independent coping at T2, no significant relationships were identified. The significant relationships identified here make intuitive sense as personal and treatment control and illness coherence are elements of CF which can be influenced by one’s actions (i.e., conducting preventative treatments, accessing practitioner support when needed, increasing one’s own understanding of the condition). Conversely, the other domains of illness perceptions are more related to the actual symptoms of CF and their impact on an individual.

Regarding analyses between patients’ other-oriented coping and illness perceptions, as patients perceived CF to be more cyclical in nature and reported greater emotional distress, other-oriented coping was engaged in more frequently at T1. These relationships were not replicated at T2; however, a significant relationship between symptoms related to CF and coping was found where the experience of more symptoms related to CF was associated with more frequent use of other-oriented coping. From the longitudinal analyses, reporting greater emotional distress related to CF at T1 was related to more frequent use of other-oriented coping at T2. These results also make intuitive sense as both the number and experience of CF-related symptoms, as well as emotional responses to one’s illness are aspects of CF which are less able to be directly changed by one’s actions. Thus, using an other-oriented approach which predominantly involves seeking support would seem appropriate for these less malleable aspects of CF.
Within the parent data, differences were also noted in the illness perception domains which correlated with parents’ coping style and, again, differences were noted in the individual correlates at T1 and T2 for each coping style. Specifically, regarding the correlates of change-oriented coping for parents, as parents perceived CF to be more cyclical in nature, change-oriented coping was used less frequently at T1. At T2, however, as parents’ perceptions of their child’s personal and treatment control over CF became more positive, parents used change-oriented coping more frequently. From the longitudinal analyses examining relationships between illness perceptions at T1 and coping style at T2, the more control parents perceived their children to have over their CF and the less parents perceived CF to be cyclical in nature, the more frequently parents reported using change-oriented coping at T2.

Regarding analyses examining the relationships between parents’ use of management-oriented coping and illness perceptions, at T1 no significant relationships were identified. However, at T2, as parents’ perceptions of their child’s personal control over CF were enhanced, parents reported engaging in management-oriented coping more frequently. This relationship was also found to be significant longitudinally between perceptions of the child’s personal control at T1 and use of management-oriented coping at T2.

These patterns of results between parents’ change-oriented coping style and illness perceptions resemble the pattern of results between patients’ independent coping style and illness perceptions. Again, it seems that for the aspects of CF which appear to be influenced by the actions of either the patient, and those close to them (i.e., participating in treatments), a coping style which enacts these changes may be used more frequently. Further to this, perceptions of timeline being cyclical, which is not easily changed by personal actions, was related to less use of a change-oriented coping style. As many of these relationships were maintained over time, it can be suggested that these forms of coping may have been utilised to assist children to cope with CF from an early age.

Finally, regarding the relationship between management-oriented coping and parents’ perceptions of their child’s personal control over their illness, it is possible that, in addition to using a change-oriented style to assist their child in conducting their treatments, parents may also need to learn to cope with frustrations that may arise when their children do not complete their treatments as prescribed, as this is common in the adolescent CF population (George et al., 2010; Modi & Quittner, 2006). Thus, parents may use a management-oriented style, which incorporates acceptance and enlisting
emotional and instrumental support, to regulate their response to this occurrence. As this relationship between child’s personal control over CF and parents’ use of management-oriented coping was also significant over time, this indicates that this form of coping is particularly important for parents of children with CF.

A point that is noted from both the patient and parent illness perception and coping correlation data is that the pattern of relationships between illness perceptions and coping styles differed at T1 and T2. As previous studies which have applied illness representations with the CF population have only reported cross-sectional results with one point of data collection (Bucks et al., 2009; Sawicki et al., 2011), it is difficult to suggest definitive reasons for this finding. However, it is suggested that as fluctuations in symptoms often occur in CF, some patients may have experienced their illness differently at each point in time. This may then have lead to some variation in the relationships obtained between illness perceptions and coping. As parents would also witness these fluctuations, this may also influence their perceptions of CF. Consistent with this suggestion, some small differences were noted in the descriptive data from T1 to T2 for patients’ and parents’ perceptions of CF. Yet, to further evaluate this proposition, repeated measures t-tests were conducted to evaluate change in patients’ and parents’ illness perceptions over time (see Appendix A). However, these analyses did not identify any significant differences in patients’ and parents’ illness perceptions. Thus, to be thorough, repeated measures t-tests were also conducted to examine potential differences in the use of coping style over time which may have also contributed to differences observed in the correlations from T1 to T2 (see Appendix B). Again, however, no differences were identified for patients or parents.

Hence, while some fluctuations may be noted in patients’ and parents’ reporting of illness perceptions and coping style from T1 to T2 which may have influenced the results of the correlational analyses, these differences were large enough to suggest that illness perceptions of CF or general coping style change substantially for patients or their parents over a 6-month period of time. Nevertheless, further investigations of the relationships between these constructs at multiple points in time are warranted to gain a richer understanding of the processes contributing to these findings.

5.4.3.2 Hypotheses 5 and 6

Hypotheses 5 and 6 predicted that patient and parent reports of negativity in illness perceptions would be positively related to their respective reports of psychological distress and well-being. These hypotheses were supported. For patients,
symptoms experienced generally, symptoms related to CF and emotional representations were significant cross-sectional correlates of all outcome measures (i.e., depression, anxiety, stress, positive affect, and sense of coherence). In addition, illness coherence was a significant cross-sectional correlate of stress and positive affect and illness coherence was also significantly related to stress. However, illness perceptions at T1 were only significantly related to depression, anxiety, stress and sense of coherence at T2, with no significant correlates identified for positive affect at T2. Symptoms experienced generally at T1 was related to depression, anxiety, stress and sense of coherence at T2 and perceptions of personal control over CF at T1 were also related to sense of coherence at T2.

Overall, these results suggest that symptoms experienced generally, symptoms related to CF and emotional representations of illness are the domains of the IPQ-R which are most indicative of patient distress. It is noted that symptoms experienced generally by patients are usually not reported in most studies using the IPQ-R, however, it appears that for this group this is an important domain to retain. It is possible that, given the large impact that CF symptoms and treatment regimes can have on patients’ lives, the experience of other symptoms or concurrent illness may be overwhelming for this group. Regarding the finding that positive affect was the only outcome measure at T2 which was not predicted by illness perceptions at T1, while inconsistent with the findings obtained for the other outcome measures, this finding appears to be consistent with the theoretical conceptualisation of affect, mood and emotion. Accordingly, an individual’s affect at a certain point in time is usually more dependent on current events than overall mood, which varies more slowly (Batson, Shaw, & Oleson, 1992).

For parents, their emotional representations of illness were consistently correlated with parents’ ratings of depression, anxiety, stress, positive affect and sense of coherence in cross-sectional analyses. Additionally, illness coherence and perceptions of the consequences of CF were significantly related to parents’ reports of stress. Further, perceptions of CF being a cyclical illness were related to positive affect. Parents’ perceptions of their child’s experience of general and CF-related symptoms, perceptions of child’s personal control over CF, parent’s illness coherence, and perceptions of CF being cyclical in nature were all significant correlates of parents’ sense of coherence. Finally, longitudinally, fewer significant relationships between illness perceptions and outcomes were observed. Parents’ emotional representations of CF at T1 were related to both reports of depression and stress at follow-up and parents’ perceptions of their child’s personal control over CF at T1 was related to sense of
coherence 6 months later. Thus, for parents, it appears that the most consistent indicator of parent distress in this group was emotional representations of CF.

Regarding the impact of the control measures identified for inclusion in analyses of parents’ sense of coherence and stress ratings at T1 and T2, the majority of relationships between illness perceptions and stress, and illness perceptions and sense of coherence, were maintained after controlling for the variance in outcomes attributed to the control measures. Of the relationships that were affected, after controlling for the impact of not being employed full-time and having experienced trauma between T1 and T2, the relationship between perceived consequences of CF and stress was not maintained for parents. Additionally, after accounting for the impact of work status, the relationship between parents’ understanding of CF and sense of coherence was not maintained. Given the few relationships between illness perceptions, stress and sense of coherence impacted by the inclusion of other correlates of distress, this suggests that the impact of illness perceptions of CF on patient outcomes are robust.

Overall, these results are consistent with the results of Hagger and Orbell’s (2003) review of studies examining applications of the common-sense model of illness. Hagger and Orbell reported that most studies identified positive relationships between negativity in illness perceptions and patients’ distress across a range of chronic illness groups. Additionally, the finding that patients’ perceptions of symptoms at T1 were related to psychological adaptation at T2 replicated that results of other longitudinal studies using the CSM (e.g., Chaboyer et al., 2010; Millar et al., 2005).

In relation to the couple of studies which examined illness perceptions of individuals with CF, the results obtained here are consistent with Sawicki et al. (2011) who identified significant relationships between several domains of the IPQ-R and psychosocial facets of health-related quality of life for adult CF patients. In addition to this, given that illness perceptions of CF have also been found to significantly mediate the relationship between age and adherence to CF-related treatment (Buck et al., 2009), it appears that the assessment of illness perceptions of CF may be an important factor for health professionals to consider when working with this population.

This suggestion is consistent with a recent review of the use of illness representations in clinical practice which suggests that patients’ perceptions of illness can be used to tailor more specific interventions (Leventhal et al., 2008). Recent psychological intervention studies have begun to pilot such programs to assist patients in diabetes management (Keogh, White, Smith, McGilloway, O’Dowd, & Gibney, 2007) and to assist spouses managing their partners’ health following myocardial
infarction (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009). These studies have reported encouraging results. Thus, this may be a promising direction for future psychosocial interventions with CF patients and their parents who are experiencing distress.

5.4.4 Hypotheses 7 and 8

Hypotheses 7 and 8 predicted that patients’ and parents’ use of avoidant coping would be positively related to their reports of distress and negatively related to their well-being. Again, as this hypothesis could not be directly tested, exploratory correlational analyses between patient and parent adjustment measures and the coping styles obtained from the reduction analysis of patients’ and parents’ coping data were conducted.

At both T1 and T2, as patients reported more stress symptoms, they also reported frequent use of an other-oriented coping style. Additionally, patients’ experience of a high level of positive affect was associated with more independent coping style. No other significant cross-sectional relationships were identified. The results of the longitudinal analyses for patients replicated their cross-sectional results; patients’ use of other-oriented coping at T1 was associated with greater stress symptoms at T2 and more frequent use of an independent coping style at T1 was associated with greater positive affect at T2.

These results for patients suggest that their coping styles may be related to both their management of CF and management of their psychological adjustment. It appears that patients’ use of independent coping strategies is particularly important in the experience of positive affect. While not examined in the current study, it is possible that perceptions of self-efficacy may play a mediating role here, as coping with both health-related and other situations independently may increase patients’ belief in their ability to cope, which may in turn lead to the experience of positive affect. Regarding the relationship between stress and other-oriented coping, however, while the cross-sectional results make intuitive sense, the longitudinal results are less easily interpreted. It is logical that if a person is experiencing stress, they may gain the assistance of others to cope with this; however, the results also suggested that, over time, the use of other-oriented coping increases patients’ stress. Following the discussion above, it may be possible that over use of the support of others may decrease an individual’s perception of their ability to cope independently. This may, in turn, increase their overall level of stress over time. Again, replication of these results is needed to assist in the interpretation of these findings. However, it appears that the investigation of the
relationship between coping style, patient outcomes and self-efficacy may be an important area for future research with the adolescent and young adult population.

Regarding the results of these analyses for parents, no significant associations between coping style and psychological adjustment were identified cross-sectionally or longitudinally. These results suggest that while the management-oriented and change-oriented styles of coping were found to be significantly related to how parents perceive their child’s illness (hypothesis 3), they do not play a central role in the management of the parent’s mood. As parents of children with CF usually are observed to play a large caring role, it is possible that they may commit more time and effort to assisting their children than they commit to their own self-care. Thus, the coping styles that they have developed over time may be more centred on managing CF and other life events than on their own needs and emotion regulation. However, as this is the first time these coping scales have been identified and reported in the literature, further replications of these results are needed before strong conclusions can be drawn.

5.4.5 Dyadic Illness Representations and Patient Adjustment

5.4.5.1 Hypotheses 9 and 10

Hypotheses 9 and 10 predicted differences in patient reports of social constraints, psychological distress and well-being between four patient and parent illness perception discrepancy dyads. Specifically, hypothesis 9 predicted that patients in dyads with mutually negative patient-parent illness representations would report more distress and less personal and social well-being than patients in dyads with mutually positive patient-parent illness representations. Additionally, hypothesis 10 predicted that patients in dyads with discrepant patient-parent illness representations would report greater distress and less personal and social well-being than patients in dyads with mutually positive patient-parent dyads. As role functioning was found to be significantly related to social constraints at T1 in the control analyses, this variable was also included as a covariate in the analysis of the effect of discrepancy group on patients’ perceptions of social constraints at T1.

In the original plan for the analysis of this hypothesis, the effect of discrepancy group on each patient outcome measure was examined within each illness perception domain. However, following these analyses, it was noted that significant effects were only found within a few illness perception domains; which was unexpected. From this, it was considered that differences in illness perceptions between patients and parents may have a more cumulative effect on patients. Hence, it was conceptualised that
patients who shared mutually positive illness perceptions with their parents across a number of illness perception domains may report significantly better adjustment than patients in dyads who shared mutually negative illness perceptions with their parent and those who had discrepant patient-parent illness perceptions across a number of domains. Accordingly, a new patient-parent illness discrepancy variable was calculated. In its final form, the variable had three levels; overall-positive, where patients and parents shared mainly positive perceptions of CF across illness perception domains; overall-negative, where patients and parents shared mainly negative perceptions of CF across a number of domains; and discrepant/mixed consisting of patients with predominantly discrepant perceptions of CF with their parents (either more negative or positive) and patients who differed in their similarity in perceptions of CF with their parents across domains (e.g., a mix of mutually positive, mutually negative, and discrepant beliefs).

It is again noted that some differences were observed in the results obtained at T1 and T2 for these hypotheses. These differences were similar to the results obtained in the correlations between illness perceptions and coping data for patients and parents. Again, it is considered that this is likely to represent natural fluctuations in patients’ perceptions of CF, more than suggesting inconsistent effects. Yet, replications of these analyses with other CF samples are also suggested to confirm this.

Regarding the effects of patient-parent illness perception discrepancy on social constraints, significant effects were found within the IPQ-R domain of general symptoms experienced and illness perception discrepancy overall. Even after controlling for the effect of role functioning on social constraint scores, patients in mutually positive dyads for both perceptions of symptoms experienced and overall illness perceptions reported fewer social constraints than patients in dyads with mutually negative perceptions of symptoms experienced and overall illness perceptions at T1. These effects were also replicated longitudinally (i.e., illness perceptions at T1 leading to group differences on social constraints ratings at T2). In addition to this, patients in dyads with overall positive perceptions of CF at T1 reported fewer social constraints at T2 than patients in dyads with overall negative perceptions. Further, patients in the mixed/ discrepant perceptions group at T1 also reported fewer social constraints at T2 than patients in the overall negative perceptions group.

These significant effects support the proposition made by the current author that the match between patients’ and parents’ illness perceptions may impact on the development of social constraints in families coping with CF. These results complement the findings of studies which have began to investigate predictors of social constraints
in couples coping with cancer (Herzer et al., 2006; Quartana et al., 2005), but are unique in the fact that the current study is the first to have utilised factors from the common-sense model of illness to predict outcomes in the social cognitive processing model. Thus, this study also makes contributions to the illness perception literature.

Firstly, while two studies were identified that compared patient and parent perceptions of the CF-related quality of life (Britto et al., 2004; Havermans et al., 2009) the current study is the first to examine dyadic illness perceptions within the CF population. Secondly, while Benyamini et al. (2007) demonstrated that discrepancies in patients’ and partners’ views of illness impact patients’ perceptions of social support and partners’ social support provision, the current study has also demonstrated that dyadic illness perceptions are also predictive of communication problems in a dyad, cross-sectionally and over time. In particular, it appears that mutually held negative illness perceptions of CF in a patient-parent dyad may be an important factor in the development of social constraints. Thus, as discussed earlier, psychological interventions with families with CF may benefit from an examination of each individual’s perceptions of CF to assist in the enhancement of overall family functioning.

Regarding the impact of patient-parent illness perception similarity on patients’ psychological adjustment, significant effects were found within specific illness perception domains and for overall patient-parent illness perceptions. A consistent finding across the five indicators of patients’ psychological adjustment was that patients who were in dyads that held negative perceptions of symptoms experienced generally by the patient reported more distress (i.e., symptoms of depression, anxiety, and stress) and less well-being (i.e., positive affection and sense of coherence) than patients in dyads that held positive perceptions of symptoms experienced by the patient. Few significant effects were identified for the remaining illness perception domains. However, overall patient-parent illness perceptions were also indicative of patient adjustment.

Regarding group differences on patient reports of depression, patients in dyads with overall negative perceptions of CF reported more depressive symptoms than those with overall positive dyadic perceptions of CF at T1 and T2, but not longitudinally. Regarding the results for anxiety, again, patients in dyads with the overall negative perceptions of CF reported more anxious symptoms than patients in the overall positive dyadic perceptions of CF at T1. This effect was also found to be replicated over time (i.e., dyadic illness perceptions at T1 predicting outcomes at T2). Additionally, patients in dyads with overall negative perceptions of CF reported more anxious symptoms than patients in the discrepant/mixed perceptions group at T1. Contrary to these significant
effects for depression and anxiety, no effect of overall dyadic illness perceptions were found on patient reports of stress cross-sectionally or longitudinally.

Finally, on the measures of psychological well-being, patients in dyads with overall negative perceptions of CF reported less positive affect/sense of coherence than patients in the overall positive dyadic perceptions and discrepant/mixed perception groups in cross-sectional analyses. Additionally, one longitudinal effect was found where patients in the overall negative perceptions group at T1 reported lower sense of coherence at T2 than patients in the overall positive perceptions group.

Thus, overall, it appears that when patients and parents perceive CF negatively, patients’ psychological adjustment may be compromised. This set of results is consistent with those of Figuerias and Weinman (2003) and Franks et al. (2002) who presented results suggesting that mutual negativity in couples’ illness perceptions was detrimental to myocardial infarction patients’ adjustment. Additionally, this study is also consistent with the results of Sterba et al. (2008) and Dempster et al. (2011) who also replicated this pattern of results with samples of rheumatoid arthritis patients and cancer patients. The results obtained in the current study, however, differ to the hypothesis that dyadic illness perception discrepancy would also compromise patient outcomes relative to patients in dyads which held positive perceptions of CF and, thus, differ to the results of dyadic illness perception studies which did report such effects (i.e., Heijmans et al., 1999; Olsen et al., 2008). This may suggest that, for the CF population, positivity in at least one member of the parent child dyad may help to buffer against decrements in psychological adjustment. Again, the implications of these findings suggest that illness representations based interventions with families of adolescents and young adults with CF would assist in the promotion of adaptive patient adjustment.

5.4.6 Sense of Coherences – Correlates and Applications

5.4.6.1 Hypotheses 11 and 12

Hypotheses 11 and 12 predicted that patients’ and parents’ ratings of sense of coherence would be negatively associated with their respective reports of distress and positively related with reports of positive affect. As noted earlier, parents’ work status was identified as a control variable for analyses pertaining to parents’ sense of coherence at T2. Thus, for the longitudinal prediction of parents’ sense of coherence at T2 from parent reports of depression, anxiety, stress and positive affect at T1, the effect of work status was controlled.
All cross-sectional analyses for patients and parents supported hypotheses 11 and 12. When patients and parents reported a high sense of coherence at T1 and T2, they also concurrently reported few symptoms of depression, anxiety and stress, and a high level of positive affect. Regarding the prediction of sense of coherence at T2, for patients, stress was the only significant predictor. As patients reported a high level of stress at T1, sense of coherence was weakened at T2. For parents, a strong sense of coherence at T2 was related to reporting few symptoms of depression, anxiety, and stress, and high positive affect at T1. However, when these predictors of parents’ sense of coherence at T2 were entered into a regression analysis with work status from T1, only depressive symptoms and positive affect at T1 accounted for significant unique variance in parents’ sense of coherence ratings at T2.

This study is the first since Baker (1998) to apply the sense of coherence construct to the examination of patient outcomes in CF. However, while Baker demonstrated that sense of coherence was related to self-care behaviour in adolescents with CF, the current study has demonstrated inter-relationships between sense of coherence and other adjustment indicators for both adolescents and young adults. Further, these relationships were also demonstrated for parents of children with CF. Thus, these results are consistent with other studies which have demonstrated a strong inverse relationship between sense of coherence and depressive (Chumbler et al., 2008; Engelhard et al., 2003; Hittner & Swickert, 2010; Konttinen et al., 2008; Myrin & Langerstrom, 2008) and anxious symptomatology (Black & White, 2005; Henje Blom et al.; Konttinen et al.) and positive affect (Oztekin & Tezer, 2009; von Bothmer & Frilund, 2003) across a range of illness and trauma affected and general populations. In addition, as suggested by the Salutogenic Model of Health and Illness it does appear that sense of coherence may play a role as a resilience or risk factor (depending on the strength of sense of coherence) in individuals’ adaption to life events.

The finding that patients’ sense of coherence at T2 was related to patients’ stress levels at T1 is also consistent with Antonovsky’s (1979; 1987; 1990) propositions for the Salutogenic Model of Health and Illness which suggest that sense of coherence is partly shaped by circumstances experienced in childhood and adolescence, as well as inherited traits. However, the findings that parents’ sense of coherence at T2 was related to other measures of parents’ psychological functioning at T1 is contradictory to Antonovsky’s suggestion that sense of coherence is crystallised in early adulthood and changes little after this time. Instead, the findings of the current study support the more recent opinions and empirical data reported in the literature pertaining to sense of coherence
which have suggested that individuals’ sense of coherence may be weakened by the experience of traumatic events experienced in adulthood, such as caring for a child facing a chronic illness (Geyer, 1997; Margalit et al., 1989; Olsson et al., 2008; Pisula and Kossakowska, 2010).

5.4.6.2 Social Constraints, Illness Perceptions and Sense of Coherence

In addition to the results of the current study indicating that sense of coherence may still be impacted by life events in adulthood, the current study also demonstrated a number of new relationships between sense of coherence and illness-related and interpersonal process variables. Firstly, the current results identified a cross-sectional relationship between CF patients’ perceptions of social constraints with their parent and their reported sense of coherence. This finding was consistent with predictions based upon studies which demonstrated that an emotionally supportive environment can assist in restoring individuals’ sense of coherence after a traumatic event or illness (Nilsson et al., 2000; Skarsater et al., 2005). Therefore, the findings of the current study suggest that, in addition to sense of coherence being related to interpersonal support, it is also related to indicators of problematic interpersonal relationships. From a social cognitive process perspective, it can be suggested that having a less supportive social environment may reduce the individual’s opportunity to process thoughts relating to distressing events which may be retained and lead to a weakening of sense of coherence. However, again, replications of these findings are needed within both the CF and other chronic illness populations to draw strong conclusions about this proposed relationship.

Secondly, Lehto (2007) identified that illness coherence impacted lung cancer patients’ reports of emotional distress and perceptions of causal factors related to their illness. Building from the results, it was considered by the current author that sense of coherence, which is a more global indicator of an individual’s perceived understanding and perceived predictability of life events, would be related to dimensions of illness perceptions for both CF patients and their parents. For patients, the results of the current study indicated that their perceptions of symptoms experienced generally were related to concurrent reports of sense of coherence. Also, perceptions of symptoms experienced generally and perceived personal control over CF at T1 were related to patients’ sense of coherence ratings 6 months later. Further to this, the current study demonstrated that patients in dyads who held negative illness perceptions of CF had lower sense of coherence than patients in dyads with positive perceptions of CF. These results were obtained both cross-sectionally and longitudinally. Again, all of these results support
Antonovsky’s (1979; 1987; 1990) suggestions that life events experienced in childhood and adulthood impact the development of sense of coherence.

Regarding the results obtained for parents, emotional representations of CF, perceptions of their child’s experience of general and CF-related symptoms and child’s personal control over CF, and parents’ reported understanding of CF were all related to concurrent reports of sense of coherence. Further, parents’ perception of their child’s personal control over CF at T1 was also related to their sense of coherence ratings at T2. Again, the cross-sectional results are consistent with Antonovsky’s (1979; 1987; 1990) theoretical proposition that sense of coherence impacts how individuals perceive and cope with life events. The longitudinal results, however, are not consistent with the original proposition from the Salutogenic Model of Health and Illness that sense of coherence is crystallised in adulthood. These longitudinal results are, instead, consistent with some of the first studies which demonstrated that sense of coherence could be altered in adulthood by traumatic life events. One early study which obtained this evidence demonstrated that parents of children with chronic illness had a weaker sense of coherence than parents who did not have children with chronic illness (Margalit et al., 1989). This finding has since been replicated in more recent studies with parents of children with autism (Pisula & Kossakowska, 2010) and intellectual disability (Olsson et al., 2008). Thus, it appears a consistent finding that the experience of having a child with a chronic illness can have a large impact on parents’ views of the predictability of their world and their ability to manage challenging events.

The implications of these findings which demonstrate a relationship between illness perceptions and sense of coherence for patients and parents are again related to the potential for psychological intervention incorporating illness perceptions. If interventions with CF patients and their families incorporated a component focussing on families’ perceptions of CF, this may both decrease psychological distress and preserve or strengthen individuals’ sense of coherence.
CHAPTER 6 – STUDY 2

6.1 Aims and Predictions

The previous study examined the social environment of the family of adolescents and young adults with CF. Extending the analysis of the social environment of young persons with CF, this study examined the perceptions and understanding of CF in the wider community. To accomplish this, the current study utilised an experimental design with a sample of university students enrolled in non-health related subjects being assigned to read one of six vignettes describing a person who coughs frequently and takes a number of medications. The vignettes differed according to the diagnosis given to this person (CF or other); additionally, the conditions that stated the person has CF also varied as to the amount of information given to the reader about CF, and who discloses this information (the patient or another party). Participants rated the likeability and perceived contagiousness of the individual described in the vignette and their illness perceptions of CF were assessed.

As no previous studies have examined CF illness representations and attitudes towards people with CF in the general population, it was difficult to generate specific hypotheses regarding the expected differences in likeability and contagiousness ratings and illness representations between the vignette conditions, as well as predicting differences between the illness perceptions of study participants and those of individuals with CF (using data obtained from Study 1). However, extending previous research findings investigating perceptions of individuals with other physical illnesses, more general stigma research, and studies examining the psychosocial adjustment of individuals with CF discussed in Chapters 2 to 4, it was suggested that if a healthy lay person did not have specific knowledge about CF and noticed the observable symptoms and treatments of CF (i.e., coughing, taking a number of medications) then unfavourable conclusions may be drawn. However, if a person was given specific and accurate information about CF, including that about its genetic basis, then more positive reactions may be observed. Accordingly, the following research questions were evaluated in the current study:

1. How do members of the general community cognitively represent CF?
2. Do illness representations differ between individuals who have been given detailed information about CF, individuals who do not have detailed knowledge of CF, and young adults with CF?
3. Does the illness label given to coughing and medicating symptoms influence individuals’ perceived likeability and perceptions of contagiousness of people who cough and take medication frequently?

4. Do individuals’ perceptions of the likeability and contagiousness of people with CF differ between individuals who have been given detailed information about CF and those who have not?

5. For individuals who receive information about CF, are there differences between the illness representations of CF, perceived likeability and perceptions of contagiousness of people with CF between individuals who received this information from the person with CF themselves or another party?

6. Are there associations between perceptions of contagiousness, illness representations of CF, and perceived likeability of people with CF in the general population?

6.2 Method

6.2.1 Participants

Participants consisted of 167 (100 female; 67 male) undergraduate university students enrolled in non-health related subjects (e.g., business statistics, politics and policy, visual arts, engineering design, hospitality) from a Queensland university. Recruitment was limited to studying in non-health related areas to reduce the likelihood of including students who may have received specific information about CF as a part of their studies. It was considered that this would allow the sample to be more representative of the wider Australian population. Participants were aged between 17 and 63 years of age (\(M = 26.32, SD = 8.76\)); with the majority of the sample identifying themselves to be of Caucasian ethnicity (70.10%). Of the remaining participants, 24.00% identified as being of Asian descent, 1 person identified as being of Aboriginal or Torres Strait Islander descent (0.60%) and 9 participants (5.40%) did not specify their ethnicity.

Upon recruitment, participants were offered the opportunity to enter a draw to win one of 10 double cinema passes following the return of an anonymous questionnaire. Participants were also informed that study participation was completely voluntary, with no feedback being given to subject convenors regarding the participation of the group as a whole, or regarding any particular student’s participation. The return of a completed questionnaire was considered by the researcher to represent passive consent for participation. Upon return, questionnaires and prize draw entry
forms were stored separately by the researcher to ensure participant anonymity. All ethical aspects of this study were approved by the Griffith University Human Research Ethics Committee (protocol number: PSY/A3/08/HREC).

While participants were recruited from non-health related subjects, it was identified in the demographic data collected that about one-fifth (22.20%) of the sample obtained were enrolled in health-related degrees, but undertaking a non-health related subject as an elective course. The remainder of participants were enrolled in business/commerce related degrees (22.70%), arts/education related degrees (16.00%), or science/technology/law related degrees (17.80%). Thus, analyses on all key dependent measures (i.e., IPQ-R subscale total scores, likeability ratings, perceptions of contagiousness ratings) were undertaken to investigate potential differences in ratings between areas of study as it was predicted that health students may have more knowledge about CF than would be expected in the general population.

Given that 10 analyses were completed, a $p$-value of .005 was used to evaluate significant differences to control for Type 1 error. While some significant differences were identified, no consistent differences were found between study areas. For ratings of chronicity of CF (timeline acute-chronic), individuals enrolled in business/commerce degrees ($M = 23.11, SE = 0.39$) perceived CF as being less chronic than individuals enrolled in health-related ($M = 26.05, SE = 0.53$), and science/technology/law related degrees ($M = 26.28, SE = 0.60$), $F(3,159) = 10.21, p < .0001, \omega^2 = .15$. For perceived understanding of CF (illness coherence) health students ($M = 16.11, SE = 0.77$) perceived individuals with CF as having a greater understanding of their illness than arts/education students ($M = 11.62, SE = 0.92$), $F(3,159) = 5.22, p = .002, \omega^2 = .07$. No other significant differences between participant responses in the four areas of study were identified for any other subscales of the IPQ-R, the Reysen Likeability Scale or perceived contagiousness scale. Given that students enrolled in health-related degrees did not demonstrate consistent differences in ratings of perceptions of illness, likeability, and contagiousness, to students enrolled in business/commerce related, arts/education related, or science/technology/law related degrees, all data obtain from participants enrolled in health-related degrees were retained for further analysis.

One section of the questionnaire completed by participants also examined their previous experience with CF and other chronic illnesses. Specifically, participants were asked to specify if they have CF, or any other chronic illness, or had known/know anyone with CF or another chronic illness. Finally, participants were also asked to specify the type of relationship they have/had with this person, if applicable. While less
than one-fifth of the sample (17.40%) had indicated that they had known someone with CF and no individuals themselves had CF, nearly half (46.70%) of the sample had known someone with another chronic illness or had a chronic illness other than CF themselves. Thus, 80.80% of participants had not known a person with CF, and 50.30% of participants had not known a person with another chronic illness. The relationships participants held with individuals with CF and other chronic illnesses are described in Table 41.

Table 41

*Relationship Characteristics and Frequency of Contact with Persons Known with CF and Other Chronic Illnesses (CI)*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Person known with CF (n = 29)</th>
<th>Person known with CI (n = 78)</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Had illness themselves</td>
<td>0.00</td>
<td>6.40</td>
</tr>
<tr>
<td>% Close relative</td>
<td>6.90</td>
<td>62.80</td>
</tr>
<tr>
<td>% Extended family member</td>
<td>6.90</td>
<td>9.00</td>
</tr>
<tr>
<td>% Close friend</td>
<td>27.60</td>
<td>12.80</td>
</tr>
<tr>
<td>% Acquaintance</td>
<td>58.60</td>
<td>9.00</td>
</tr>
</tbody>
</table>

*Frequency of contact (with other person with CF or CI)*

| % Involved in person’s care     | 0.00                           | 11.00                         |
| % Lived with person             | 0.00                           | 16.40                         |
| % Saw person regularly          | 13.80                          | 37.00                         |
| % Saw person occasionally       | 86.20                          | 35.60                         |

The final section of the questionnaire assessed participants’ knowledge of CF before participating in the study as compared to the information provided in the questionnaire about CF. Over half (59.70%) of the sample reported that they had not heard of CF or were unsure of what CF was and about one-third (31.30%) of the sample reported either mistaking CF for another disease or knowing very little about it. Thus,
only 9.00% of the sample reported knowing either most or all of the information about CF given in the questionnaire prior to participation.

6.2.2 Stimuli

Participants received one of six vignettes. As a part of the vignettes, participants were asked to imagine that they worked in an office of 20 staff and a new employee was hired. In all conditions the new employee was described as having a phlegmy-cough and taking a number of pills every lunch time. The six conditions differed, however, on the reason that was supplied for the symptoms (no reason supplied, allergies, or CF), the amount of information supplied about CF (none or overview of condition), and who the CF explanation came from (the employee or another colleague). The six conditions derived from the combination of these variables are outlined in Table 42 and the full vignettes are presented in Appendix C.

The information given about CF in conditions 5 and 6 was based upon the overview of CF given in the CFQ (2001) Information Manual and WHO (1996b) Manual for Cystic Fibrosis Patients and their Parents as these resources are aimed at individuals with a non-medical background, which is consistent with the characteristics of the sample of the current study. The information presented in this format for lay individuals was updated, however, with the most current information about CF available at the time of questionnaire production (i.e., CGE, 2007a). For individuals in conditions 1 to 4, this information was also given to participants. However, in these questionnaires, the information page was located after rating scales of the person described in the vignette were presented and after the participants’ illness representations of CF were assessed. This allowed comparisons to be made between the illness perceptions, likeability, and contagiousness ratings of participants who had received information on CF and those who had not. Further, this also allowed all participants to give a rating of their level of knowledge of CF prior to entering the study, compared to that of the information received.

Additionally, in all versions of the questionnaire, the IPQ-R was placed directly after the vignette and its related likeability and contagiousness ratings. This order was chosen so that the completion of the IPQ-R regarding CF would not influence responses to the vignettes which did not specify CF as the reason for the symptoms described. Finally, to avoid potential interactions of participants’ gender and gender of the target character in the vignettes on participants’ ratings of likeability and contagiousness of the target character, male participants received versions of the vignette with a male target (‘Mark’) and females rated a female target (‘Fiona’).
Table 42

Characteristics of the Six Vignette Conditions and Condition Sample Sizes

<table>
<thead>
<tr>
<th>Condition</th>
<th>Symptoms</th>
<th>Reason Given for Symptoms</th>
<th>Information Given about CF</th>
<th>Reason and/or Information Giver</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Phlegmy-coughing</td>
<td>No reason given</td>
<td>N/A</td>
<td>N/A</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>Taking Pills at Meals</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Phlegmy-coughing</td>
<td>Allergies</td>
<td>N/A</td>
<td>N/A</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td>Taking Pills at Meals</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Phlegmy-coughing</td>
<td>Cystic</td>
<td>No information given</td>
<td>Person with CF</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>Taking Pills at Meals</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Phlegmy-coughing</td>
<td>Cystic</td>
<td>No information given</td>
<td>Other colleague</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>Taking Pills at Meals</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Phlegmy-coughing</td>
<td>Cystic</td>
<td>Overview of condition given</td>
<td>Person with CF</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>Taking Pills at Meals</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Phlegmy-coughing</td>
<td>Cystic</td>
<td>Overview of condition given</td>
<td>Other colleague</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>Taking Pills at Meals</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6.2.3 Measures

6.2.3.1 Dependent Measures

Likeability ratings. The perceived likeability of the individual described in the vignette was assessed using the Reysen Likeability Scale (Reysen, 2005). This scale measures respondents’ perceptions of a number of positive personality traits in another individual and also rates respondents’ willingness to socially interact with another individual. It consists of 11 items rated on a 7-point Likert-type scale (1-Very strongly disagree to 7-Very strongly agree). Examples items include “This person is warm” and “I would like this person as a roommate”. Possible total scores on this scale range from 11 to 77. Higher scores indicated greater likeability.

The Reysen Likeability Scale has been described as both a reliable and valid measure. Cronbach’s α coefficients for this scale are reported at .90 and above (Graham et al., 2008; Reysen, 2005) and convergent validity demonstrated with a significant association with the Agreeableness subscale of Goldberg’s (1992) 100-Adjective Big
In the current study, internal consistency of this scale was also high (α = .84).

*Perceptions of contagiousness.* Three questions addressed participants’ perceived contagiousness of the individual described in the vignette included in their questionnaire: “This person is likely to pass an illness onto me”, “I think this person could have a negative impact on my health” and “For health reasons I would avoid this person”. These items were measured on a 7-point Likert-type scale (1-very strongly disagree to 7-very strongly agree). Possible total scores for this scale ranged between 3 and 21; with a higher score indicating that the person is conceived as very contagious.

As no psychometrically validated scales could be identified which examined individuals’ perceptions of contagiousness of another individual, the items included in the current measure were derived by the current author in conjunction with an experienced researcher in health psychology and a clinical psychologist. In addition, feedback on these items was obtained from an expert in scale development. High internal consistency was obtained for this measure of perceived contagiousness, with α = .90. This measure was also significantly correlated with likeability scores, r (134) = -.37, p <.0001. As would be expected in the relationship between perceptions of contagiousness and likeability, as perceived contagiousness of the individual described in the vignette increased, their likeability ratings decreased.

*Illness representations.* Participants’ cognitive representations of CF were measured using the Illness Perception Questionnaire-Revised (IPQ-R; Moss-Morris et al., 2002). This measure examines individuals’ perceptions of illness symptomatology, timeline, cure/control, consequences, causality, illness understanding and emotional representations of illness.

The symptom subscale included a 14-item symptom checklist and required participants to indicate whether or not they believed particular symptoms (e.g., weight loss, fatigue) are related to CF. This was measured with yes/no dichotomous response options. A total score was generated for the number of symptoms attributed to CF. These scores were calculated by summing together the number of ‘yes’ responses on each symptom subscale.

The causality subscale included 18 possible causes of illness (e.g., heredity, poor medical care, chance/bad luck) and required participants to endorse the extent to which they believe each cause contributed to CF on a 5-point Likert-type scale (1 - strongly disagree to 5 - strongly agree). Moss-Morris et al. (2002) suggest that the causality items should not be added to generate a causality subscale; instead, they suggest the use
of factor analysis to identify groups of causal beliefs. This procedure was followed with the current sample. These results are reported in section 6.3.2.1.

Participant beliefs regarding symptom management and curability of illness were measured on two subscales; one six-item scale (one reverse scored) examining *person control* of illness (e.g., “People with CF have the power to influence their illness”) and one five-item subscale (two reverse scored) examining participants’ perceptions of the effectiveness of medical treatment (*treatment control*) for CF (e.g., “Treatment can control CF”). Next, the *consequences* of illness subscale examined individuals’ anticipated outcomes and effects stemming from the illness (e.g., “CF causes difficulties for those who are close to someone with CF”) with six items (one reverse scored). Perceptions of the chronicity of CF were measured with the *timeline-acute/chronic* subscale which included five items (three reverse scored) (e.g., “CF passes quickly”). Perceptions of the nature of CF over time were assessed with the four items on the *timeline-cyclical* subscale (e.g., “CF is very unpredictable”). Participants’ overall understanding of CF and its implications was measured with the five-item (four reverse scored) *illness coherence* subscale (e.g., “CF is a mystery to me”). Finally, participants’ *emotional representations* of illness were examined on a six-item subscale (one reverse scored) (e.g., “When people with CF think about their illness they become upset”). These final seven subscales of the IPQ-R required the participant to indicate the degree to which they endorsed each statement listed about CF on a 5-point Likert-type scale (1- *strongly disagree* to 5- *strongly agree*).

Total scores for each of these subscales were calculated by summing each item in the subscale. The four-item scales had a possible score range of 4 to 16; for five-item scales the range was 5 to 25; and the range was 6 to 36 for the six-item scales. A high score on the consequences, emotional representations, timeline-acute/chronic and timeline-cyclical subscales indicated negative perceptions of these domains of CF; whereas high scores on the personal control, treatment control, and illness coherence subscales indicated more positive perceptions of CF.

As reviewed in Study 1 (Chapter 5) a number of authors (e.g., Horne & Weinman, 2002; Llewellyn et al., 2006; Moss-Morris et al., 2002) have reported excellent reliability and validity for the IPQ-R. Good to excellent internal consistency was also found for most subscales in the current study including timeline-acute/chronic ($\alpha = .81$), consequences ($\alpha = .76$), illness coherence ($\alpha = .93$), emotional representations ($\alpha = .80$) and timeline-cyclical ($\alpha = .69$) subscales. However, lower reliability was
observed for the personal control (α = .63) and treatment control (α = .56) subscales. Accordingly, care was taken when interpreting results incorporating these measures.

Similarly, Holliday et al. (2005) reported alphas of .55 and .56 for the personal and treatment control subscales of the IPQ-R for a lay sample when rating their perceptions of individuals with anorexia nervosa. Additionally, Anagnostopoulos and Spanea reported internal consistency measures of the IPQ-R with a lay sample of individuals rating perceptions of breast cancer ranging between .63 and .80. and Vollman et al. (2010) reported alphas of .50 to .85 for a never-depressed group of individuals reporting their illness perceptions of depression. In these studies, however, it was not specified which subscale had the lower internal consistencies. Considering this psychometric data from past research and that from the current study, the results appear to suggest that the internal consistency of the IPQ-R may be lower when applied to samples other than individuals with chronic illness. This may reflect that when individuals have not experienced a particular illness they are less familiar with the realities of its lived experience and, therefore, may display greater variability in responses to questions around the experience of the illness. Further testing with lay samples is needed, however, before strong conclusions can be drawn.

6.2.3.2 Potential Control Variables

Demographics. The basic demographic information of age, gender, and ethnicity was gathered. Participants were also asked to indicate their current area of study. Given the small number of individuals enrolled in some degrees who participated in the current study, participants were grouped into one of four broader areas of study; health, business/commerce, arts/education, and science/technology/law.

Experience with CF and other chronic illnesses. Participants were required to indicate whether they themselves have CF or if they know/had known anyone with CF, as well as their relationship to this person (i.e., close relative, extended family member, close friend, acquaintance) and how often they see/saw this person (i.e., occasionally, regularly, lived with person, involved in person’s care). Further, participants were also asked to indicate the level of knowledge they had about CF before participating in this study. Participants were to choose either one of “None, I had never heard of cystic fibrosis”, “I had heard of cystic fibrosis, but was unsure of what this was”, “I thought I knew what cystic fibrosis was, but I had mistaken it for another condition”, “A little, I knew some of the information presented”, “Some, I knew about half of the information
given”, “Quite a lot, I knew most of the information given”, “A lot, I knew all of the information given”.

Participants were also required to indicate if they themselves had chronic illness, other than CF, or if they know/had known anyone with another chronic illness. As with the assessment of contact with individuals with CF, participants were again asked to indicate their relationship with this person with chronic illness and how often they see/saw this person.

6.2.4 Procedure

6.2.4.1 Pilot Testing

As the vignettes and perceived contagiousness scale were being used for the first time in the current research and the IPQ-R and Reysen’s Likeability Scale were being utilized for the first time for the assessment of lay persons’ perceptions of individuals with CF, the questionnaire was piloted before being used in the main testing phase. This piloting phase examined the readability and clarity of the questionnaire as well as generating preliminary psychometric data for the quantitative measures.

Twelve students from a non-health related subject completed the questionnaire; with one male and one female being randomly assigned to each of the six conditions. Participants were given a study information sheet, questionnaire and a questionnaire feedback form to complete. The return of these questionnaires to the researcher was considered as implicit consent to participate. As with the main sample, these participants were also eligible to enter the study’s prize draw.

The feedback form asked pilot participants to comment on how easily the questionnaire instructions were understood and how comfortable they felt completing the questionnaire. Additionally, any general comments on the questionnaire were also requested. The feedback obtained suggested that the vignette was realistic and the dependent measures were easy to comprehend and respond to. Finally, at this time, questionnaire completion time was also noted; being approximately 15 minutes.

Preliminary reliability analyses suggested that the likeability and contagiousness scales, as with five of the seven quantitative IPQ-R subscales, had adequate to excellent internal consistency (i.e., $\hat{\alpha} = .60 \text{ to } .95$). The personal and treatment control subscales of the IPQ-R, however, had poor reliability (i.e., .26 and .58, respectively). Yet, given that low internal reliability estimates (i.e., personal control = .55 and treatment control = .56) had also been reported for these subscales when they were applied in the assessment of lay individuals’ perceptions of anorexia nervosa with a substantially
larger sample (Holliday et al., 2005), these scales were retained in further testing in the main phase of the current study. Additionally, all other quantitative scales and vignettes piloted were retained in the main testing phase.

6.2.4.2 Main Testing

Prior to participant testing, a number of course convenors from one Queensland university were contacted by the current researcher to seek permission to recruit participants for the current study from their individual courses. Specifically, it was requested that the current researcher could briefly speak to students at the end of two consecutive lectures; at the first, to give participants information about the study and distribute questionnaire packages, and at the second, to collect completed questionnaires. Accordingly, students from consenting convenors were contacted in this manner and randomly assigned to questionnaire conditions after showing interest in participation. Participants were allowed to complete the questionnaire at a time and place of their convenience. However, they were directed to complete the questionnaire independently and not to discuss their responses with others participating in the study. The return of a complete questionnaire to the researcher was considered to represent passive consent for participation. Questionnaires contained no identifiable information (i.e., name, student number, contact details).

As discussed earlier, participants were also offered the opportunity to enter a draw to win one of 10 double cinema passes following the return of a completed questionnaire. Following the cessation of data collection prizes were drawn and all winners contacted.

6.3 Results

6.3.1 Preliminary Analyses

6.3.1.1 Missing Data

No variable had more than 5.00% missing data, suggesting that data was omitted by participants completely at random (Munro, 2005); accordingly, an imputation approach was considered to be appropriate to replace missing values on selected scales (Hair et al., 2006). As with Study 1 (Chapter 5), where particular imputation approaches were suggested by scale authors, their suggestions were followed. When suggestions for treatment of missing data were not made by original scale authors, approaches adopted in recent research for the particular scales were followed.
As followed in Study 1, for missing data on the IPQ-R (Moss-Morris et al., 2002) Moss-Morris and colleagues recommend that a maximum of two items on the six-item subscales (consequences, personal control, emotional representations), and a maximum of one item from five- and four-item subscales (treatment control, illness coherence, timeline cyclical) can be replaced with each participant’s individual mean of their responses from the remaining subscale items. Accordingly, when a participant had more than the suggested number of missing items for a particular subscale, a total subscale score was not calculated.

For the Reysen Likeability Scale, no specific information regarding the management of missing data could be retrieved from the applications of the scale by the author or that of other researchers utilising the scale. Thus, general procedures followed in Study 1 (Chapter 5) for missing data on scales with eight or more items were followed, using an individual mean substitution approach. Accordingly, missing data was substituted when a maximum of two data points were missing. When three or more items had missing data, no total score was calculated. For the scale assessing perceptions of contagiousness, procedures utilised in Study 1 for missing data on scales with three items or less were also followed. Accordingly, no missing data was substituted on this scale. Thus, total scores were not calculated for participants with any missing data on the three perceived contagiousness items.

6.3.1.2 Examination of Potential Control Variables

Of the demographic variables and variables examining individuals’ exposure to chronic illness, age, gender, ethnicity, experience with CF and experience with other chronic illnesses, were tested as potential control variables in analyses with all dependent measures (i.e., IPQ-R subscales, likeability ratings, perceived contagiousness ratings). As all dependent measures were continuous variables, when examining the impact of control variables, correlational analyses were completed with continuous controls and either ANOVA or t-test analyses were completed with categorical controls. Considering the large number of analyses completed, the alpha level was set at .001 to reduce Type 1 error.

No significant relationships were found between age or gender and any of the dependent measures. Conversely, differences were found between ethnic groups on two subscales of the IPQ-R. For ratings of chronicity of CF (timeline acute-chronic), individuals of Asian descent ($M = 21.75, SE = 0.49$) perceived CF as being less chronic than individuals of Caucasian descent ($M = 25.71, SE = 0.28$), $F(3,160) = 16.17, p < .0001, \omega^2 = .22$. For perceived consequences of CF, individuals of Asian descent ($M$
=21.30, SE = 0.46) perceived less impact of CF in individuals’ lives than individuals of Caucasian descent (M =24.49, SE = 0.27), F(3,160) = 12.37, p < .0001, ω² = .17. No other significant differences were identified between ethnic groups for any other dependent measure. As no significant differences were found between individuals of Caucasian descent, participants identifying as Aboriginal or Torres Strait Islander descent (ATSI), or those not specifying their ethnicity, ethnicity was recoded into two groups; Asian descent and Caucasian/ATSI/other. This recoded ethnicity variable was then used as a control measure in analyses with the timeline-acute/chronic subscale, and consequence subscales as dependent measures.

In analyses investigating potential differences between individuals who had experience with CF or other chronic illnesses, and those who had not, significant differences were found on a number of the IPQ-R subscales. Individuals who had known someone with CF perceived individuals with CF as having more personal control over their illness (t(162) = 3.99, p<.0001, d=.63), having a greater understanding of their illness (t(162) = 5.99, p<.0001, d=.94), and perceiving their illness as being more cyclical (t(162) = 4.50, p<.0001, d=.70) than those who had not known someone with CF. The descriptive statistics for these analyses are displayed in Table 43. Regarding experience of other chronic illnesses, individuals who had a chronic illness themselves, or knew someone with a chronic illness (represented in one group – known person with chronic illness) perceived CF as having a longer timeline (t(162) = 3.05, p=.0003, d=.48) and having more impact on individuals’ lives (t(162) = 5.28, p<.0001, d=.83) than those who had not known someone with chronic illness. The descriptive statistics for these analyses are also shown in Table 43.

On the basis of these results, the variable examining experience with CF was used as a control variable in analyses with personal control, illness coherence, and timeline-cyclical as dependent measures. Additionally, the variable examining experience with other chronic illnesses was used as a control in analyses with timeline-acute/chronic and consequences as dependent measures.
Table 43

Descriptive Statistics (Mean and Standard Error) for Differences Between CF and Other Chronic Illnesses (CI) Experience Groups on IPQ-R Subscales with Significant Group Differences

<table>
<thead>
<tr>
<th>IPQ-R domain</th>
<th>Experience with CF</th>
<th>Experience with other CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Known person with CF</td>
<td>Not known person with CF</td>
</tr>
<tr>
<td></td>
<td>(n = 29)</td>
<td>(n = 135)</td>
</tr>
<tr>
<td>Timeline-acute/chronic</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Consequences</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Personal Control</td>
<td>22.62 (.52)</td>
<td>20.34 (.24)</td>
</tr>
<tr>
<td>Illness Coherence</td>
<td>18.59 (.83)</td>
<td>13.16 (.38)</td>
</tr>
<tr>
<td>Timeline-cyclical</td>
<td>14.44 (.38)</td>
<td>12.60 (.17)</td>
</tr>
</tbody>
</table>

6.3.2 Main Analyses

6.3.2.1 Illness Representations of Cystic Fibrosis in the General Community

The first aim of the current study was to examine the cognitive representations of CF in the general community. Of the data generated in the current study, it was considered that the illness perceptions data from participants in conditions 1 to 4 would be the closest approximation of the representations of CF held in the general community as in these conditions participants did not receive the detailed information about CF until after completing the IPQ-R.

Causal attributions. As discussed previously, the cause subscale of the IPQ-R contains a list of 18 potential causes of an illness and instructs participants to indicate how likely it is that each cause listed contributes to the experience of that illness. Unlike the remaining subscales of the IPQ-R, Moss-Morris et al. (2002) advised that a total score based upon the number of causes endorsed not be calculated, instead, recommending that a factor analysis of the items be completed to identify clusters of causal beliefs. Within Moss-Morris et al.’s research and studies of other authors completing factor analysis with IPQ-R data (e.g., Page, Husain, Dowson, Weinman, & Wessley, 2004; Wittkowski, Richards, Williams, & Main, 2008) exploratory principal
component analyses with varimax rotations were used for the analysis of the causal data. Thus, this approach was also adopted in the current study. All assumptions for this analysis (i.e., data normality, sampling adequacy, and sphericity) were met.

As displayed in Table 44, four factors were extracted, accounting for 69.31% of the total variance. The four factors attained were very similar to those obtained by Moss-Morris et al. (2002) in their original analysis of the IPQ-R cause scale with a mixed sample of chronically ill patients. Moss-Morris et al. identified *psychological attributions* (stress; attitude; family problems; overwork; emotional state; personality), *risk factors* (heredity; diet; poor medical care; own behaviour; ageing; smoking; alcohol), *immunity* (germ/ virus; pollution; poor immunity), and *accident or chance* (chance; accident/ injury) as the dimensions of causes. The main differences between Moss-Morris et al.’s factor structure and that obtained in the current study can be attributed to the known medical causes for CF. Accordingly, Factor 4 (*heredity*) obtained in the current study reflected the genetic basis of CF. Factors 1 (*psychological and behavioural attributions*) and 2 (*physical and external risk factors*) obtained in the current study only differ to those of Moss-Morris et al. in that the current data presents both psychological and behavioural risk factors on one dimension, with physical and teratogenic factors being represented in another. In comparison, the data obtained by Moss-Morris et al. represented behavioural, physical and teratogenic risk factors on one dimension, with psychological attributions represented independently on one factor as shown above. Finally, Factor 3 (*immunity*) obtained in the current study included the same three items as that of Moss-Morris et al., with similar factor loadings.

In addition to examining the factor structure of the causes of CF perceived in the current student sample, the importance of each of the 18 factors was also examined. To obtain this data, the original continuous causal variables were recoded into categorical variables each with two levels; important cause (rated 4 or 5 agree/strongly agree on continuous measure) and not important cause (rated 1 to 3 disagree to neither agree nor disagree). As shown in Table 45, a hereditary basis was the cause most frequently endorsed as an important cause, as expected, whereas the more psychological and behavioural-based causes were those endorsed least frequently as likely causes of CF.
Table 44

Principal Component Analysis of the IPQ-R Causal Items Examining Perceived Causes of Cystic Fibrosis within a Student Community Sample (n=111)

<table>
<thead>
<tr>
<th></th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
<th>Factor 4</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Eigenvalue</strong></td>
<td>8.83</td>
<td>1.48</td>
<td>1.12</td>
<td>1.04</td>
</tr>
<tr>
<td><strong>% of variance accounted for</strong></td>
<td>49.06</td>
<td>8.24</td>
<td>6.24</td>
<td>5.76</td>
</tr>
<tr>
<td><strong>Psychological and Behavioural Attributions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family problems</td>
<td>.89</td>
<td>.15</td>
<td>.18</td>
<td>-.06</td>
</tr>
<tr>
<td>Emotional state</td>
<td>.86</td>
<td>.31</td>
<td>.10</td>
<td>-.05</td>
</tr>
<tr>
<td>Overwork</td>
<td>.82</td>
<td>.32</td>
<td>.18</td>
<td>-.03</td>
</tr>
<tr>
<td>Mental attitude</td>
<td>.79</td>
<td>.26</td>
<td>.15</td>
<td>-.18</td>
</tr>
<tr>
<td>Stress/worry</td>
<td>.77</td>
<td>.20</td>
<td>.11</td>
<td>.07</td>
</tr>
<tr>
<td>Personal behaviour</td>
<td>.74</td>
<td>.39</td>
<td>.21</td>
<td>-.01</td>
</tr>
<tr>
<td>Eating habits</td>
<td>.62</td>
<td>.41</td>
<td>.28</td>
<td>.07</td>
</tr>
<tr>
<td>Personality factors</td>
<td>.60</td>
<td>.50</td>
<td>.28</td>
<td>.07</td>
</tr>
<tr>
<td><strong>Physical and External Risk Factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ageing</td>
<td>.30</td>
<td>.77</td>
<td>.16</td>
<td>.13</td>
</tr>
<tr>
<td>Accident/injury</td>
<td>.19</td>
<td>.75</td>
<td>.08</td>
<td>-.22</td>
</tr>
<tr>
<td>Smoking</td>
<td>.38</td>
<td>.71</td>
<td>.23</td>
<td>-.06</td>
</tr>
<tr>
<td>Alcohol</td>
<td>.51</td>
<td>.71</td>
<td>.05</td>
<td>-.05</td>
</tr>
<tr>
<td>Poor medical care</td>
<td>.37</td>
<td>.70</td>
<td>.29</td>
<td>.11</td>
</tr>
<tr>
<td><strong>Immunity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Germ/virus</td>
<td>.26</td>
<td>.04</td>
<td>.78</td>
<td>-.20</td>
</tr>
<tr>
<td>Poor immunity</td>
<td>.18</td>
<td>.33</td>
<td>.71</td>
<td>.18</td>
</tr>
<tr>
<td>Pollution in environment</td>
<td>.21</td>
<td>.47</td>
<td>.51</td>
<td>.11</td>
</tr>
<tr>
<td><strong>Heredity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hereditary basis</td>
<td>-.01</td>
<td>-.15</td>
<td>-.27</td>
<td>.77</td>
</tr>
<tr>
<td>Chance/bad luck</td>
<td>-.08</td>
<td>.08</td>
<td>.25</td>
<td>.59</td>
</tr>
</tbody>
</table>
Table 45

*Frequency of Causes of Cystic Fibrosis Endorsed by a Student Community Sample (n=111)*

<table>
<thead>
<tr>
<th>Cause</th>
<th>Important cause (% endorsed)</th>
<th>Not important cause (% endorsed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hereditary basis</td>
<td>78.10</td>
<td>21.90</td>
</tr>
<tr>
<td>Poor immunity</td>
<td>47.40</td>
<td>52.60</td>
</tr>
<tr>
<td>Ageing</td>
<td>35.10</td>
<td>64.90</td>
</tr>
<tr>
<td>Chance</td>
<td>34.20</td>
<td>65.80</td>
</tr>
<tr>
<td>Smoking</td>
<td>33.35</td>
<td>66.65</td>
</tr>
<tr>
<td>Germ/virus</td>
<td>32.50</td>
<td>67.50</td>
</tr>
<tr>
<td>Pollution in environment</td>
<td>30.70</td>
<td>69.30</td>
</tr>
<tr>
<td>Poor medical care</td>
<td>27.20</td>
<td>72.80</td>
</tr>
<tr>
<td>Alcohol</td>
<td>19.30</td>
<td>80.70</td>
</tr>
<tr>
<td>Eating habits</td>
<td>19.30</td>
<td>80.70</td>
</tr>
<tr>
<td>Stress/worry</td>
<td>19.30</td>
<td>80.70</td>
</tr>
<tr>
<td>Personal behaviour</td>
<td>17.50</td>
<td>82.50</td>
</tr>
<tr>
<td>Overwork</td>
<td>15.80</td>
<td>84.20</td>
</tr>
<tr>
<td>Personality factors</td>
<td>14.00</td>
<td>86.00</td>
</tr>
<tr>
<td>Accident/injury</td>
<td>13.20</td>
<td>86.80</td>
</tr>
<tr>
<td>Emotional state</td>
<td>13.20</td>
<td>86.80</td>
</tr>
<tr>
<td>Family problems</td>
<td>12.30</td>
<td>87.70</td>
</tr>
<tr>
<td>Mental attitude</td>
<td>9.60</td>
<td>90.40</td>
</tr>
</tbody>
</table>

*Illness identity.* In the majority of studies examining individuals’ perceptions of the symptoms of an illness using the IPQ-R, only the total score on illness identity (total number of symptoms associated with an illness) is used for descriptive purposes or within more complex statistical analyses. This descriptive data is presented for the illness identity data obtained from participants in conditions 1 to 4 of the current sample in Table 47. However, in addition to this descriptive data, in the current study, frequency of symptoms being endorsed as those experienced by individuals with CF, as rated by the current student community sample, was included as it was considered that a closer analysis of this data is important for gaining a greater awareness of the understanding of CF in the general community. This data is presented in Table 46. While the underlying cause of CF appeared to be relatively well known in the current sample, the data suggested that particular symptoms associated with CF are less well
understood, with 10 of the 14 general symptom items being endorsed by at least half of the current sample as a symptom related to CF. Further, breathlessness and wheeziness, key symptoms experienced by those with CF, were only rated as the sixth and tenth most common symptoms.

Table 46

*Frequency of Symptoms Related to Cystic Fibrosis as Endorsed by a Student Community Sample (n=114)*

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Related to cystic fibrosis (% endorsed)</th>
<th>Not related to cystic fibrosis (% endorsed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>89.50</td>
<td>10.50</td>
</tr>
<tr>
<td>Loss of strength</td>
<td>85.10</td>
<td>14.90</td>
</tr>
<tr>
<td>Fatigue</td>
<td>82.50</td>
<td>17.50</td>
</tr>
<tr>
<td>Sleep difficulties</td>
<td>77.20</td>
<td>22.80</td>
</tr>
<tr>
<td>Weight loss</td>
<td>64.90</td>
<td>35.10</td>
</tr>
<tr>
<td>Breathlessness</td>
<td>63.20</td>
<td>36.80</td>
</tr>
<tr>
<td>Dizziness</td>
<td>60.50</td>
<td>39.50</td>
</tr>
<tr>
<td>Stiff joints</td>
<td>60.50</td>
<td>39.50</td>
</tr>
<tr>
<td>Headache</td>
<td>57.90</td>
<td>42.10</td>
</tr>
<tr>
<td>Wheeziness</td>
<td>53.50</td>
<td>46.50</td>
</tr>
<tr>
<td>Sore throat</td>
<td>41.20</td>
<td>58.80</td>
</tr>
<tr>
<td>Nausea</td>
<td>40.40</td>
<td>59.60</td>
</tr>
<tr>
<td>An upset stomach</td>
<td>38.60</td>
<td>61.40</td>
</tr>
<tr>
<td>Sore eyes</td>
<td>26.30</td>
<td>73.70</td>
</tr>
</tbody>
</table>

*Illness consequences, control, timeline, understanding and emotional representations of illness.* Table 47 presents the descriptive statistics for the remaining IPQ-R domains (i.e., symptoms experienced, timeline-acute/chronic, consequences, personal control, treatment control, illness coherence, timeline-cyclical, emotional representations) for the current student sample who did not receive detailed information about CF. This table also contains the descriptive data for these domains obtained from adolescents and young adults with CF at T1 of Study 1 of the current research. Thus, these descriptive statistics are examining aspects of both the first and second research questions of the current study. As discussed in Study 1, the timeline-acute/chronic dimension of the IPQ-R was not assessed by the CF patient and parent sample in the current study as it was considered that little variability would be obtained on this
measure and it may be considered insensitive by the population. Also discussed in Study 1, the CF patient and parent sample completed two versions of the illness identity measures – one measuring symptoms experienced in the previous year generally, and another measuring symptoms experienced in the previous year related to CF. Thus, the general symptom illness identity measure was not completed by the student community sample in the current study.

Comparing across the three samples, the data suggested that illness perceptions of CF differed between the student, CF patient groups and CF parent groups. Thus, ANOVA was completed for each of the IPQ-R domains, examining differences between the student, patient and parent groups. For all analyses all assumptions (i.e., normality and homogeneity of variance) were met and all effect sizes reported in this section and those for all other results presented in this chapter were interpreted using Cohen’s (1988) conventions. The descriptive statistics for all analyses are displayed in Table 47.

Regarding the CF illness identity subscale, a significant effect of group was obtained, $F(2, 218) = 6.57, p=.002, \omega^2=.05$. The effect sizes obtained suggest that the group had a small effect on illness identity ratings. Students perceived significantly more symptoms being experienced by individuals with CF than symptoms reported by the CF patient group ($p=.001, d=.68$). This represented a moderate effect size of over half a standard deviation between the student and patient groups. No significant differences were identified between the student and parent groups ($p=.314$) or the patient and parent groups ($p=.194$).

Examining the results for perceptions of consequences of CF, a moderate significant effect of group was obtained, $F(2, 217) = 12.51, p<.0001, \omega^2=.09$. Patients reported CF as having fewer consequences than both students ($p<.0001, d=.63$) and parents ($p<.0001, d=.82$), who did not significantly differ ($p=.237$). The difference between patients and students was a moderate effect size of over one half of a standard deviation unit. The difference between patients and parents was a large effect, approaching one standard deviation unit.

Regarding the personal control subscale, a large significant effect of group was obtained, $F(2, 218) = 22.98, p<.0001, \omega^2=.17$. All groups significantly differed to one another. Students perceived individuals with CF as having less control over their illness than both patients ($p<.0001, d=1.16$) and parents ($p<.0001, d=.43$). The effects represented large and small differences between groups, respectively, with over a one standard deviation unit difference between students and patients, and nearly a half a standard deviation unit difference between students and parents. Additionally, patients
perceived significantly greater personal control over CF than parents \( (p = .014, d = .63) \); being a moderate sized difference of over one half of a standard deviation unit between the groups. A small significant effect of group on perceptions of treatment control of CF was also attained, \( F(2, 217) = 3.74, p = .025, \omega^2 = .02 \), where patients perceived significantly more impact of medical treatments on CF than parents \( (p = .03, d = .46) \). This represented a moderate sized difference between the groups approaching one half of a standard deviation unit.

Examining the results for the impact of group on understanding of illness, a large significant effect was found, \( F(2, 218) = 94.79, p < .0001, \omega^2 = .46 \). Students reported significantly less understanding of CF than both patients \( (p < .0001, d = 1.79) \) and parents \( (p < .0001, d = 1.89) \), who did not differ \( (p = .999) \). Both of these effects represented large differences approaching two standard deviation units between both students and patients, and students and parents.

A marginally significant effect of group was found on perceptions of the cyclical nature of CF, \( F(2, 218) = 2.92, p = .056, \omega^2 = .02 \). The student group perceived CF as being more cyclical than the patient group \( (p = .071, d = .35) \). This represented a small difference between the groups of one third of a standard deviation unit.

Finally, regarding the effect of group on emotional representations, a large significant effect was found, \( F(2, 218) = 21.62, p < .0001, \omega^2 = .16 \). Two significant differences between the three groups were identified, with patients reporting less emotional distress related to CF than that perceived by students \( (p < .0001, d = 1.11) \) and parents \( (p < .0001, d = 0.73) \), who did not significantly differ \( (p = .467) \). These differences represented a large effect of over one standard deviation unit between patients and students, and a moderate size effect of nearly three-quarters of a standard deviation unit between patients and parents.

To summarise the significant effects obtained in these analyses, students’ illness representations of CF were more negative than those of patients, with the student group perceiving more symptoms, consequences, and emotional concerns associated with CF, and less personal control and understanding of CF than the patient group. Additionally, students also held more negative perceptions of CF than parents of children with CF within both the personal control and understanding domains of illness representations. Finally, patients were also identified to have more negative representations of illness than parents in a number of illness representation domains. The patient group perceived fewer consequences, more personal and treatment control and fewer emotional concerns associated with CF than the parent group.
Table 47

*IPQ-R Domain Student (n=110), Patient, (n=49), and Parent (n=61) Descriptive Statistics*

<table>
<thead>
<tr>
<th>Domain</th>
<th>Student sample</th>
<th>CF patient sample</th>
<th>CF parent sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>SE</td>
</tr>
<tr>
<td>Symptoms Experienced</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Symptoms Related to CF</td>
<td>8.47</td>
<td>2.61</td>
<td>.25</td>
</tr>
<tr>
<td>Consequences</td>
<td>23.87</td>
<td>3.02</td>
<td>.29</td>
</tr>
<tr>
<td>Personal Control</td>
<td>20.75</td>
<td>2.75</td>
<td>.26</td>
</tr>
<tr>
<td>Treatment Control</td>
<td>16.26</td>
<td>2.79</td>
<td>.27</td>
</tr>
<tr>
<td>Illness Coherence</td>
<td>13.51</td>
<td>4.97</td>
<td>.47</td>
</tr>
<tr>
<td>Timeline-cyclical</td>
<td>13.00</td>
<td>2.00</td>
<td>.20</td>
</tr>
<tr>
<td>Timeline-acute/chronic</td>
<td>24.41</td>
<td>3.38</td>
<td>.32</td>
</tr>
<tr>
<td>Emotional Representations</td>
<td>20.96</td>
<td>3.09</td>
<td>.29</td>
</tr>
</tbody>
</table>
6.3.2.2 Experimental Analyses

Research questions 2 to 5 of the current study examined the effects of reasons for the experience of symptoms of illness on individuals’ likeability and perceived contagiousness, and the effect of information about CF and the person delivering the CF-related information on illness perceptions of CF and likeability and perceived contagiousness of individuals with CF, as rated by a student community sample. The condition variable which was used to signify which vignette participants received (see Table 42) was recoded to best capture the effects tested in each of these research questions. Recodings of the vignette conditions are discussed as needed below.

Illness label – impact on likeability ratings and perceived contagiousness.
Research question 3 examined whether the reason given for the experience of general symptoms of illness impacted likeability ratings and perceived contagiousness of individuals experiencing symptoms of illness. In the vignettes given to participants in the current study, three different illness labels were given to explain general illness symptoms (i.e., having a phlegmy-sounding cough and taking medications) experienced by a new employee in a workplace. Participants were either given no reason for the symptoms, told that allergies were the cause of the person’s symptoms, or told that CF was causing the symptoms. As 4 of the 6 conditions gave CF as the reason for experiencing symptoms the four CF conditions were merged to create one ‘CF reason’ group. Accordingly, one-way ANOVAs were completed to examine differences between the ‘no reason’, ‘allergy reason’ and ‘CF reason’ groups on likeability ratings and perceptions of contagiousness.

While no violations of normality were observed for the no reason group on either the likeability or contagiousness measures, some skew was observed for the allergy reason and CF reason group on likeability and for the CF reason group on contagiousness. In all cases, the majority of the sample had low to moderate likeability/contagiousness ratings with few high scores. Accordingly, care was taken when interpreting the results of analyses including these variables. For both the analysis of likeability and contagiousness ratings, the assumption of homogeneity of variance was met.

Reasons given for symptoms were found to have a significant effect on both likeability ratings \( F(2,164) = 3.08, p = .048, \omega^2 = .02 \) and perceptions of contagiousness \( F(2,164) = 28.12, p < .0001, \omega^2 = .25 \). The effect sizes obtained suggest that the reasons for symptoms had a small effect on likeability ratings and a large effect on perceptions of contagiousness.
For likeability ratings, a significant difference was obtained between the allergy reason group and CF reason group \((p=.043, \, d=.049)\). Likeability ratings were significantly lower for individuals perceived to have allergies than for individuals perceived to have CF. This represented a moderate effect size, indicating a difference of about one half of a standard deviation unit between the allergy reason and CF reason groups. Yet, no significant differences were obtained between the allergy reason and no reason groups \((p=.627)\), or the no reason group and the CF reason group \((p=.999)\). The descriptive statistics for this analysis are displayed in Table 48.

For contagiousness ratings, significant differences were obtained between both the CF reason group and no reason group \((p<.0001, \, d=1.24)\) and CF reason group and allergy reason group \((p<.0001, \, d=1.23)\). Contagiousness ratings were significantly lower for individuals perceived to have CF than for individuals perceived to have either allergies or an unknown cause for their symptoms. Both of these effects were large, with ratings for the CF reason group over 1 standard deviation lower than those of the no reason and allergy reason groups. No difference was obtained between the no reason group and allergy reason group \((p=.999)\). The descriptive statistics for this analysis are also displayed in Table 48.

Table 48

Descriptive Statistics for Ratings of Likeability and Perceptions of Contagiousness for the No Reason \((n=28)\), Allergy Reason \((n=34)\) and CF Reason \((n=105)\) Groups as Rated by a Student Sample

<table>
<thead>
<tr>
<th>Group</th>
<th>Mean</th>
<th>SD</th>
<th>SE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Likeability</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No reason</td>
<td>51.25</td>
<td>7.19</td>
<td>1.37</td>
</tr>
<tr>
<td>Allergy reason</td>
<td>48.92</td>
<td>7.00</td>
<td>1.25</td>
</tr>
<tr>
<td>CF reason</td>
<td>51.53</td>
<td>7.36</td>
<td>0.71</td>
</tr>
<tr>
<td><strong>Contagiousness</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No reason</td>
<td>10.86</td>
<td>3.41</td>
<td>0.69</td>
</tr>
<tr>
<td>Allergy reason</td>
<td>10.82</td>
<td>3.76</td>
<td>0.63</td>
</tr>
<tr>
<td>CF reason</td>
<td>6.46</td>
<td>3.67</td>
<td>0.36</td>
</tr>
</tbody>
</table>
Information about CF – impact on likeability ratings, perceived contagiousness and illness perceptions of CF. Research questions 2 and 4 examined the impact of receiving detailed information about CF on likeability and perceived contagiousness ratings of individuals known to have CF and on general illness representations of CF. In the vignettes given to participants, 4 of the 6 conditions described a person with CF and of these, two conditions specified CF as the reason for the person’s coughing and medication use without providing detailed information about CF, and the other two conditions both specified CF as the reason for the person’s symptoms and outlined specific information about CF to the reader. Thus, these four groups were recoded to form two groups; a ‘CF information’ group and a ‘no-CF information’ group. Accordingly, the two vignette conditions which did not specify CF as a cause of the person’s symptoms were excluded from these analyses.

As discussed in section 6.3.1.2, three demographic and illness experience variables were identified which had significant effects on some domains of illness perception ratings in the current study. Accordingly, for analyses with either timeline-acute/chronic and consequences as dependent measures, ethnicity and experience with chronic illness were used as control variables and for analyses with either personal control, timeline-cyclical or illness coherence as dependent measures, experience with CF was used as a control measure. Thus, for analyses including control measures, factorial ANOVA was utilised to test the effects of information and the control variables on the dependent measures. For analyses examining the effect of information only on dependent measures, *t*-tests were utilised.

No violations of normality were observed for either the CF information group or no-CF information group on any of the illness perception domains. However, for both ratings of likeability and contagiousness slight skew was observed in both information groups. In all cases, the majority of the sample had low to moderate likeability/contagiousness rating with few high scores. Accordingly, care was taken when interpreting the results of analyses including these variables. No violations of normality were observed for any groups within the control measures on any of the dependent variables. For all analyses, the assumption of homogeneity of variance was met.

For both likeability ratings (*t*(103) = -0.52, *p* = 0.603) and perceptions of contagiousness (*t*(103) = 1.73, *p* = 0.087), no significant effects of information were obtained. Further, no significant effects of information were identified on either the illness identity (*t*(103) = -0.31, *p* = 0.76), treatment control (*t*(103) = 1.86, *p* = 0.066) or
emotional representations ($t(103) = 1.05, p = .296$) subscales of the IPQ-R. A number of significant effects were identified, however, for the remainder of the IPQ-R subscales.

For perceptions of the chronicity of CF, a large significant effect of ethnicity was obtained ($F(1,97) = 22.77, p < .0001, \omega^2 = .17$), but no significant effects were identified for either information ($F(1,97) = .36, p = .553$) or experience with chronic illness ($F(1,97) = .01, p = .941$). Further, no interactions were obtained between any combinations of these three factors. Participants of Asian ethnicity ($M = 22.20, SE = .77, SD = 3.42$) perceived CF as being a less chronic condition than participants of Caucasian/Indigenous/other ethnicity ($M = 25.89, SE = .40, SD = 2.89$), $p < .0001, d = 1.17$. This represented a large difference of over one standard deviation unit between the groups.

For perceived consequences of CF, a moderate significant effect of ethnicity ($F(1,97) = 10.01, p = .002, \omega^2 = .07$), and a small significant effect of experience with chronic illness ($F(1,97) = 5.33, p = .023, \omega^2 = .05$) were obtained; yet, no significant effect of information ($F(1,97) = 1.06, p = .309$) was observed. Further, no interactions were obtained between any combinations of these three factors. Participants of Asian ethnicity ($M = 21.45, SE = .60, SD = 2.67$) perceived CF as having less impact on individuals’ lives than participants of Caucasian/Indigenous/other ethnicity ($M = 24.38, SE = .41, SD = 2.95$), $p = .002, d = 1.04$; being a large difference between groups of just over one standard deviation. Additionally, individuals with previous experience with a person with chronic illness ($M = 24.91, SE = .41, SD = 2.37$) perceived CF as having a greater impact on individuals’ lives than participants who had not had previous experience with chronic illness ($M = 22.41, SE = .53, SD = 3.30$), $p = .023, d = .87$; being a large difference of just under one standard deviation between groups.

In the examination of perceived personal control over CF, a moderate effect of experience with CF ($F(1,101) = 16.01, p < .0001, \omega^2 = .13$) was obtained. Conversely, no significant effect of information ($F(1,101) = .15, p = .700$) or the interaction between information and experience with CF ($F(1,101) = 0.14, p = .906$) was obtained. Individuals with previous experience with a person with CF ($M = 23.50, SE = .74, SD = 2.77$) perceived individuals with CF as having greater control over their illness than participants who had not had previous experience with CF ($M = 20.46, SE = .39, SD = 2.89$), $p < .0001, d = 1.07$. This represented a large difference between groups of over one standard deviation.

Regarding perceptions of the cyclical nature of CF, a moderate significant effect of experience with CF ($F(1,101) = 11.10, p = .001, \omega^2 = .09$) was obtained. Conversely, no significant effect of information ($F(1,101) = .00, p = .998$) or the interaction between
information and experience with CF ($F(1,101) = 0.97, p = .328$) was obtained. Individuals with previous experience with a person with CF ($M = 14.07, SE = .44, SD = 1.74$) perceived CF as being more cyclical than participants who had not had previous experience with CF ($M = 12.71, SE = .26, SD = 2.02$), $p=.001, d=.72$; being a moderate sized difference of close to three quarters of a standard deviation unit between groups.

Finally, for participants’ perceived understanding of CF, a large significant effect of experience with CF ($F(1,101) = 23.00 , p <.0001, \omega^2 = .17$) was obtained. Conversely, no significant effect of information ($F(1,101) = .75, p = .390$) or the interaction between information and experience with CF ($F(1,101) = 1.88, p = .173$) was identified. Individuals with previous experience with a person with CF ($M = 18.00, SE = 1.05, SD = 3.94$) reported a greater understanding of CF than participants who had not had previous experience with CF ($M = 13.12, SE = .54, SD = 2.42$), $p<.0001, d=2.42$. This represented a large difference of nearly two and a half standard deviation units between groups.

To summarise the significant effects obtained in these analyses, the receipt of information about CF was not found to change individuals’ illness representations of CF, or their perceptions of the likeability or contagiousness of individuals with CF. However, a number of significant effects of the control variables were obtained. Individuals of Asian ethnicity perceived fewer consequences and a less chronic nature of CF than individuals of Caucasian/Indigenous/other ethnicities, thus holding more positive representations of CF, overall. Additionally, previous experience with either chronic illness or CF impacted illness representations of CF, with individuals with experience with chronic illness perceiving more consequences of CF than individuals with no previous experience with chronic illness. Additionally, individuals with previous experience with CF perceived more positive representations of CF than individuals with no previous experience with CF in the domains of understanding of illness and perception of personal control over CF. However, individuals with experience with CF also perceived a more cyclical nature of illness than individuals with no previous experience with CF, being a more negative experience.

**Identity of the giver of information about CF – impact on likeability ratings, perceived contagiousness and illness perceptions of CF.** Research question 5 examined whether the identity of the giver of information about CF would affect likeability or contagiousness ratings of a person with CF, or illness perceptions of CF in the general community. In the vignettes given to participants, conditions 5 and 6 presented CF as the reason for the coughing and medication use of the person described in the vignette and also gave detailed information about CF. These vignettes differed, however, in that
in condition 5, the person with CF information about their condition (‘self CF information group’); whereas in condition 6, the office manager provided the information about CF (‘other CF information group’). Thus, participants in the four other vignette conditions, where no information about CF was given, were excluded from these analyses.

As mentioned in the previous section, for analyses with either timeline-acute/chronic and consequences as dependent measures, ethnicity and experience with chronic illness were used as control variables and for analyses with either personal control, timeline-cyclical or illness coherence as dependent measures, experience with CF was used as a control measure. Thus, for analyses including control measures, factorial ANOVA was utilised to test the effects of information and the control variables on the dependent measures. For analyses examining the effect of information only on dependent measures, analyses were conducted using t-tests.

No violations of normality were observed for either the self-CF information group or other-CF information group on any of the illness perception domains, or for likeability or contagiousness ratings. Also, no violations of normality were observed for any groups within the control variables on any of the dependent measures. For all analyses, the assumption of homogeneity of variance was met.

For both likeability ratings (t(51) = 1.15, p = .258) and perceptions of contagiousness (t(51) = -.85, p = .398), no significant effects of information giver were obtained. Further, no significant effects of information giver were observed on either the illness identity (t(51) = .91, p = .365), treatment control (t(51) = -.71, p = .484) or emotional representations (t(51) = -.69, p = .493) subscales of the IPQ-R. Of the five remaining subscales of the IPQ-R, including those involving control measures, significant effects were only found for 3 of the 5 subscales. For both the consequences subscales, no significant effect of information giver (F(1,45) = .11, p=.748), ethnicity (F(1,45) = 2.14, p=.150), previous experience with chronic illness (F(1,45) = .98, p=.329), or any combination of interactions between these variables were obtained. Further, for the emotional representations subscale, no significant effects of information giver (F(1,49) = .01, p=.934), previous experience with CF (F(1,49) = 2.49, p=.121), or the interaction between these two variables (F(1,49) = .30, p=.584) were obtained.

Regarding perceptions of the chronicity of CF, a large significant effect of ethnicity was obtained (F(1,45) = 8.30, p =.006, $\omega^2 = .13$), but no significant effects were observed for either information giver (F(1,45) = .09, p = .769) or experience with chronic illness (F(1,45) = .67, p = .418). Further, no significant interactions were obtained between any
combinations of these three factors. Participants of Asian ethnicity (\(M = 22.20, SE = 1.11, SD = 3.52\)) perceived CF as being a less chronic condition than participants of Caucasian/Indigenous/other ethnicity (\(M = 26.00, SE = .54, SD = 3.52\)), \(p = .006, d = 1.08\). This represented a large difference of just over one standard deviation unit between the groups.

In the examination of perceived personal control over CF, a moderate significant effect of experience with CF \((F(1,49) = 7.31, p = .009, \omega^2 = .11)\) was obtained. Conversely, no significant effect of information giver \((F(1,49) = .41, p = .830)\), or the interaction between information giver and experience with CF \((F(1,49) = 1.44, p = .236)\) was obtained. Individuals with previous experience with a person with CF \((M = 23.10, SE = .97, SD = 3.07)\) perceived individuals with CF as having a greater control over their illness than participants who had not had previous experience with CF \((M = 20.37, SE = .45, SD = 2.94), p = .009, d = .91\). This represented a large difference between groups of just under one standard deviation.

Finally, examining the perceptions of the cyclical nature of CF, a moderate significant effect of experience with CF \((F(1,49) = 7.34, p = .009, \omega^2 = .11)\) was obtained. Conversely, no significant effect of information giver \((F(1,49) = .08, p = .777)\) or the interaction between information giver and experience with CF \((F(1,49) = .01, p = .937)\) was obtained. Individuals with previous experience with a person with CF \((M = 14.60, SE = .40, SD = 1.26)\) rated CF as being more cyclical than participants who had not had previous experience with CF \((M = 12.37, SE = .37, SD = 2.40), p = .009, d = 1.16\); being a large difference of over one standard deviation unit between groups.

Thus, taken together, these results suggest that when individuals are presented with information about CF, their perceptions of individuals with CF or their illness perceptions of CF more generally are not impacted by who presents this information. However, similar to the results in the previous section, three significant effects were identified from analyses with control variables. Firstly, individuals of Asian ethnicity perceived fewer consequences and a less chronic nature of CF than individuals of Caucasian/Indigenous/other ethnicities. Next, individuals with experience with chronic illness perceived more consequences of CF than individuals with no previous experience with chronic illness. Lastly, individuals with previous experience with CF perceived persons with CF as having more personal control over their illness, and CF, in general, having a more cyclical nature than individuals with no previous experience with CF.
6.3.2.3 **Associations Between Illness Representations of Cystic Fibrosis and Likeability and Perceived Contagiousness Ratings of Individuals with Cystic Fibrosis in the General Community**

The final research question investigated the relationships between the three dependent measures used to examine individuals’ perceptions of CF itself and individuals with CF. Specifically, the relationships between the IPQ-R domains, and perceptions of contagiousness and likeability ratings were examined. For these analyses, only individuals from conditions 3 to 6 were included, as participants in conditions 1 and 2 were either informed in their vignette that the individual described had either allergies which caused their coughing and need for medication (condition 2) or no reason for their symptoms was given (condition 1). Further, as individuals in conditions 3 and 4 did not receive detailed information about CF until after they responded to the likeability, contagiousness, and IPQ-R items, separate analyses were completed for the participants in conditions 3 and 4 and participants included in conditions 5 and 6 who received detailed information about CF in their vignette. This also allowed comparisons to be completed examining differences between the strengths of the relationships between illness and contagiousness perceptions and likeability ratings for the participants who did and did not receive detailed information about CF.

Pearson’s $r$ correlations between the IPQ-R subscales, perceptions of contagiousness, and likeability ratings are presented in Table 50 for participants who did not receive detailed information about CF (no-CF information group), and in Table 51 for participants who did receive detailed information about CF (CF information group). Descriptive data for these analyses are presented in Table 49. As these tables detail all relationships between the IPQ-R, contagiousness and likeability variables, the key relationships of interest for the current research question are highlighted in bold. For comparisons between correlations for the CF information and no-CF information groups Fisher’s transformations were completed and standardised difference scores were calculated following the procedures detailed in Howell (2007).

**Impact of illness perceptions on likeability and contagiousness ratings.** As displayed in Tables 50 and 51, no significant relationships were observed between perceptions of likeability and any of the IPQ-R domains for either the no-CF information group or the CF information group. Further, regarding the relationships between IPQ-R subscales and perceptions of contagiousness, no significant relationships were found for the IPQ-R subscales of illness identity, personal control, treatment control, illness coherence, or emotional representations and perceptions of
contagiousness for either the CF information group or the no-CF information group. However, moderately strong significant relationships were found between perceptions of the chronicity of CF and perceptions of contagiousness for both the CF information and no-CF information groups. In both cases, the correlations indicated that the more chronic CF was perceived to be, the less contagious a person with CF was perceived to be.

Additionally, moderately strong significant relationships between both perceived consequences of CF and the perceived cyclical nature of CF and perceptions of contagiousness were identified for the no-CF information group. As perceptions of the impact of CF decreased and as CF was perceived to be more cyclical, the more contagious the individual with CF was perceived to be. While these relationships were not significant for the CF information group, the difference between the strength of the correlations for the no-CF information group and CF information group were not significant (i.e., for either the relationship between timeline-cyclical \( p > .05 \) and perceptions of contagiousness \( p > .05 \) or perceived consequences and perceptions of contagiousness).

**Relationship between perceptions of contagiousness and likeability ratings.**

Regarding the relationship between likeability ratings and perceptions of contagiousness, a weak significant relationship was identified for the CF information group, and marginally significant \( (p = .059) \) for the no-CF information group. For both groups, as the individual with CF was perceived as less contagious, likeability ratings for this person increased.

**Interrelations between the IPQ-R subscales.** While no specific research questions were proposed to examine differences between the relationships between IPQ-R subscales for the participants who did and did not receive detailed information about CF, the data in Tables 50 and 51 suggested that significant differences may be present. Thus, further analyses were completed to examine these differences.

Specifically, significant relationships were found between perceptions of the chronicity of CF and consequences of CF, perceptions of chronicity of CF and understanding of CF, and perceived symptoms and consequences of CF for both the no-CF information and CF information groups. In relation to the no-CF information group only, significant relationships were found between the perceived consequences of CF and personal control of CF, perceptions of chronicity of CF and perceptions of CF being cyclical, perceptions of personal control of CF and understanding of CF, perceptions of the consequences of CF and perceptions of CF being cyclical, perceptions of the consequences of CF and emotional representations of CF, perceptions of CF being cyclical and understanding of CF, and perceptions of the personal control of CF,
perceptions of chronicity of CF and personal control of CF perceptions of CF being cyclical. While these relationships were not significant for the CF information group, the differences between the strength of the correlations for the no-CF information group and CF information group were only significant for 4 of the 8 relationships. These differences are detailed in Table 52.

Additionally, for the no-CF information group, no significant relationships were found between perceptions of chronicity of CF and treatment control of CF, perceptions of the consequences of CF treatment control of CF, perceptions of the personal control of CF and treatment control of CF, and perceptions of CF symptoms and emotional representations of CF. However, these variables were significantly correlated for participants receiving detailed information about CF. Yet, the difference between the strength of the correlations for the no-CF information group and in CF information group was only significant for 2 of the 4 relationships. These differences are also detailed in Table 52.

For both the CF information and no-CF information groups, as the number of perceived symptoms of CF increased and as chronic CF was perceived to be more chronic, the perceived impact of CF also increased. Also as participants’ perceived understanding of CF increased, the more chronic CF was perceived to be. Regarding the relationships between IPQ-R subscales that were significant for only the no-CF information group, as CF was perceived to be more cyclical, CF was also perceived to be more chronic, to have more consequences and to be under a higher degree of personal control. Further, as participants’ perceived understanding of CF increased and CF was perceived to be more chronic, and as the perceived impact of CF increased, perceptions of the degree of CF being under personal control also increased. Also as participants’ perceived understanding of CF increased, CF was perceived to be more cyclical, and as the perceived impact of CF increased, the perceived emotional distress associated with CF also increased.

Finally, regarding the IPQ-R subscales that were only significant for the CF information group, as the number of perceived symptoms of CF increased, the perceived emotional distress associated with CF also increased. Additionally, as a greater degree of treatment control for CF was perceived, more personal control over CF, a lesser impact of CF, and a shorter timeline for CF were also perceived. With the exception of a strong relationship between perceptions of the chronicity and consequences of CF, all significant relationships identified for the CF information and no-information groups were in the weak to moderate range (Cohen, 1988).
Table 49

Descriptive Statistics for Ratings of Likeability and Perceived Contagiousness of Individuals with CF and IPQ-R Domains for the No-CF Information (n=52) and CF Information Groups (n=53)

<table>
<thead>
<tr>
<th>Domain</th>
<th>No-CF information group</th>
<th>CF information group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Likeability Rating</td>
<td>52.08</td>
<td>7.42</td>
</tr>
<tr>
<td>Perceived Contagiousness</td>
<td>7.07</td>
<td>3.76</td>
</tr>
<tr>
<td>Symptoms Experienced</td>
<td>8.77</td>
<td>2.35</td>
</tr>
<tr>
<td>Consequences</td>
<td>23.94</td>
<td>2.96</td>
</tr>
<tr>
<td>Personal Control</td>
<td>21.17</td>
<td>3.00</td>
</tr>
<tr>
<td>Treatment Control</td>
<td>16.54</td>
<td>2.62</td>
</tr>
<tr>
<td>Illness Coherence</td>
<td>13.87</td>
<td>4.83</td>
</tr>
<tr>
<td>Timeline-cyclical</td>
<td>13.13</td>
<td>2.02</td>
</tr>
<tr>
<td>Timeline-acute/chronic</td>
<td>25.02</td>
<td>3.36</td>
</tr>
<tr>
<td>Emotional Representations</td>
<td>20.76</td>
<td>3.22</td>
</tr>
</tbody>
</table>
Table 50

Pearson’s r Correlations Between IPQ-R Subscales, Perceptions of Contagiousness, and Likeability Ratings for Participants who did not Receive Detailed Information about Cystic Fibrosis (n=52)

<table>
<thead>
<tr>
<th></th>
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<th></th>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Symptoms Related to CF</td>
<td>1.00</td>
<td>.06</td>
<td>.33*</td>
<td>-.16</td>
<td>.09</td>
<td>-.07</td>
<td>-.09</td>
<td>.14</td>
<td>.12</td>
<td>-.05</td>
</tr>
<tr>
<td>2. Timeline-acute/chronic</td>
<td>1.00</td>
<td>.73**</td>
<td>.44**</td>
<td>-.08</td>
<td>.27*</td>
<td>.30*</td>
<td>.07</td>
<td>.17</td>
<td>-.40**</td>
<td></td>
</tr>
<tr>
<td>3. Consequences</td>
<td>1.00</td>
<td>.38**</td>
<td>.05</td>
<td>.15</td>
<td>.32*</td>
<td>.30*</td>
<td>.06</td>
<td>-.42**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Personal Control</td>
<td>1.00</td>
<td>.06</td>
<td>.46**</td>
<td>.46**</td>
<td>.24</td>
<td>.07</td>
<td>-.23</td>
<td>.07</td>
<td>-.23</td>
<td></td>
</tr>
<tr>
<td>5. Treatment Control</td>
<td>1.00</td>
<td>.04</td>
<td>-.01</td>
<td>.19</td>
<td>.15</td>
<td>.04</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Illness Coherence</td>
<td>1.00</td>
<td>.30*</td>
<td>-.18</td>
<td>.16</td>
<td>-.01</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Timeline-cyclical</td>
<td>1.00</td>
<td>.23</td>
<td>.09</td>
<td>.30*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Emotional Representations</td>
<td>1.00</td>
<td>-.19</td>
<td>.12</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Reysen’s Likeability Rating</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Perceptions of Contagousness</td>
<td>1.00</td>
<td></td>
<td></td>
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<td></td>
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</tbody>
</table>

* p<.05  ** p<.01
Table 51

Pearson’s r Correlations Between IPQ-R Subscales, Perceptions of Contagiousness, and Likeability Ratings for Participants who Received Detailed Information about Cystic Fibrosis (n=53)

<table>
<thead>
<tr>
<th></th>
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<tr>
<td>1.00</td>
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<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>.11</td>
<td>.65**</td>
<td>.12</td>
<td>.34*</td>
<td>.20</td>
<td>-.12</td>
<td>-.11</td>
<td>-11</td>
<td>-11</td>
<td>1.00</td>
</tr>
<tr>
<td>.41**</td>
<td>-.03</td>
<td>-.35**</td>
<td>.10</td>
<td>.05</td>
<td>-.12</td>
<td>.13</td>
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<td>.25</td>
<td>-.07</td>
<td>-.21</td>
<td>.24</td>
<td>-.25</td>
<td>-.25</td>
<td>1.00</td>
</tr>
<tr>
<td>-.04</td>
<td>.30*</td>
<td>-.06</td>
<td>-.06</td>
<td>-.01</td>
<td>.24</td>
<td>-.02</td>
<td>.02</td>
<td>-.10</td>
<td>1.00</td>
</tr>
<tr>
<td>-.01</td>
<td>-.17</td>
<td>.00</td>
<td>.02</td>
<td>-.01</td>
<td>-.25</td>
<td>.27</td>
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<td>1.00</td>
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<tr>
<td>-.03</td>
<td>-.13</td>
<td>-.00</td>
<td>-.06</td>
<td>-.07</td>
<td>-.48**</td>
<td>.25</td>
<td>-.48**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-.27**</td>
<td>.22</td>
<td>.01</td>
<td>.02</td>
<td>-.01</td>
<td>.27</td>
<td>-11</td>
<td>.25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-.08</td>
<td>-.47**</td>
<td>-.16</td>
<td>-.10</td>
<td>.27</td>
<td>-.25</td>
<td>.25</td>
<td>-11</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p < .05  ** p < .01
Table 52

*Differences Between the Strengths of Correlations for Selected IPQ-R Subscale Inter-
correlations for the CF Information and No-CF Information Groups*

<table>
<thead>
<tr>
<th>Pair</th>
<th>CF information group r'</th>
<th>No-CF information group r'</th>
<th>Z (standardised difference) ^a</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Timeline-acute/chronic –</td>
<td>.03</td>
<td>.47**</td>
<td>-2.51*</td>
</tr>
<tr>
<td>Consequences</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Timeline-acute/chronic –</td>
<td>-.17</td>
<td>.31*</td>
<td>-2.40*</td>
</tr>
<tr>
<td>Timeline-cyclical</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Consequences –</td>
<td>.12</td>
<td>.40**</td>
<td>-1.41</td>
</tr>
<tr>
<td>Personal control</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Consequences –</td>
<td>-.06</td>
<td>.33*</td>
<td>-1.93</td>
</tr>
<tr>
<td>Timeline-cyclical</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Consequences –</td>
<td>.00</td>
<td>.31*</td>
<td>-0.31</td>
</tr>
<tr>
<td>Emotional representations</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Personal control –</td>
<td>.11</td>
<td>.50**</td>
<td>-1.98*</td>
</tr>
<tr>
<td>Illness coherence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Personal control –</td>
<td>.25</td>
<td>.50**</td>
<td>-1.25</td>
</tr>
<tr>
<td>Timeline-cyclical</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Illness coherence –</td>
<td>-.12</td>
<td>.31*</td>
<td>-2.18*</td>
</tr>
<tr>
<td>Timeline-cyclical</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Treatment control –</td>
<td>-.53**</td>
<td>.07</td>
<td>-2.29*</td>
</tr>
<tr>
<td>Timeline-acute/chronic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Treatment control –</td>
<td>-.37**</td>
<td>.28</td>
<td>-2.07*</td>
</tr>
<tr>
<td>Consequences</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Treatment control –</td>
<td>.35*</td>
<td>.06</td>
<td>1.47</td>
</tr>
<tr>
<td>Personal control</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Perceived symptoms –</td>
<td>-.27*</td>
<td>.14</td>
<td>0.76</td>
</tr>
<tr>
<td>Emotional representations</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*correlation significant at p<.05  **correlation significant at p<.01
^a standard error = .20 for all analyses
6.4 Discussion

The overarching aim of the current study was to extend the analysis of the social environment of young persons with CF by examining how CF as an illness is understood by members of the general community, and how information about CF impacts both lay individuals’ representations of CF and their ratings of likeability and contagiousness of individuals with CF. To achieve this aim, an experimental design was used where participants were randomly assigned to one of six conditions involving a hypothetical workplace scenario where participants were asked to rate the likeability and perceived contagiousness of a new co-worker who frequently has a phlegmy-sounding cough and takes medications. Following these ratings, participants also completed the IPQ-R in relation to their perceptions of CF. The six conditions differed, however, in regards to the diagnosis given to the co-worker, being either no diagnosis (condition 1), allergies (condition 2), or CF (conditions 3 to 6). The CF conditions also differed to one another in that either the diagnosis of CF alone was given to the reader (conditions 3 and 4) or detailed information about CF was supplied in the vignette (conditions 5 and 6). The information conditions also differed in relation to the source of the information about CF; being either the co-worker with CF (condition 5), or the co-worker and hypothetical manager (condition 6).

6.4.1 Illness Representations of Cystic Fibrosis in the General Community

6.4.1.1 Research Question 1

The first aim of the current study was to examine the cognitive representations of CF in the general community. As discussed previously, only participants from conditions 1 to 4 were included in these analyses, as they did not receive detailed information about CF until after they had completed their IPQ-R ratings. With the data obtained, exploratory analyses of the IPQ-R data were conducted, as well as more specific analyses comparing the illness representations of the current student sample to those of the CF patient and parent samples obtained at T1 of Study 1 of the current research. As no studies to date have examined illness representations of CF in a lay sample, the results of these analyses greatly assist in obtaining information about the understanding of CF in the general community.

Regarding the perceived causes of CF in the general community, the frequency data suggested that the genetic basis of CF is well known in the community with nearly 80% of the sample endorsing this as an important cause of CF; this being the cause most frequently endorsed as an important cause of CF by the current sample. Further, the second to fourth most frequently endorsed causes of CF in the current sample
represented factors known to be associated with exacerbations of CF (i.e., poor immunity) or factors more commonly known to be associated with genetic disorders (i.e., ageing and chance). While age does not affect the likelihood of a person having a child with CF, as in genetic disorders such as Down’s Syndrome, this suggests that there is some understanding of common factors associated with genetic disorders in the general community (Batshaw, 2008).

Analyses examining the factor structure of causes of CF perceived in the general community identified four cause domains; psychological and behavioural, physical and external risk factors, immunity, and heredity. As noted earlier, this factor structure was very similar to that obtained by Moss-Morris et al. (2002) in their initial psychometric evaluation of the IPQ-R which utilised a large mixed sample of chronically ill patients. The main differences between the factor structure obtained in the current study and that of Moss-Morris et al. can be attributed to the known genetic basis of CF. The heredity factor obtained in the current study replaced Moss-Morris et al.’s accident or chance factor. The immunity factor in the current study included the same cause items as Moss-Morris et al. obtained. The domains involving psychological and behavioural attributions, and physical and external risk factors closely resembled Moss-Morris et al.’s psychological attributions and risk factors domains. Thus, it appears that the cause subscale of the IPQ-R is a good measure of causal representations of CF in a lay sample.

The next subscale of the IPQ-R applied to the examination of illness representations of CF in the general community was the illness identity subscale. As noted earlier, comparative to the causal representations of CF in the general community, which were, overall, quite accurate perceptions relative to the known medical causes, perceptions of the symptoms of CF in the general community were quite different to those actually experienced by patients. Of the symptoms noted on the IPQ-R, those which are most representative of CF are wheeziness and breathlessness, which were only rated as the tenth and sixth most frequently endorsed symptoms of CF by the current student sample. Further, for individuals with severe CF, having an upset stomach is also a symptom from the IPQ-R subscale likely to be experienced from time to time. However, this symptom was rated the second least frequently endorsed symptom of CF by the student sample.

More globally, of the 14 symptom items listed in the IPQ-R, 10 symptoms were endorsed by at least 50% of the student sample as being related to CF. Additionally, of the remaining four symptoms, each symptom was endorsed as being related to CF by at
least 25% of the sample. Also, when comparing students’ endorsement of symptoms related to CF to those of CF patients, students perceived significantly more symptoms than the patient group. Taken together, these findings appear to suggest that when individuals do not have a good understanding of CF, they are likely to overestimate the number of physical symptoms experienced by individuals with CF. Moreover, this suggests that the physical manifestations of CF are not well understood in the general community.

6.4.1.2 Research Questions 1 and 2

Regarding the remaining subscales of the IPQ-R (i.e., consequences, personal control, treatment control, illness coherence, timeline-cyclical and emotional representations), the analyses suggested that students’ illness representations of CF were more negative than those of the patient and parent groups in a number of domains. The student group perceived more consequences, and emotional concerns associated with CF than the patient group and perceived less personal control and understanding of CF than both the patient and parent groups. Interestingly, patients and parents also significantly differed in their perceptions on a number of the illness representation domains. The patient group perceived fewer consequences, more personal and treatment control and fewer emotional concerns associated with CF than their parent group. Thus, overall, patients held more positive illness representations than parents.

The differences between the student and CF patient samples are similar to those of both Ananagostopoulos and Spanea (2005), who investigated the perceptions of breast cancer in individuals with and without the disease, and those of Vollman et al. (2010) who examined perceptions of depression in individuals with and without a history of depression. In both of these studies, individuals without a history of illness were found to have more negative perceptions of illness, as rated by the IPQ-R, than individuals who had been affected by the illness. Thus, the results of the current study differ to those of Holliday et al. (2005) who found that individuals without a history of anorexia nervosa had more positive perceptions of illness than those with a diagnosis of anorexia nervosa. However, in the context of the results of the Ananagostopoulou and Spanea and Vollman et al. and those of the current study it appears that Holliday et al.’s results may be specific to the anorexia nervosa population comparative to a healthy group, which would be consistent with evidence of cognitive distortions in presentations of this disorder (Garner & Bemis, 1982; Radomsky, de Silva, Todd, Treasure, & Murphy, 2002). Hence, more generally, the outcomes of studies examining illness
representations in lay populations suggest that when little is known about an illness in the general community, individuals without a history of a particular illness are likely to overestimate the overall impact of the illness on patients’ lives.

Specific to the case of CF, it is also possible that outdated perceptions of CF in the general community may have contributed to the current study sample having more negative perceptions of CF than individuals with CF. As discussed in Chapter 2, the prognosis for individuals with CF has improved greatly over the last two decades. Accordingly, CF may still be perceived by those who are not familiar with recent medical literature as a fatal disease of childhood. Thus, even individuals who may have held some prior knowledge about CF may have represented this illness more negatively than those with more recent and accurate knowledge about the prognosis of CF.

The differences in illness perceptions of CF between the CF patient and parent samples are consistent with those of Olsen et al. (2008) who examined illness representations of diabetes in an adolescent sample of diabetic patients and their mothers. This study identified that mothers held more negative perceptions of diabetes than adolescent patients. Further, reviewing the results of previous studies which have examined parent and child perceptions of health-related quality of life in CF, with both primary school aged children (Havermans et al., 2009) and adolescents (Britto et al., 2004), children were found to have more positive perceptions of their health and perceive fewer limitations to functioning than parents. Hence, the results of the current study are also consistent with these findings.

Olsen et al. (2008) suggested that mothers may express more negative views to counter more optimistic, and possibly unrealistic, views of adolescents. Similarly, Britto et al. (2004) suggested that these differences may also reflect the adolescents’ state of cognitive development where beliefs of invincibility are often held. While the current sample of individuals with CF was somewhat older than Britto et al.’s sample (i.e., 19.81 years compared to 13.70 years) the cognitive development literature suggests that perceptions of invincibility in adolescents may persist into the young adult years until such time as myelination is completed in the brain’s prefrontal cortex which enhances executive cognitive functioning (National Institute of Mental Health, 2010; Wickham, Anderson, Smith-Greenberg, 2008). Thus, these cognitive mechanisms are also likely to have contributed to the results of differences between perceptions of CF of the patient and parent groups in the current study.

The current study is the first known to the current author to compare illness perceptions of a parent group to a lay sample. Thus, the studies of Ananagostopoulos
and Spanea (2005) and Vollman et al. (2010) are the most relevant studies to which these results can be compared. Again, it appears that persons without experience with an illness may have more negative perceptions of the illness than individuals with a high level of experience, even if this person with experience is not personally affected. Additionally, given that parents are found to have more negative perceptions of illness than adolescents with illness, identifying that the student sample of the current study held significantly more negative perceptions of illness than parents in two IPQ-R domains exemplifies the overestimation by students of the impact of CF on patients’ lives.

More generally, this examination of illness perceptions of CF with a general population sample highlights the usefulness of the IPQ-R as a measure of cognitive representations of illness in lay populations. It is noted, however, that limitations to the psychometric properties of the personal control and treatment control subscales of the IPQ-R were noted with both the current lay sample and Vollman et al.’s (2010) sample. The pattern of relationships identified between the illness perceptions of the student sample and those of the CF patient and parent groups were similar to those identified in other studies using the IPQ-R with other patient groups and studies using other outcome measures with CF patient samples (i.e., Britto et al., 2004; Havermans et al., 2009). It would, therefore appear that the personal and treatment control subscales of the IPQ-R are suitable for use with lay samples, although further development of these subscales may be warranted.

6.4.2 Experimental Analyses

The next set of research questions examined in the current study investigated the effects of reasons for the experience of general illness symptoms (i.e., coughing and taking medications) on individuals’ likeability and perceived contagiousness, and the effect of information about CF and the person delivering this information on illness perceptions of CF in the general population and likeability and perceived contagiousness ratings of individuals with CF. Each of these results is reviewed in turn.

6.4.2.1 Research Question 3

Utilising participants from all vignette conditions, research question 3 examined whether the reason given for an individual’s coughing and taking of medications impacted the student sample’s ratings of the individual’s likeability and perceived contagiousness. Accordingly, likeability and contagiousness ratings were compared between conditions where students received no reason for the individual’s symptoms
(condition 1), received allergies as the reason for symptoms (condition 2), or were informed that the person had CF (conditions 3 to 6 merged as one ‘CF’ group).

The results of these analyses suggested that the reason for symptoms had a small, but significant, effect on likeability ratings and a large significant effect on contagiousness ratings. Individuals perceived to have CF were rated as both more likeable and less contagious than individuals perceived to have allergies. Additionally, individuals with CF were perceived as having less contagiousness than individuals whose reason for their symptoms was not known to the rater. These findings suggest that disclosing one’s CF status may improve social interactions with individuals with whom the person with CF will have contact on a regular basis. This may prevent the person from misinterpreting the observable symptoms of CF and making unfavourable conclusions about their chances of catching an illness from the person with CF. It may also increase their willingness to interact with the person socially.

These findings are consistent with stigma research findings which have suggested that illnesses which are considered to be under personal control and have detrimental effects for both the patient and those around them are likely to lead to social rejection (e.g., Crandall & Moriarty, 1995; Swendeman et al., 2006; Zacks et al., 2006). Accordingly, it appears that CF, which is widely known to be a genetic condition in the current student sample, may be perceived as less controllable and less threatening to others than allergies, or an unknown illness which may, in turn, have affected likeability and contagiousness ratings. From another perspective, the findings of the current study are also consistent with communication and relationship research (Graham et al., 2008; Magsamen-Conrad et al., 2008) which suggests that disclosure in close friendships may strengthen these relationships by increasing their level of intimacy. Finally, the implications of this finding also suggest that disclosing one’s illness status may both improve social interactions and decrease any psychological tension which may stem from concern about being ‘found out’ by others (Panchankis, 2007; Lotwon, 2004; Quinn & Chaudoir, 2009).

6.4.2.2 Research Questions 2 and 4

While research question 3 compared the impact of the label given to an illness on likeability and perceived contagiousness ratings, research question 4 examined whether giving individuals detailed information about CF improves likeability and contagiousness ratings of individuals with CF, relative to ratings made by individuals without specific knowledge about CF. Additionally, research question 2 examined
whether the receipt of information about CF impacted raters’ illness perceptions of CF. Thus, only participants who received CF as the reason for the individual’s coughing and medication use in their vignette were used in these analyses (conditions 3 to 6). The likeability, contagiousness, and illness perception ratings were compared between individuals who did (conditions 5 and 6) and did not (conditions 3 and 4) receive detailed information about CF.

Although no specific hypotheses were made regarding these findings, extending the stigma research discussed above, it was expected that receipt of detailed information about CF may further improve likeability ratings and decrease perceptions of contagiousness of individuals with CF. Further, it was also considered that the receipt of information about CF may change individuals’ illness representations of CF. Contrary to these suggestions, no significant differences were identified between individuals who did and did not receive detailed information about CF on either likeability or perceived contagiousness ratings, or on any dimension of the IPQ-R. However, the control variables included in the analysis of a number of the IPQ-R variables did have significant effects on perceptions across a number of domains.

Individuals of Asian ethnicity perceived fewer consequences of CF and perceived CF as being less chronic than individuals of other ethnicities (i.e., Caucasian, Indigenous and individuals who did not specify their ethnicity – represented in one ‘other ethnicity’ group). Additionally, previous experience with chronic illness impacted individuals’ perceptions of the impact of CF on everyday functioning with individuals with experience with chronic illness perceiving more consequences of CF than individuals with no previous experience with chronic illness. Finally, previous experience with CF was also found to have a significant impact on illness perceptions of CF. Specifically, with individuals with previous experience with CF perceived individuals as having more control over their CF, perceived CF as having a more cyclical timeline, and reported a greater understanding of CF than individuals who had not had previous experience with CF.

The non-significant differences between the CF information and no-information groups on the IPQ-R domains were compared to the significant differences between the experience with chronic illness/CF and no experience with chronic illness/CF groups. This comparison suggests that experiences and knowledge gained over an extended period of time from interaction with a person with chronic illness has a greater impact on cognitive representations of CF than providing a person with information about CF. While these results were not hypothesized, they are consistent with broader research
examining approaches to changing health beliefs and health behaviours in the general population; with some studies suggesting that educational interventions alone may not significantly impact individuals’ health beliefs or behaviour (Bandura, 2004; T. Baranowski, Cullen, Nicklas, Thompson, & J. Baranowski, 2003). From a practical perspective, it may be difficult to implement interventions with a large interactive component with individuals with chronic illness with the aim of altering illness representations of the general population. However, the inclusion of personal reports of the experience of patients, as opposed to simply providing facts about an illness, may be an option to evaluate in future intervention studies.

Regarding the differences in illness perceptions of the consequences and chronicity of CF between the participants of Asian ethnicity and those of Caucasian/Indigenous/other ethnicities, these findings were compared to those from research in wider areas of health psychology as ethnicity was not assessed in either Ananagostopoulos and Spanea’s (2005) or Vollman et al.’s (2010) examination of illness representations in lay samples. Similar to the results of the current study, Becker, Beyene, Newsom, and Rodgers (1998) reported that, compared to individuals of African-American and Latino ethnicity, Philippine-American participants had a tendency to minimize the seriousness of both mild and severe chronic illnesses. Becker et al. suggested that this minimisation of illness severity may be related to the more global concept of individuals of Asian heritage maintaining “face” and portraying themselves as happy and healthy. Thus, if individuals have a tendency to minimise their own experience of illness, they may also project this tendency when evaluating the likely illness experience of others. It is likely that this mechanism may also account for the cultural differences identified in the current study.

Furthermore, in consideration of the finding that information about CF did not impact students’ perceptions of likeability or contagiousness of individuals’ with CF, this may be attributed to the finding discussed in the previous section that most individuals in the current study rated heredity as an important cause of CF. Thus, given that the current student population appeared to have some knowledge about genetic conditions in general, it is likely that the sample would also be aware that a genetic condition cannot be ‘caught’. Hence, if CF was known to most individuals as a genetic condition, it would make sense that the information provided on the genetic basis of CF would not have impacted participants’ contagiousness rating of CF. Further to this, if individuals’ ratings of likeability of individuals were related to perceptions of personal control over illness, as suggested in stigma research (e.g., Crandall & Moriarty, 1995;
Swendeman et al., 2006; Zacks et al., 2006), it may also be that individuals’ knowledge of the genetic basis of CF also alerted participants to the fact that personal control over CF is limited. Thus, the information provided to participants may not have impacted their belief about personal control over illness and, in turn, overall likeability ratings may not have been impacted.

6.4.2.3 Research Question 5

The last research question pertaining to the experimental analyses of the current study examined the impact of the identity of the giver of information about CF on likeability and perceived contagiousness rating of individuals with CF, and illness perceptions of CF more globally. Thus, only participants from conditions 5 and 6, which presented CF as the reason for the symptoms of the person described in the vignette and gave the reader detailed information about CF within the vignette, were included. The likeability, perceived contagiousness, and illness perception subscale ratings of participants receiving information about CF from their “co-worker” in the vignette (condition 5) were compared to the ratings of the participants receiving information about their co-worker’s diagnosis of CF from their “manager” in the vignette (condition 6).

No specific hypotheses were tested regarding potential differences between those receiving information from individuals with CF or another party. However, given the variability in how information about CF is presented to the peer group for school-aged individuals with CF (i.e., information sheet given to peers and their parents or personal disclosures from individuals with CF and/or their parents); it was considered important to identify any differences in social ratings attributable to how information is presented.

The results of the current study identified that likeability and perceived contagiousness ratings, as well as illness perception ratings, did not significantly differ between individuals who received information about CF from their co-worker with CF or another party. Yet, similar to the results of the impact of information on illness perception ratings, individuals of Asian ethnicity perceived fewer consequences and a less chronic nature of CF than others. Also, participants with experience with chronic illness perceived a greater impact of CF on individuals’ lives than participants with no previous experience with chronic illness. Finally, participants with experience with CF perceived persons with CF as having more personal control over their illness, and the experience of CF as being more cyclical than participants with no previous experience with CF.
Consistent with the results in the previous section, these results also suggest that experience with chronic illness has a greater impact on cognitive representations of illness than information given about CF and the presenter of this information. Further, also as discussed in the previous section, it appears that knowledge of the genetic basis of CF may be more important to likeability and contagiousness ratings of CF than that of the presenter of information about CF.

Regarding the impact of ethnicity on the illness representation domains of chronicity and consequences for participants in conditions 5 and 6, the same pattern of results was found for the larger subset of participants (those from conditions 3 to 6) reported in the previous section. Again, it appears that individuals of Asian ethnicity may minimise the perceived impact of illness for others as a part of the process of maintaining “face” to peers.

Thus, applying these results to the mechanisms of disclosure about CF to peers, acquaintances or closer friends, it can be suggested that the way in which information about CF is presented to individuals in the social network is likely to have little impact on the social interactions of individuals with CF. Instead, the results of the current study suggest that the experiences which peers, acquaintances, or friends have with the person with CF themselves, on an interpersonal level, will have a much greater impact on their understanding of CF and motivation for social contact with this person.

6.4.3 Associations Between Illness Representations of Cystic Fibrosis and Likeability and Perceived Contagiousness Ratings of Individuals with Cystic Fibrosis in the General Community

6.4.3.1 Research Question 6

The final research question investigated examined the relationships between the CF illness perception domains, perceptions of contagiousness of CF and the likeability of individuals with CF. For these analyses, only participants from conditions 3 to 6 were included, as those from conditions 1 and 2 did not receive CF as a reason for the symptoms of the person described in the vignette. Further, separate analyses were conducted for participants who received CF as a reason for the person’s symptoms, but no further information about CF (conditions 3 and 4) and those who received both CF as a reason for the person’s symptoms and detailed information about CF in the vignette (conditions 5 and 6). The analyses conducted were of an exploratory nature as no previous literature had examined this relationship between illness representations and likeability of individuals with chronic illness.
The first analyses examined relationships between illness perceptions of CF and likeability and contagiousness ratings of individuals with CF. No significant relationships were identified between any illness perception domain and likeability for either the no-CF information group or the CF information group. However, a significant relationship was identified between perceptions of chronicity and contagiousness for both the no-CF information group and the CF information group. For both groups, the more chronic CF was perceived to be, the less contagious a person with CF was perceived to be. Given the relatively well known genetic cause of CF across the sample, it makes sense that a genetic condition would be viewed as both chronic and non-contagious.

Significant relationships between the perceived consequences of CF and contagiousness and the perceived cyclical nature of CF and contagiousness were also identified for the no-CF information group only. As perceptions of the impact of CF decreased and as CF was perceived to be more cyclical, the more contagious the individual with CF was perceived to be. No other significant relationships were found between illness perceptions and contagiousness for either the no-CF information group or the CF information group.

Regarding the relationships between both consequences and the cyclical nature of CF and perceived contagiousness which were significant only for the group who did not receive detailed information about CF, these findings are unexpected. Given the relatively well known genetic basis of CF across the sample it would have been expected that similar relationships between contagiousness and the IPQ-R domains would have been observed for both groups. It is noted, though, that the strength of the correlations did not significantly differ between the CF information and no-CF information groups. Thus, these findings would need to be replicated before strong conclusions can be drawn. These results suggest that without specific information about CF, individuals may have applied more general associations between aspects of illness to their illness perception ratings of CF. Contagious illnesses may generally be viewed as more transient and having less impact on an individual than more chronic, non-contagious illnesses. Further, if an illness is perceived to be contagious, a person may be able to catch the illness more than once, and hence the illness may be perceived more cyclical over time.

Examining the relationship between likeability ratings and perceptions of contagiousness, significant relationships were identified for both the no-CF information and CF information groups. As the individual with CF was perceived as less contagious,
likeability ratings for this person increased. This finding is consistent with stigma research which suggests, as previously discussed, that when an individual is perceived to be threatening to others they are more likely to experience social rejection (e.g., Crandall & Moriarty, 1995; Swendeman et al., 2006; Zacks et al., 2006).

Regarding the intercorrelations between the subscales of the IPQ-R, three significant relationships were identified for both the no-CF information and CF information groups. As the number of perceived symptoms of CF increased and the more chronic CF was perceived to be, the perceived impact of CF on individuals’ lives also increased. Additionally, as participants’ perceived understanding of CF increased, the more chronic CF was perceived to be.

As only a general description of symptoms was given to participants who received information about CF, as opposed to the information listing a specific number of symptoms, it is understandable that similar relationships between the symptom domain and the chronicity and consequences domains may be seen. Accordingly, it is logical that an illness with many symptoms would be thought to take longer to recover from and have a greater impact of a person’s life than an illness with few symptoms. Further, in a meta-analysis of applications of the CSM of illness, Hagger and Orbell (2003) also noted that, across a range of illness populations, the number of symptoms perceived, and perceptions of the impact and chronicity of illness were all positively related to avoidant and emotionally expressive coping strategies. Thus, although not tested by Hagger and Orbell, it also makes sense that these domains would be interrelated.

Four relationships were identified between subscales of the IPQ-R which were significant for the no-CF information group only and significantly larger than those of the CF information group; being those between the perceived chronicity and consequences of CF, perceived chronicity and perceptions of the cyclical nature of CF, reported understanding and perceived control of CF, and reported understanding and perceptions of the cyclical nature of CF. Regarding the direction of these effects, as CF was perceived to be more chronic, a greater impact of CF and a more cyclical nature of CF were also perceived. Also, as a greater understanding of CF was reported, CF was perceived to be under greater personal control and to have a more cyclical nature.

Regarding the relationship between understanding of CF and the personal control and cyclical nature of CF for the no-CF information group, the positive relationships found between these variables are consistent with the current medical understanding of CF. Treatments carried out by a person with CF (e.g., physical
exercise, taking enzymes, conducting own physiotherapy) do have a positive impact on individuals’ quality of life. Further, CF, in itself can be a cyclical illness, as individuals may be negatively impacted by chest infections and other acute exacerbating factors over time (CFQ, 2001). Given that this group did not receive specific information about CF, a wider range of CF knowledge would, therefore, be expected in this group than in the group who received specific CF-related information. Thus, from a statistical perspective, the relationship between the understanding of CF in general and more specific aspects of its experience for patients and management would be more easily identified.

The relationships obtained between the chronicity and consequences of CF, and the chronicity and cyclical nature of CF for the group who did not receive specific information about CF also make sense when the information provided to individuals in the CF information group is considered. As highlighted previously, it is likely that some individuals may have held the belief that CF is a fatal disease of childhood. For those who received information about CF, these beliefs would have been challenged as the information provided discussed that even though CF is a chronic condition, current medical management of CF allows individuals to live a much fuller life than in previous years. Thus, it would make sense that after receiving information about CF, the perceived relationships between the chronic nature of CF and its impact on individuals’ lives may decrease, leaving these relationships significant for the no-CF information group only.

Two relationships were identified between subscales of the IPQ-R which were both significant for the CF information group only and significantly larger than those of the no-CF information group. These were the relationships between perceptions of treatment control of CF and the chronicity of CF, and perceptions of the treatment control and perceived consequences of CF. The direction of these effects indicated that as a greater degree of treatment control for CF was perceived, a lesser impact of CF, and a shorter timeline for CF were also perceived.

Thus, it appears that after individuals receive information about CF, some change may be identified in their perceptions of the efficacy of treatments for the management of CF. As stated in the information given to participants, while CF cannot be cured, effective management of CF can increase the life expectancy of individuals with CF and does improve quality of life compared to individuals who do not effectively manage their treatments (Crosier & Wise, 2001). As noted earlier, improved prognosis for patients with CF is starkly different to that of those diagnosed prior to the
1980s and 1990s. Thus, if this bleaker outlook for patients with CF was that most widely known within the student sample, this may explain why the relationships between the treatment, chronicity and consequence domains of the IPQ-R were those most greatly impacted by the receipt of current information about CF.

The significant differences in the relationships between the illness perceptions domains of the CF information and no-CF information groups make intuitive sense given the literature discussed. However, given that no significant differences in ratings on individual domains of the IPQ-R were noted between the groups, it is surprising that such strong differences in relationships between the domains for the two groups were identified here. This suggests that new relationships in the cognitive network of an illness held by an individual may be formed more quickly than specific information changes within the nodes. Future replications of this research involving collaboration between health and cognitive psychologists may assist in further explaining these findings.
CHAPTER 7 – STUDY 3

7.1 Research Aims

In the current study, the psychosocial experiences of both patients with CF and their parents were investigated using a qualitative approach. The participants were a subset of those participating in Study 1 (Chapter 5) of the current research. The current study aimed to combine aspects of Studies 1 and 2, by examining experiences within a family coping with CF, as well as patient and parent experiences of discussing CF with individuals from outside of the family unit. Participants were given the opportunity to participate in a semi-structured interview examining concepts presented in the questionnaires completed in Study 1. The interview involved examining patient/parent experiences relating to disclosure with non-family members. Participants were also given an alternative mean of discussing these issues. This involved written open-ended comments to their experiences of by completing a feedback page at the end of the T2 questionnaire from Study 1.

As discussed in Chapter 4 (section 4.3.2), a number of qualitative studies have previously been undertaken examining both the more global lived experience of CF (e.g., Jessup & Parkinson, 2010) and more specific aspects of the CF experience such as ways of coping with the challenges of CF (Hayes & Savage, 2008), navigating the social world (D’Auria et al., 2000; Lowton & Gabe, 2003), reflections of the transition from childhood to adulthood (Berge et al., 2007; Tuchman et al., 2008) and family interactions (Lowton, 2002). From the review of these studies, it was noted that the majority of previous qualitative research with the CF population utilised a naturalistic inquiry approach (e.g., Lincoln & Guba, 1985). Accordingly, a qualitative content approach to data collection and analysis (E.g., Hsieh & Shannon, 2005) was undertaken in the current study.

7.2 Method

7.2.1 Participants and Procedure

7.2.1.1 Recruitment

Participants in the current study were a subset the CF patient and parent sample who participated in Study 1. In Study 1, participants completed a written questionnaire at two points in time, 6 months apart. While the majority of the content in the T1 and T2 questionnaires was the same at both data collection points, two extra sections were added at the end of the T2 questionnaire and these were utilised in the current study.
Firstly, participants were given the opportunity to provide written feedback to elaborate on their experiences pertaining to the topics covered in the questionnaire or any other experiences they felt were important to discuss. Participants were informed that they did not have to complete this part of the questionnaire, or any other component, if they did not want to. The final section of the T2 questionnaire was an invitation for participants to receive an information package about participating in a telephone-based interview to further discuss the topics covered in the questionnaire. Participants who were interested in receiving an information package were required to provide a contact name and address for the package to be sent to. Participants were informed that, upon the receipt of the questionnaire by the researcher, the section of the questionnaire including their contact details would immediately be removed to protect their anonymity.

Once the questionnaires were received, both the invitations to participate in the current study, and the written data from the questionnaire were removed and each component was stored separately by the researcher. Written qualitative data was received from 21 patients and 28 parents from Study 1 and 12 patients and 19 parents requested an information package about the current study. These participants were then sent an information sheet with details pertaining to the current study and a consent form which requested the participant’s name, a contact phone number and preferences for days/times to be contacted. A reply-paid envelope was also provided to participants to assist in the return of the consent form to the primary investigator.

Upon recruitment for the current study, participants were informed that following their participation in an interview, they would be sent a $20 Coles-Myer gift voucher for their participation. While most participants were willing to receive the voucher, two participants alternatively requested that a $20 donation be made to their state CF organisation. Thus, instead of being sent a gift voucher these participants were sent the receipt for the donation made on their behalf. All ethical aspects of the current study were approved by the Griffith University Human Research Ethics Committee (protocol number: PSY/G1/07/HREC).

7.2.1.2 Interview Procedure

Of the 12 patients and 19 parents who were interested in receiving information about participating in an interview, seven patients and 10 parents were able to be reached on their given contact number and a mutually convenient time negotiated. Given that a number of the participants had work or study commitments, and the requirements of the University’s ethics board which stipulated how and where the interviews needed to be
conducted, for some participants, a mutually convenient time could not be established and they could not be included in the current study.

All interviews began with an overview of the topics to be discussed and an estimate of interview duration, a discussion on the digital recording of the interviews for data analysis purposes and a discussion of the interviewer’s ethical obligations as a psychology intern (i.e., confidentiality, limits to confidentiality, supervision process). Participants were then given the opportunity to ask any questions about the upcoming content or related procedures. Once each participant expressed verbal consent to continue with the interview, digital recording began and the first interview topic was introduced. No participants withdrew participation at this time or throughout the discussion of core content.

At the end of the specified content, participants were given the opportunity to discuss other topics they felt were central to the experience of CF and an assessment of participants’ mood following the interview was conducted. While no participants reported distress, it was confirmed that they all had a copy of the researcher’s contact details should they experience distress related to the interview at a later stage. It was noted, however, that one participant reported a history of suicidal behaviour and subsequent hospitalisations; thus a more structured assessment was completed regarding the participant’s adjustment at the time of interview. While it appeared that the participant was not experiencing distress at the time of interview, the assessment of functioning was reviewed with the primary researcher’s clinical supervisor who was comfortable with the assessment procedure and outcomes.

The interviews conducted with the CF patients averaged just under half an hour’s duration ($M = 26.71$ minutes, $SD = 9.03$ minutes), ranging between 17 and 40 minutes. For parents, the interview lasted just over three-quarters of an hour on average ($M = 47.30$ minutes, $SD = 15.14$ minutes), ranging between 25 and 70 minutes.

Following the completion of all interviews, the participants were sent their gift-card/receipt of donation as well as a thank-you letter for their participation in the study. After the completion of the content analysis, participants were then sent a summary of the themes arising from the interviews and written data, as well as a new copy of the researcher’s contact details in the event that any participant had any concerns following their participation. At this time, participants were also sent a brief feedback form enquiring as to how accurately the themes reported reflected their experience as CF a patient/parent and a reply-paid envelope addressed. All participants were informed that they were under no obligation to complete this form and that this was the final
correspondence they would receive as part of their participation in the study. On the form, participants were simply requested to tick a ‘yes’ box if they believed the themes were an accurate depiction of CF-related experiences and a ‘no’ box if they thought that the themes were not an accurate depiction of their experiences. If selecting ‘no’, participants were given the opportunity to specify how the themes deviated from the actual experience of CF. One patient and three parents returned this feedback form and all reported that they believed the themes were an accurate depiction of the experience of CF. Finally, no participants contacted the researcher with questions or concerns following their participation in the study.

7.2.1.3 Sample Characteristics

Patients. Regarding the characteristics of the patient sample providing written data for the current study, 14 participants were female and seven were male. The average age of participants was 20.31 years ($SD = 2.44$ years), ranging between 16 and 25 years. Over two-thirds (68.80%) of the sample were in a relationship (31.30% single). Over half of the sample reported living at home (62.50%) with the remainder either living with their partner (18.75%) or with friends (18.75%). The majority of the sample reported full-time study as their occupation (68.60%) and 18.80% of participants reported both working and studying part-time. Of the three remaining participants, one (6.30%) worked full-time, one was not working due to health restrictions and one was not working for an other undisclosed reason. Regarding the lung functioning status of this group, 19.00% reported an FEV% in the normal range, 47.65% reported mild impairment, 19.00% reported moderate impairment and 14.35% of the sample reported severe impairment. The sample characteristics for each interview participant are presented in Table 53. All patient participants reported being of Caucasian descent.

Parents. Regarding the characteristics of the parent sample providing written data for the current study, 25 participants were female and 3 were male. The average age of participants was 50.59 years ($SD = 6.80$ years), ranging between 40 and 64 years. All parents reported being of Caucasian descent. The vast majority of the parent participants were married (92.60%); only two participants reporting being divorced. The majority of parents either reported having one (25.90%) or two (33.30%) children living at home, with 18.80% having three children residing with them and 22.20% having no children at home. Over half of the sample reported that they only had one child with CF (59.30%), 29.60% reported having two children with CF, and 11.10% reported having three children with CF. Finally, the vast majority of parents reported working full- or
part-time outside of the home (88.90), with the remainder either working as a homemaker (7.40%) or not working for undisclosed reasons (3.70%). The sample characteristics for each parent who participated in the interview component are presented in Table 54. All parent participants reported being of Caucasian descent.

For both patients and parents, statistical analyses were completed to compare the sample characteristics of the interview participants and those of the participants providing written data in the current study. No significant differences were identified for any demographic variables for patients or parents. Thus, it appears that the smaller interview sample was representative of the wider participant group.

Table 53

Patient Demographic Information for Interview Participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age</th>
<th>Relationship status</th>
<th>Living arrangements</th>
<th>Occupation</th>
<th>FEV% Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient 1</td>
<td>Male</td>
<td>25</td>
<td>Single</td>
<td>With parents</td>
<td>Work FT</td>
<td>Mild</td>
</tr>
<tr>
<td>Patient 2</td>
<td>Female</td>
<td>24</td>
<td>Partner</td>
<td>With parents</td>
<td>Study FT</td>
<td>Moderate</td>
</tr>
<tr>
<td>Patient 3</td>
<td>Female</td>
<td>24</td>
<td>Partner</td>
<td>With parents</td>
<td>Not working due to health</td>
<td>Severe</td>
</tr>
<tr>
<td>Patient 4</td>
<td>Male</td>
<td>20</td>
<td>Partner</td>
<td>With friends</td>
<td>Work PT/Study PT</td>
<td>Mild</td>
</tr>
<tr>
<td>Patient 5</td>
<td>Female</td>
<td>23</td>
<td>Single</td>
<td>With friends</td>
<td>Work PT/Study PT</td>
<td>Moderate</td>
</tr>
<tr>
<td>Patient 6</td>
<td>Male</td>
<td>18</td>
<td>Single</td>
<td>With parents</td>
<td>Work FT</td>
<td>Mild</td>
</tr>
<tr>
<td>Patient 7</td>
<td>Female</td>
<td>24</td>
<td>Single</td>
<td>With parents</td>
<td>Study FT</td>
<td>Mild</td>
</tr>
</tbody>
</table>

Note: FT = full-time  PT = part-time
Table 54

**Parent Demographic Information for Interview Participants**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age</th>
<th>Relationship status</th>
<th>Number of children at home</th>
<th>Number of children with CF</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent 1</td>
<td>Male</td>
<td>54</td>
<td>Married</td>
<td>0</td>
<td>1</td>
<td>Work FT</td>
</tr>
<tr>
<td>Parent 2</td>
<td>Female</td>
<td>50</td>
<td>Married</td>
<td>2</td>
<td>1</td>
<td>Homemaker</td>
</tr>
<tr>
<td>Parent 3</td>
<td>Female</td>
<td>55</td>
<td>Married</td>
<td>0</td>
<td>1</td>
<td>Work FT</td>
</tr>
<tr>
<td>Parent 4</td>
<td>Female</td>
<td>46</td>
<td>Married</td>
<td>2</td>
<td>2</td>
<td>Work PT</td>
</tr>
<tr>
<td>Parent 5</td>
<td>Female</td>
<td>54</td>
<td>Married</td>
<td>1</td>
<td>1</td>
<td>Work PT</td>
</tr>
<tr>
<td>Parent 6</td>
<td>Male</td>
<td>47</td>
<td>Married</td>
<td>2</td>
<td>1</td>
<td>Work FT</td>
</tr>
<tr>
<td>Parent 7</td>
<td>Male</td>
<td>55</td>
<td>Divorced</td>
<td>1</td>
<td>1</td>
<td>Work FT</td>
</tr>
<tr>
<td>Parent 8</td>
<td>Female</td>
<td>53</td>
<td>Married</td>
<td>1</td>
<td>2</td>
<td>Work PT</td>
</tr>
<tr>
<td>Parent 9</td>
<td>Female</td>
<td>49</td>
<td>Divorced</td>
<td>0</td>
<td>1</td>
<td>Work FT</td>
</tr>
<tr>
<td>Parent 10</td>
<td>Female</td>
<td>52</td>
<td>Married</td>
<td>2</td>
<td>1</td>
<td>Work FT</td>
</tr>
</tbody>
</table>

Note: FT = full-time  PT = part-time

7.2.2  **Data Sources**

7.2.2.1  **Study Design**

As introduced in Chapter 4, a qualitative content approach was selected for the collection and analysis of the qualitative data. This approach was selected so that a rich understanding of the data could be obtained. In this approach, both the manifest content and the latent content (contextual meaning) of the data can be taken into consideration when identifying units of meaning (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). While the content obtained was derived from semi-structured research questions based upon elements of the theoretical framework applied in Studies 1 (i.e., social cognitive processing model (Lepore, 2001); dyadic representations of illness applied from the common-sense model of illness (Leventhal et al., 1980) and Antonovsky’s (1979) concept of ‘sense of coherence’) and 2 (perceptions of CF in the wider community based upon applications of the common-sense model of illness), the data
collection procedures also allowed patients and parents to discuss topics not suggested in the questionnaire or by the interviewer. Further, the process of qualitative content data analysis, where meaning is drawn from the data obtained and not ‘fitted’ into an expected model, also allowed the data obtained to be independent of the structure of the theoretical models which the research questions were based upon. It was considered that this approach assisted in overcoming potential problems related to over-direction of the interview/written responses by the interviewer/researcher when initial content is based upon a particular theoretical framework. Thus, the approach encouraged authenticity of the data obtained (Manning, 1997).

7.2.2.2 Content

Introduced in the section above, the topics examined in the current study were based upon the concepts covered in the social cognitive processing model (Lepore, 2001), dyadic representations of illness applied from the common-sense model of illness (Leventhal et al., 1980) and Antonovsky’s (1979) concept of sense of coherence. For the written data obtained, patients and parents were directed to write about their experiences related to topics covered in the questionnaires or other topics that they felt were important to discuss about their CF-related experiences. The specific instructions given to patients and parents are presented in Appendix D. The demographic information reported here pertaining to the participants supplying written data was obtained from the demographic database obtained in Study 1.

Given that there was a substantial period of time between participants completing the T2 questionnaire and completing the interviews for the current study, the content of the interviews was more structured as it was considered that many participants may not remember the exact topics covered in the questionnaires. The specific items were structured to examine each of the important concepts from the theoretical framework used to derive the questionnaire content.

For both the patient and parent interviews, six questions were assigned to the examination of the topics covered in conversations between the patient and parent, the quality of these conversations and whether or not any aspects of the patient-parent conversations had changed since the transition from paediatric to adult-based care. These topics were chosen to obtain information related to the presence of social constraints in the dyad and the impact of dissimilar perceptions of CF in the dyad.

For patients, the remainder of the interview was centred on personal and social experiences related to CF. Specifically, three questions were asked focusing on
challenges of CF, ways of coping, and aspirations for the future. These questions were chosen to obtain information pertaining to patients’ psychological adjustment, particularly their sense of coherence. Additionally, four questions were asked examining the experience of disclosing having CF to individuals outside of the family. The questions were selected to examine the patients’ sense of perceptions of CF in the general community and whether individuals are accepting and understanding of their condition. The specific questions included in the patient interviews are listed in Appendix E.

For parents, the remainder of the interview investigated their experiences of raising a child with CF and their views on discussing CF outside the family. Parents were asked four questions pertaining to their experiences of raising a child with CF: examining the diagnosis process, challenges faced and ways of coping, and changes noticed in parents’ orientation to life after the diagnosis of their child’s CF. Thus, these questions were chosen to examine elements of parental adjustment and possible changes in sense of coherence following their experience of having a child with a chronic illness. The final section of the parent interviews included two questions examining the discussion of CF outside the family, specifically their feelings towards their child’s discussion of CF with others, and advice they may give their child regarding disclosure outside of the family. Hence, this section of the interview was examining parents’ perceptions of the understanding of CF in the general community and expected reactions following their child’s disclosure of their CF to others. The specific questions included in the parent interviews are listed in Appendix F.

In interviews with both patients and parents, while the specific questions stated above were covered in all interviews, the order of questions was not necessarily followed to allow for a more natural conversational flow. Additionally, if new topics arose which were central to the experience of CF for the patient or parent, the researcher encouraged the discussion of these topics and probed for further details of the experience. Following the discussion of the main content questions in both the patient and parent interviews, participants were given the opportunity to discuss any other topics related to CF that they thought were important for someone working with families with CF to know, if not already covered within the main body of the interview. Finally, if not covered in the interview, information pertaining to the patients’ (age, gender, relationship status, living arrangements, work status, and lung functioning) parents’ (age, gender, relationship status, number of children at home, number of children with CF, and occupation) demographic information was collected from participants.
All questions discussed with interview participants and the structure of the stimulus questions assisting participants in providing written data in the questionnaires were derived in correspondence with an experienced clinical psychologist and experienced researcher in health psychology.

7.2.3  Data Analysis

7.2.3.1  Procedure

The seven patient and 10 parent interviews which were digitally recorded were transcribed and given a participant code to protect participants’ anonymity. To ensure consistency in transcription, the psychotherapy transcription guidelines of Mergenthaler and Stinson (1992) were followed. The written responses provided by participants were also re-typed and printed for analysis with the transcripts of the written interviews.

As introduced in Chapter 4, a conventional (inductive) content analysis approach was selected for the analysis of the interview data, which was used to generate thematic frameworks for each of the experiences of CF patients and their parents. Alternatively, for the written data obtained, a directed (deductive) content analysis approach was used to validate the thematic framework obtained from the interview data (Elo & Kyngas, 2007; Hsieh & Shannon, 2005). As described by Elo and Kyngas and Graneheim and Lundman (2004), the first step of content analysis, following data preparation, is the selection of a unit of analysis for coding. In the current study, paragraphs were chosen as the unit of analysis. Specifically, consecutive sentences containing related content were considered to represent a unit of analysis, as well as stand alone sentences which represented a single idea, differing to those preceding or following it.

In the inductive analyses, individual units of analysis were then labelled with preliminary codes. The coding labels were generated as specific ideas appeared to be repeated within and across individual transcripts and were refined, as needed, as more transcripts were analysed and greater understanding of the data was obtained by the researcher. As a part of this process, definitions were assigned to each code. Following the initial coding of transcripts, two patient and two parent transcripts were read by a second researcher and the codes for patients and parents generated by this researcher were compared to the original researcher’s coding. Across each transcript, between 70% and 90% of codes were agreed upon by the two researchers. For the units of meaning where discrepancies were noted, coding was negotiated and refinements made to the code names and their definitions. The primary researcher then reviewed the remaining
transcripts and made required adjustments to coding. Following this, one patient and one parent transcript was coded by the second researcher. At this point agreement was obtained in over 90% of the codes given.

Following the generation of codes, the analytic process of abstraction was undertaken. Accordingly, the codes were grouped into wider categories which were then refined to include subcategories to which codes were then assigned. Finally, higher-order themes were generated from the wider categories obtained. As this process is dependent on the interpretation of the relationships between the categories by the researcher, the abstraction process was also reviewed with a second researcher and refinements were made where required.

Once a thematic structure for the interview data was agreed upon, the deductive analysis of the written data was completed. In this process, the codes and related definitions were applied in the coding of the units of analysis in each of the transcripts from the written data. All units of analysis met criteria to be assigned to a pre-existing code. However, to ensure the validity of this process, one parent and one patient transcript from the written data were again coded by a second researcher. In both cases, the coding obtained here was consistent with that of the primary researcher. Thus, from this deductive approach, it was considered that the thematic structure of the codes, subcategories, categories, and theme obtained from the written data were an accurate representation of the experience of CF. The final codes and definitions from the patient analysis are displayed in Table 55 and those for parents are displayed in Table 56. Additionally, the thematic structure of the patient data is displayed in Figure 9, and that for the parent data is displayed in Figure 10.
Table 55

**Coding Labels and Definitions from the Patient Data**

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance of illness</td>
<td>Patient’s recognition and acceptance of CF being a part of life, such as: feeling that CF does not negatively impact life, not worrying about CF</td>
</tr>
<tr>
<td>Bond for disclosure</td>
<td>Patient deciding to disclose/discuss their illness with someone they trust/feel understood by/they feel similar to</td>
</tr>
<tr>
<td>Child directed care</td>
<td>Patient doing care related tasks such as: being solely involved in clinics, making own decision about care, having a sense of having as much CF knowledge as parent</td>
</tr>
<tr>
<td>Comparative functioning</td>
<td>Person with CF feeling as though: they are as healthy as their peers, CF is well managed</td>
</tr>
<tr>
<td>Crisis support</td>
<td>Parental support for their child when a challenging health or emotional event occurs, such as: a significant drop in health status, death of a friend with CF</td>
</tr>
<tr>
<td>Cystic fibrosis and identity</td>
<td>Balance of illness related identity and other facets of identity, centred upon wanting to be seen as more than a person with CF</td>
</tr>
<tr>
<td>Disclosure response uncomfortable</td>
<td>Patient getting the sense that a person to whom they have disclosed their illness status is uncomfortable in the conversation (e.g., seems overwhelmed by information)</td>
</tr>
<tr>
<td>Feeling different to others</td>
<td>Feeling different from others growing up, due to CF related issues such as: restrictions placed on activities/lifestyle, differential treatment by peers</td>
</tr>
<tr>
<td>Friends emotional support</td>
<td>Discussions with friends around: emotional concerns about CF, existential concerns about CF</td>
</tr>
<tr>
<td>Future desires</td>
<td>Patient making significant plans for the future, such as: career/educational planning, travel planning, relationship/family planning</td>
</tr>
<tr>
<td>Health care concerns</td>
<td>Conversations with parents (mainly parent initiated) about: parents concerns about patient’s health, protecting child</td>
</tr>
<tr>
<td>Impact of non-disclosure</td>
<td>Negative consequences for patient due to not disclosing their illness status to certain individuals (e.g., work demands exceeding physical capability)</td>
</tr>
<tr>
<td>Code</td>
<td>Definition</td>
</tr>
<tr>
<td>-----------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Interaction of cystic fibrosis and other life challenges</td>
<td>Heightened stress of patient due to combination of CF and negative events, e.g., relationship breakdown, school/work concerns)</td>
</tr>
<tr>
<td>Low CF awareness</td>
<td>Patient feeling as though CF is not well recognised either by their peers or in the wider community</td>
</tr>
<tr>
<td>Negative hospital experiences</td>
<td>Experiences in hospital that the patient perceived as: having a negative impact on their physical or emotional well-being, being unprofessional</td>
</tr>
<tr>
<td>Other initiated disclosure</td>
<td>Patient disclosing CF to someone after they ask questions around their health status or related treatment regimes, or the patient pre-empts these questions being asked of them</td>
</tr>
<tr>
<td>Others perception of cystic fibrosis</td>
<td>Concern of the patient about other individual’s perception of CF and their impact on things such as employability</td>
</tr>
<tr>
<td>Paediatric parent-directed care</td>
<td>Parents doing CF care-related tasks such as: initiating patient’s treatment or making decisions about child’s treatment, usually referring to past experiences of this</td>
</tr>
<tr>
<td>Parent and child blame</td>
<td>Child and parent feeling guilty around: parent ‘giving’ CF to their child, child feeling a ‘burden’ to parents/carers</td>
</tr>
<tr>
<td>Parental avoidance</td>
<td>Parents reducing their discomfort with CF topics with patient to reduce their distress (e.g., parent avoidance of particular topics or taking an overly positive outlook)</td>
</tr>
<tr>
<td>Physical health</td>
<td>Conversations with parents (usually patient initiated) about: clinics, medications etc.</td>
</tr>
<tr>
<td>Protecting others</td>
<td>Patient not discussing or continuing a discussion about health or emotional CF-related topics to: reduce the emotional response of another person, prevent an emotional reaction from another person</td>
</tr>
<tr>
<td>Realisation of illness severity</td>
<td>Emotionally provoking events for patients when they realise the terminal nature of their illness, being instigated by events such as: the death of a known individual with CF, a significant drop in health status, a challenging CF-related complication</td>
</tr>
<tr>
<td>Understanding of illness</td>
<td>Ease of conversations and getting advice from individuals who understand CF, such as: parents, close friends, others with CF, trusted health professionals</td>
</tr>
<tr>
<td>Code</td>
<td>Definition</td>
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<td>------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Advocate for child</td>
<td>Parent endeavouring to provide quality of life for child with CF by: ensuring adequate care, protecting from negative emotional experiences; feeling resentful towards individuals who are not supportive of child, educating others about CF</td>
</tr>
<tr>
<td>Assisting in illness management</td>
<td>Constructive parent/child discussions around concerns for child’s treatment, challenges children have faced discussing CF in the general community, and future planning</td>
</tr>
<tr>
<td>Barriers to interaction</td>
<td>Barriers to, and negative consequences of, children with CF interacting with other children with CF (e.g., impact of cross-infection policies, impact on child’s emotional well-being losing a friend with CF)</td>
</tr>
<tr>
<td>Comfort in paediatric services</td>
<td>Stated feelings of comfort/trust/security in services received while in paediatric care (e.g., developing good rapport with medical staff over time, confidence in care received)</td>
</tr>
<tr>
<td>Confidence in care</td>
<td>Parent’s development of a sense of efficacy in being able to: conduct child’s treatment, coordinate child’s treatment</td>
</tr>
<tr>
<td>Cystic fibrosis-related parental distress</td>
<td>Emotional distress experienced by parent due to: child’s emotional distress, child’s health deterioration, medical mishaps, child disengagement with treatment, death/severe illness of CF patient, shock following diagnosis, as well as use of negative coping strategies</td>
</tr>
<tr>
<td>Development in child’s coping</td>
<td>Positive changes in child’s ability to cope with CF management over time, as noted by parent e.g., more openness to CF related discussions, uptake of treatment management</td>
</tr>
<tr>
<td>Diagnosis information overwhelming</td>
<td>Parent feeling overwhelmed by CF related information and treatment advice discussed following diagnosis of child (e.g., feeling ‘over-loaded’ with information or by the responsibility for child’s CF-related treatment)</td>
</tr>
<tr>
<td>Code</td>
<td>Definition</td>
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<tr>
<td>-------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Encouraging a balanced identity</td>
<td>Parent taking steps to facilitate child’s involvement in activities in an attempt to reduce the perceived impact of CF (e.g., recreational/social/academic pursuits, integrating CF treatments into schedule in a benign manner)</td>
</tr>
<tr>
<td>Encouraging education about cystic fibrosis</td>
<td>Encouraging child to keep other informed about CF to help promote: understanding of CF in the wider community, child receiving support for CF when required</td>
</tr>
<tr>
<td>Extreme emotional distress</td>
<td>Parent experience of distress leading to symptoms warranting a diagnosis of a psychiatric disorder either related to child’s illness or other stressors</td>
</tr>
<tr>
<td>Facilitating independence</td>
<td>Parental facilitation of child becoming responsible for CF treatment/management, such as: allowing child to make decisions around CF or complete treatments independently, constructive prompting for care, being comfortable with children being responsible for care</td>
</tr>
<tr>
<td>Fear of infection</td>
<td>Parents fear that child will catch germs from other persons either with CF or people with other known infections</td>
</tr>
<tr>
<td>Fight to be diagnosed</td>
<td>Perceived challenge for parents in receiving a diagnosis and medical treatment for child (e.g., challenge to get a referral to a specialist, challenge to have child receive CF testing, misdiagnosis of condition)</td>
</tr>
<tr>
<td>Illness monitoring</td>
<td>Parent-initiated discussions around: child’s symptoms of CF, child’s experiences of CF, common experiences of people with CF, monitoring of child’s health status</td>
</tr>
<tr>
<td>Illness severity and mortality</td>
<td>Parent-child discussion around: death of another person with CF, need for extreme treatments (e.g., transplant, major complications of CF such as sterility)</td>
</tr>
<tr>
<td>Interaction of cystic fibrosis and other life occurrences</td>
<td>Impact of coping with CF and other stressful life events concurrently (e.g., other death/illness in family, financial/work stressors)</td>
</tr>
<tr>
<td>Letting go</td>
<td>Difficulties for parent in: having to rely on child for CF health updates, trusting their child is doing treatments as directed, feeling uninvolved in adult clinics</td>
</tr>
<tr>
<td>Code</td>
<td>Definition</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Limited cystic fibrosis awareness</td>
<td>Parent feeling that CF is not well known/supported in the community either by: friends/family, employers, health professionals, more general community members, or the sense that people hold a stigma about CF</td>
</tr>
<tr>
<td>Negative transition experiences</td>
<td>Perceived mismanagement of their child’s transition from paediatric to adult care, such as: sense that child was ‘abandoned’, parent feeling excluded by staff, dissatisfaction with treatment received from staff, mismanagement of child’s health information. May also apply to negative experiences transferring to a new hospital generally.</td>
</tr>
<tr>
<td>Need for interaction</td>
<td>Parent’s perception that families with CF benefit from interaction with other families with CF to gain increased understanding/empathy of experiences</td>
</tr>
<tr>
<td>Parent illness understanding</td>
<td>Parent taking steps to gain knowledge about CF to best support child's wellbeing, such as: attending all clinics, researching treatment options, promptly obtaining treatment advice</td>
</tr>
<tr>
<td>Parent’s positive coping</td>
<td>Adaptive coping strategies used by parents with CF-related or other difficulties, such as: obtaining social support, religious practices, use of positive reframing, obtaining professional support if required, awareness/engagement in positive self-care</td>
</tr>
<tr>
<td>Parent decision doubt</td>
<td>Concerns of parent around decision making for child’s CF treatment/management such as: questioning past decisions, being unsure as to how to best care for child, differences in opinion between parents point of view regarding CF care</td>
</tr>
<tr>
<td>Parent-child bond</td>
<td>Relationship between parent and child described to be: close/trusting, open/comfortable</td>
</tr>
<tr>
<td>Positive interactions with practitioners</td>
<td>Parent describing feelings of comfort/security/trust/rapport in services from or interactions with health professionals involved in child’s care</td>
</tr>
<tr>
<td>Code</td>
<td>Definition</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Positive life experiences</td>
<td>Positive experiences of parent or child that would most likely not have occurred without CF diagnosis, such as: new appreciation for life, positive self-development, meeting inspirational people, being thankful for the opportunity to care for a child with special needs</td>
</tr>
<tr>
<td>Pride in children</td>
<td>Parent’s sense of being proud of their child’s strength/tenacity or achievements</td>
</tr>
<tr>
<td>Recognition of genetic contribution</td>
<td>Parent acceptance of the genetic nature of CF</td>
</tr>
<tr>
<td>Sibling management</td>
<td>Parental management of having children both with and without CF, such as: managing attention given to CF child vs. other siblings, endeavouring to meet all children’s physical and emotional needs, managing jealousy between children</td>
</tr>
<tr>
<td>Support from state organisations</td>
<td>Appreciation of support received from the CF state organisations (e.g., events to promote interaction/support for shared experiences, feeling part of a community, having a ‘go to’ person)</td>
</tr>
<tr>
<td>Supporting child’s disclosure decision</td>
<td>Parent showing support for child’s decision to disclose detail of illness status to others</td>
</tr>
<tr>
<td>Treatment logistics</td>
<td>Impact of hospital stays and treatment on: family interaction, work commitments, social/recreational engagements. Also may include added difficulty of treatment access in rural/regional communities and the financial costs of treatments and travel etc.</td>
</tr>
</tbody>
</table>
### Figure 9. Themes obtained from the qualitative content analysis of patients’ interviews and written data.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Extra-personal Experiences</th>
<th>Intra-personal Experiences</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Category</strong></td>
<td>Wider Community</td>
<td>Personal Relationships</td>
</tr>
<tr>
<td><strong>Sub-category</strong></td>
<td>Challenges</td>
<td>Others’ understanding of CF</td>
</tr>
<tr>
<td><strong>Codes</strong></td>
<td><em>Impact of non-disclosure</em></td>
<td><em>Others’ perceptions of illness</em></td>
</tr>
<tr>
<td></td>
<td><em>Interaction of CF and other challenges</em></td>
<td><em>Low CF awareness</em></td>
</tr>
<tr>
<td></td>
<td><em>Emotionality in relationships</em></td>
<td><em>Friends’ emotional support</em></td>
</tr>
<tr>
<td></td>
<td><em>Feeling comfortable/understood</em></td>
<td><em>Supports for CF-related emotions</em></td>
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</tr>
</tbody>
</table>

### Figure 10. Themes obtained from the qualitative content analysis of parents’ interviews and written data.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Extra-familial Experiences</th>
<th>Intra-familial Experiences</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Category</strong></td>
<td>General Community</td>
<td>Health Professionals</td>
</tr>
<tr>
<td><strong>Sub-category</strong></td>
<td>Discussion of CF</td>
<td>Interactions in the CF community</td>
</tr>
<tr>
<td><strong>Codes</strong></td>
<td><em>Supporting child’s disclosure decision</em></td>
<td><em>Encouraging education about CF</em></td>
</tr>
<tr>
<td></td>
<td><em>Barriers to interactions</em></td>
<td><em>Need for interaction</em></td>
</tr>
<tr>
<td></td>
<td><em>Pride in children</em></td>
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</tr>
</tbody>
</table>

*Figure 9.* Themes obtained from the qualitative content analysis of patients’ interviews and written data.

*Figure 10.* Themes obtained from the qualitative content analysis of parents’ interviews and written data.
7.2.3.2 Trustworthiness

Lincoln and Guba (1985) described three criteria for assessing the trustworthiness of qualitative data, which are comparative to establishing internal and external validity and reliability in quantitative research methods. First, ‘credibility’, analogous to internal validity, pertains to whether the results obtained adequately reflect the experiences of the sample from which they were obtained. Next, ‘transferability’ of the data represents the extent to which the findings obtained are applicable to other members of the population, or other populations within a similar context; thus, being comparative to external validity. The third criterion, being analogous to reliability, is ‘dependability’, which refers to whether results of the inquiry would be replicated if the data collection and analysis process was repeated with the same, or a different, investigator. A number of steps were taken to ensure that all criteria of trustworthiness were met in the current study.

Credibility. Lincoln and Guba (1985) discussed that ‘prolonged engagement’ and ‘persistent observation’ of the researcher increases credibility. Specifically, this means taking the time to learn about the ‘culture’ of the population and learning which elements of their population’s experiences are the most important to them. Prior to the commencement of the current study, the primary researcher interacted with a number of professionals working with the CF population as well as CF patients and family members. In addition to this, a review of the literature pertaining to the psychosocial experiences of the population was undertaken. Thus, it is considered that these activities were consistent with Lincoln and Guba’s suggestions for increasing credibility.

In addition to this, a number of other steps were taken to ensure credibility of the data. As suggested by both Lincoln and Guba (1985) and Patton (1999), ‘triangulation’ and ‘member checks’ enhance the credibility of data obtained. Triangulation of sources, methods, and investigators was undertaken in the current study, with a number of patients and parents from different states in Australia recruited, both interview and written data used in analyses, and two researchers verifying the codes and thematic structure obtained. Regarding the use of member checks, all interview respondents were sent a copy of the thematic framework and code examples, and were given the opportunity to give feedback. While less than one-third of participants did respond, all feedback suggested that the results obtained were consistent with their experiences of CF.

Regarding the triangulation of methods, however, a limitation is noted; there was a possibility that participants who volunteered to take part in the interviews may
have already submitted written data. Thus, some overlap is likely between the written and interview patient and parent samples. Yet, this limitation was difficult to overcome without compromising the anonymity of the written data respondents and removing the written data of interview volunteers. As the written participant samples were considerably larger than the interview participant samples, the effects of data repetition were minimized in that the number of other individuals, potentially with different experiences, comprised the largest proportion of the sample. Despite this limitation, it is considered that given the number of strategies used to enhance credibility, this criterion was sufficiently met.

Transferability. Lincoln and Guba (1985) suggest that to enhance the transferability of data a rich description of the time and context within which the data is collected needs to be described to those interpreting the results of the qualitative investigation. As outlined in section 7.2.3.1, a specific description of the demographic and medical characteristics of the patient sample is given, as well as a specific description of demographic and family-structure characteristics of parents. In addition to this, the sample in itself, being adolescents and young adults transitioning or recently transitioned from paediatric to adult care, and parents of this group, is quite specific. Thus, it is considered that readers of these results could ascertain whether these findings are applicable for comparison with other CF samples or chronic illness patients.

Dependability. Lincoln and Guba (1985) suggest that an ‘auditing’ process can enhance the dependability of a naturalistic investigation. Given that a second researcher was consulted in a number of the data analysis processes, and the supervision of the procedural aspects of the current study, it is considered that these actions enhanced the dependability of the results obtained.

7.3 Results

7.3.1 Patients’ Results

The analysis of the patient data identified two overarching themes for this group. The first theme pertained to the impact of CF on patients on a personal level, termed ‘intra-personal experiences’, which included their personal feelings toward CF, and their health experiences related to CF. Secondly, a number of experiences relating to interactions with individuals in the wider community and the impact of CF on personal relationships were noted as elements of CF patients’ ‘extra-personal experiences’. These themes and categories, and their constituent subcategories and codes are presented in Figure 9 (p. 258).
Regarding patients’ intra-personal experiences, within the category of personal feelings, two subcategories, self-acceptance and strong emotions, were identified. Self-acceptance included the degree to which patients had accepted that CF was a life-long illness and had integrated CF into their identity. Although patients were able to recognise that while they would have CF for the rest of their lives, it was not the defining factor of who they were. This subcategory also included a code describing the degree to which the patient sample had begun to plan or pursue future educational, career, recreational or relationship attainments. Patient examples of these codes include:

*Acceptance of illness:* “It’s kind of like… you go to the dentist to get your teeth checked up on... It’s the same for me… I go to the doctor to get CF checked up on. That’s the way I treat it.”

*CF and identity:* “I also don’t want to look like I’m trying to get attention. But there are some people who, kind of, use CF, “look at me, I’m sick”, you know, “give me attention”. I have never wanted to be like that at all. So… I don’t want to be too over the top with it.”

*Future desires:* “Once I get a job and get money I promised one of my mates I’d come to Rio with her… and there’s a couple of mates I want to go to Las Vegas with.”

Although many patients reported that they had accepted their CF diagnosis and were determined to live life as fully as possible, strong emotions related to CF were still experienced by most patients from time to time. These included the moments when patients are reminded that their illness can be severe and life-threatening and the difficulties associated with parents’ and children’s recognition that CF is inherited, where parents may feel guilt for ‘giving’ CF to their child or patients may feel like a burden to their carers. Patient examples of these codes include:

*Realisation of illness severity:* “What I found the most difficult, the time that it actually became difficult for me when I was 18 or 19. It was time I had a… really, really bad chest infection. And I actually had an abscess in one of the lobes of my lungs, and they started talking about giving me a lobectomy and cutting out that part of my lung because it was so damaged and dead. At that point, I remember when they told me. It just hit me like a tonne of bricks… ‘I’m sick!’”

*Parent and child blame:* “I don’t blame them [my parents] at all [for my illness]. I don’t… have any issues like that. I’m quite comfortable with it really. But because it’s obviously, it’s a sore point, it’s an issue that’s quite tender for them. Whether it be guilt, or whatever, like that, that makes them feel… you know… negative… it’s quite a sore point, I’d say. So that’s why I’d imagine they’d find it difficult.”

Within the category of health experiences, three subcategories were identified; *health management, positive health outcomes,* and *negative health outcomes.* Health
management pertained to the CF treatment activities carried out by patients, and those which parents still assist with, or discussions of parents’ assistance with treatment when the patient was younger. Patient examples of these codes include:

*Child-directed care:* “There was a medication addition, changes to my diet, and general, I suppose, a general awareness of yourself has come along with that – to know when you’re feeling well, and to know when you need to eat, I have to be a lot more aware of that now.”

*Paediatric parent-directed care:* “When I lived at home, my parents came to all my clinics and stuff, but now they don’t, obviously. So, yeah the conversations were a bit different then, because they already knew a lot of stuff.”

In addition to the activities related to maintaining one’s health, patients also discussed topics pertaining to positive outcomes of health management, such as perceiving oneself as being as fit as peers and feeling comfortable discussing CF-related topics with parents when needed. However, some negative aspects of health management were also noted by patients in the current study. Specifically, some patients reported negative experiences during hospital visits and others reported that, at times, doing their CF-related treatment made them feel ‘different’ to others.

*Comparative functioning:* “Stay as fit as I can, as healthy as I can, and healthier hopefully than the average bloke as long as I can [in the future].”

*Physical health:* “It would probably be a bit of both [parents and me bringing up a discussion about CF]. It depends, like say if I’d been to a doctor’s appointment or something, I think mum or dad might ask that was. So yeah I would it would probably be a bit of both. Depending, maybe if I had an extra question or something I’d ask my parents first to see if they had the answer.”

*Negative hospital experiences:* “They [my children’s hospital] already knew my history, so they were ahead, they’d only clarify stuff really, I guess. Whereas, it’s not like that at [my current adult hospital]… It’s a bit of a frustrating process.”

*Feeling different to others:* “Other people had medication as well [at camp]. I wasn’t the only kid going to the sick bay to get the medication. But, I guess I just felt “ohhhh”… a bit funny about it. I did grow out of that a bit in high school, and things like that, and I just told who I wanted to tell, and that was about it.”

As noted earlier, in addition to the inter-personal experiences described above, a number of experiences pertaining to the impact of CF on personal relationships and patients’ experiences discussing CF in the wider community were also identified. Four subcategories were identified within the wider category of personal relationships for patients with CF. Firstly, a number of topics were discussed which identified a high
level of emotionality in relationships. Specifically, some patients noted that their parents often had difficulty discussing more serious implications of CF (e.g., mortality, sterility) as it lead them to become upset. Additionally, some patients also reported that after disclosing their illness to a person for the first time, some people would be shocked or became upset. Related to these topics, some patients also reported that they would sometimes avoid discussing CF to protect others from becoming distressed. Examples of these codes are given below.

**Parental avoidance:** “I have raised such things [deeper emotional issues] with mum and dad before. You know, I came to them first, because it was such a tender point, and so uncomfortable…”

**Disclosure response uncomfortable:** “I think there is a certain amount of judgement that I worry about as well… about coming from other people. But yeah, it’s hard to know how someone is going to react.”

**Protecting others:** “Yeah I do… that is harder [talking about things like a friend passing away], because my mum is likely to become emotional and that’s difficult, and it’s easier probably not to talk about it with them.”

While these elements of emotionality were identified by a number of patients, a number of circumstances were discussed where patients reported feeling comfortable/understood discussing CF with others. Additionally, patients also identified a number of supports for CF-related emotions. Specifically, patients reported feeling comfortable discussing CF with individuals whom they felt they could trust and who had a good understanding of CF. Further, patients also identified that while their parents may avoid emotionally provoking topics at times, in most cases, when a health-related crisis occurred, their parents did support them. Patients also identified that their friends, both with and without CF, are usually happy to discuss their concerns about CF if needed. Patient examples of these codes include:

**Bond for disclosure/discussion:** “I’m very open about having cystic fibrosis, but I only bring it up… when it’s appropriate. When I meet someone new, you know, I will just be myself and knock around and have fun and build a friendship as we do.”

**Understanding of illness:** “But with mum and dad, it’s a lot easier… you don’t have to explain things so much. You just say, “This is what we are doing”, and they are already on the same page.”

**Crisis support:** “My parents and I talk a lot about it [CF] when I’m in hospital, or when I get sick, but generally we don’t talk about it a lot. It’s not that that subject is off the radar or anything, we talk about everything.”

**Friends’ emotional support:** “I have some of my friends that I’ve known for longer periods of time I’d go to them more often than I’d go to someone I’ve know recently when it’s more emotional things there.”
One final aspect of personal relationships in the context of CF was also discussed by patients. This pertained to CF health related inquiries and demonstrated that while some individuals may react negatively to CF, a number of people are also considerate and inquisitive and are interested to know more about the patient’s experience. Additionally, patients generally reported that most support persons in their life had their best interests at heart and would often express any health care concerns they had for the patient.

Other initiated disclosure: “You know, usually if they ask about why I’m taking these tablets or why I cough so much or why did I have to go to the doctors appointment then or something like that. So it… usually they raise it, along the way if they notice things but once they do ask, I am very open about sharing it.”

Health care concerns: “Just when I’m getting a bit sick… mum might bring it up… Not too much else at the moment. Like I can usually handle a lot of things myself, and I think she understands that now so…”

While patients highlighted both the challenges that occur, at times, in personal relationships, and the support that often balances out these challenges, patients predominantly highlighted difficulties, more the supportive experiences, in general community. Regarding these challenges, patients highlighted the negative impacts of not discussing CF with others, as well as the difficulties that can occur when trying to manage CF and other important life events. Additionally, patients also noted that there were limitations in others’ understanding of CF, in that many individuals in the general community are unaware of what CF is and what it entails, which may lead to negative conclusions erroneously being drawn about CF. Examples of these codes include:

Impact of non-disclosure: “There have been occasions when I haven’t mentioned it [having CF], and then I really probably should have mentioned it… at one of the places I work in at the moment, it’s a football club, and they are expecting me to be able to run water to all of the players, and then when it’s hot, I was really, physically struggling to do it. And they thought I just wasn’t running very much because I’m lazy. I hadn’t mentioned it… so it’s a hard balance. From when you do mention it to when you don’t.”

Interaction of CF and other challenges: “I don’t really get any down time. The only time I get down time is… sleep, ‘cause I go straight from uni to work and home to bed. I also manage a moto-sport team as well. So I don’t really get much down time, but when I do get down time I like to watch movies or sleep really. Just not doing anything… just not having to have any thoughts…. Just watch a movie and tune out.”

Low CF awareness: ‘I feel fine [discussing CF with my friends], but usually, they don’t look at me blankly, but they’ll say something like “oh, ok”, and I’ll think ‘of you have no idea what that [CF] is, do you?’… and they’re like “no”… and I’ll usually explain to them what it is and that sort of thing.”
Others’ perceptions of CF: “I’m getting to the stage now where I’m not sure if I’ll mention it in job interviews or not. I did mention it in interviews, then I constantly didn’t get the jobs, so I don’t know if it was because of that or not.”

7.3.2 Parents’ Results

Similar to the analysis of the patient data, the thematic structure obtained for parents also included two overarching themes. The first theme pertained to parents’ experiences within the family, relating directly to the management/support of their child’s illness and their ability to fulfil other roles in the family home and externally. This theme was termed ‘intra-familial experiences’ and included the categories of illness management, personal experiences, and managing activities and relationships. Thus, the second theme, ‘extra-familial experiences’ pertained to parents’ experiences related to CF which occurred outside of the family unit, including those in the general community, and those, more specifically, relating to their interactions with their child’s health professionals. These themes and categories, and their constituent subcategories and codes are presented in Figure 10 (p. 258).

Regarding parents’ intra-familial experiences, three subcategories were identified within the category of parents’ illness management experiences: parent-child CF discussion, encouraging independence, and protecting child. Regarding the topics which parents identified as common themes in their discussions about CF with their child, general monitoring of symptoms, treatments and outcomes of clinic visits were discussed. Parents also reported trying to problem-solve difficulties in their child’s CF management or their interactions in the wider community involving CF (e.g., approaching a job interview). Additionally, parents also reported that events such as a friend with CF passing away may, at times, lead to conversations about the long-term and more severe implications of CF (e.g., mortality, sterility). Examples of these codes include:

Illness monitoring: “If [my son] mentions to me that he is [going on a visit to the Brisbane] I will still say to him ‘Maybe you should just check into the day clinic while you are there?’ and sometimes he does, sometimes he doesn’t. But he knows how he’s going from day to day, I’m sure he can tell within himself.”

Assistance in illness management: “[My son] runs everything past me though [regarding his concerns about CF] and I guess, more recently, there has been discussion around pending future things like intimacy and so forth because up until now it’s been sort of enough information for him to deal with.”
Illness severity and mortality: “I would [usually begin a discussion about CF with my child]… Our child is nearly 18 so [a discussion could come up] around the social events. In the media in our area we have just had the anniversary of a child that died from the school a couple of years ago. So I have talked to [my son] about… ‘you know her birthday-anniversary is coming up’…. I’ll bring those sorts of things up prior to [events].”

In the subcategory of encouraging independence, three codes were also identified. Parents discussed the difficulties that can first occur when passing over the responsibility of their child’s CF care to their child; including the concern that children will not complete treatments as directed and that this could lead to negative health implications. Despite these concerns, parents also discussed the ways in which they encouraged their child’s independence (e.g., having them organise their enzymes for the day before school) as well as noting how children’s management of CF had developed over time, both with encouragement and independently.

Challenge of letting go: “I was excluded from the doctor’s visits. That, for me, was quite… it was emotionally hard because I had to let go and let her assume the responsibility.”

Facilitating independence: “So I think I would encourage her [my daughter] to probably get as much information as she can then make her decision. I would share my opinion but try not to make it sound like I think she should do.”

Development in child’s coping: “We have had a few little happenings [health challenges] in the past few weeks that have really made an impact on [my daughter], she been really helpful. I think, perhaps, it’s a maturity thing too, by the time they get to 18 the penny just starts to drop a little bit.”

Regarding the final subcategory of illness management, three topics were also identified in the parent data which pertained to parents’ endeavours to protect their children from adverse events. This included parents’ effort to separate children from those who had a known respiratory infection; parents acting as an advocate for their child (e.g., obtaining extra supports at home or school, when required); and parents actively engaging their children in activities and conversations not relating to CF to assist children in developing a balanced identity not centred around CF.

Fear of infection: “When our daughter was once in hospital having an operation there was another person in her ward with pseudomonas, but her mother made sure that the nurses and the CF advocate knew that the nurses hadn’t done anything about it.”

Advocate for child: “Her sister’s even helped out with her physio, so they were very supportive and we were very lucky in that regard. We have all got her at heart. So she’s had not just mum and dad, but sisters, brothers-in-laws and grandparents all helping too.”
Encouraging a balanced identity: “I think probably the biggest thing is [our family] has always kept it ‘you are just a normal, everyday, kid, you’ve just got some extra things you have got to deal with’. So we have always been very open about it.”

Regarding parents’ personal experiences and reactions to CF, this included parents’ discussion of their skills in CF management and their approaches to positive coping and adaptation to CF. However, challenges in coping with CF were also indentified. Regarding the skills parents reported developing in CF care, a number of parents reported that they actively sought information about CF outside of their specialist appointments and tried to stay up to date in CF management approaches. Parents also noted how their confidence in caring for a child with CF grew quickly after having their baby, but yet, parents also reported that, at times, they may question their decisions pertaining to their child’s care (e.g., not getting a second opinion if they were unhappy with the approaches of their child’s health care team). Regarding parents’ approaches to positive coping and adaptation to CF, parents who reported coping well with CF reported positive approaches to stress management such as talking to friends/professionals and positively reframing experiences, as well as identifying positive changes in their life following the diagnosis of their child’s illness (e.g., positive self-development). Finally, parents also noted that being able to accept the genetic nature of the illness was an indicator of individuals coping with CF as it was reported that family members who wanted to deny that their family were carriers of CF generally did not cope well with their child’s diagnosis of CF. Parent examples of these codes are included below.

*Parent illness understanding:* “So quite often, for example, my husband will look at a lot of the research all of the time, looking overseas, and we’ve had two medications that our son has been put on purely because we’ve pushed it.”

*Confidence in care:* “When I did find out she had CF, even though I knew most likely she would have [due to the amniocentesis] I was a little bit upset to start with. But it was so much easier because I knew what I was doing. I knew what I had to do and we just got on with it and did it.”

*Parent decision doubt:* “But there was always that nagging feeling at the back of my mind thinking ‘Am I doing the right thing? Am I taking them to the right doctors?’”

*Positive life experiences:* “I guess until [I found out my child had CF] I was very… not carefree, but a bit self-centred and I guess it kind of comes with being a parent anyway when you have your first child we would have become more focused on other people anyway. I actually think it was probably a very, very good for character development for me having a child with CF.”

*Adaptive coping:* “Knowing that the possibilities were out there, of adverse things coming upon my daughter’s life, we didn’t want to live like that. We wanted to live with a positive outlook and provide a positive outlook and positive care for her to give her every chance to live life to the full.”
Recognising genetic contributions: “Being the recessive one [CF], with both of us needing to be carriers, I suppose it’s the best way it could have been to know in the heat of the moment and the emotions and things like that when people can say things they don’t really mean, you can’t throw the blame anywhere, as far as one being a carrier, you know, ‘you caused it’, or whatever. There had to be some bonuses there I suppose.” Finally, challenges in coping with CF were also identified by parents.

Some parents also identified that they found the diagnosis of their child’s CF overwhelming. It was a challenge to process all of the information given to them by professionals about CF in general and their role as a carer of a child with CF while trying to cope with the experience of having a newborn. Additionally, most parents noted that, over the course of their child’s life, they experienced distress related to CF at some point (e.g., when child is hospitalised, following children not being able to participate in things they like to do due to CF). Further, a few parents also reported extreme emotional distress requiring professional assistance, usually following a stressful period with their child’s illness and the experience of other distressing life event (e.g., job loss, death of another family member).

Diagnosis information overwhelming: “The rumours came back [after diagnosis of my son’s CF] that he would have to live in an enclosed room in a dust tent all of his life… My wife and I were distraught at that stage. Then it was off to the [Children’s hospital in the capital] where we spent six weeks learning his treatments and his physios and whatever else.”

CF-related personal distress: “It’s probably the hardest part of all [seeing your child really sick] and it’s not like, while I nag her a lot about exercise and diet and stuff like that there’s not a lot I can control. I can’t make CF go away, so that is very frustrating.”

Extreme emotional distress: “At the end of last year, I was in a terrible hole… I knew that I was in depression and I knew that if I wanted to get any enjoyment out of life I had to do something about it. So I saw the doctor and I have been on an anti-anxiety medication.”

Regarding parents’ management of activities and relationships, which was the final domain of parents’ intra-familial experiences, two subcategories were identified. The first, balancing CF and other commitments, included parents’ attempts to balance their time spent with their child(ren) with CF and other children not affected by illness as well as parents’ attempts to manage and cope with non-CF related challenges (e.g., work/financial stress, maintaining other personal relationships). Despite these challenges, parents also noted the positive relationship they had with their child with CF, which incorporated a close bond with their child and the pride they held for their child and their ability to cope with CF. Examples of these codes include:
Sibling management: “We were very lucky [with our daughter] that there was a big gap between her and her two older sisters. So we were able to focus a lot on her treatments when she was younger, which can be difficult for parents when they have other children of a similar age.”

Interaction of CF and other life occurrence: “When my daughter was diagnosed with [CF related] diabetes…. My mother was dying of [a neurological disease] and we lost my mum… and my sister had a brain haemorrhage… she ended up in a nursing home… and my dad died of cancer the same year. So it was a terrible, terrible year.”

Parent-child bond: “If something is worrying [my daughter she will come to me to talk about it]. Like the other day, she was doing her PEP and she coughed up some mucus and she showed me because she was a little bit worried about the colour of it and that kind of thing.”

Pride in children: “You have really got to give my son credit and be proud of him [for wanting to work]. The social workers in the hospital were wanting to give him paperwork for the pension, but he did not want to do that. I have explained though, that if things do ever get worse he may have to take that option.”

As noted previously, two categories were identified within parents’ reports of their experiences outside the family unit. Firstly, those in the general community pertained to parents’ opinions regarding the discussion of CF with individuals outside the family, and parents’ interactions in the CF community. Within the subcategory of discussion of CF, three topics were discussed by parents. Similar to that identified by patients, parents also reported that most people in the general community had a limited awareness of CF. From this, a number of parents also discussed that they encourage their child to increase others awareness of CF in the general community by being open about their illness. However, parents also report that they respected their children’s decisions in relation to disclosing their illness to others. Parent examples of these codes include:

Limited CF awareness in the community: “[Regarding access to respite and support services] back in the early days, CF was kind of lost in the system… it wasn’t recognised as a childhood illness you could get assistance for like asthma… It was really difficult to get services and it was frustrating that we had to pay for them [when families with children with other illnesses didn’t].”

Encouraging education about CF: I encourage my daughter to talk about [CF]. I encourage her to give people facts, and research things, but also let them know how she feels about things to try to open up a little bit. I think she is sort of good at that now. But yeah, I guess educate people so that they understand why thing occur and that sort of thing.

Supporting child’s disclosure decision: “I wouldn’t mind if [my son] did discuss CF outside of the family, but that’s his private business really. And if he doesn’t want people to know he’s not well, you know, that’s his business.”
Regarding parents’ reports of their interactions in the CF community, both challenges and positive aspects of interactions were discussed. While some parents noted that they often could see the benefits of their child interacting with other children with CF (e.g., understanding and encouraging each other), they also discussed the barriers to these interactions. These included factors such as the cross-infection policies in hospitals and also the negative consequences of interacting with other children with CF (e.g., the potential of them passing away and this potentially being distressing for their child). Finally, the majority of parents noted the positive role that their state CF organisation had had on their lives and the support they were able to provide for their family. Examples of these codes include:

**Need for interaction:** “You would meet all of the other parents at some stage and that too was great. They were going through exactly the same experience.”

**Barriers to interactions:** “They don’t mix the CF people at all anymore. [The CF people] can’t even go to the gym room together, they have got allotted times. It’s really segregated. The means of communication with them now is with the internet.”

**Support from state organisations:** “The support we have received from our state CF organisation has made family life so much better because we knew we had that support. Going to functions etc. with other CFers there has just all helped in family life and make things normal and really enjoyable.”

The final aspect of parents’ interaction outside the home pertained to parents’ interactions with their child’s health care team. Again, parents noted both positive and negative experiences in this domain. Regarding the positive experiences, parents identified that the majority of their child’s practitioners were very supportive, especially those from whom they received their paediatric care. Regarding the challenges, many parents reported difficulties in their child’s transition from paediatric to adult care, particularly noting that this was often not a smooth process. Parents also noted that, before the routine heel-prick test was implemented for newborns, many parents of children with CF faced difficulty accessing specialists before their child was diagnosed even when they informed practitioners they had a strong sense something was ‘wrong’ with their child (e.g., difficulty feeding, sloppy nappies, failure to thrive). Additionally, a number of parents, especially those living in remote and regional areas of Australia, noted difficulties accessing CF-related treatment and financial and personal impacts of the travel required to access medical and other supports.
Practitioner support: “My son now has a female doctor, who he has a fabulous relationship with, and it’s back to being more like it was when my son was a younger child. She is a proactive doctor and she is determined for him to get well and stay well.”

Comfort in paediatric services: “When [my son] was a very young child, the approach was very positive from his medical people. It was always about being proactive, maintain good health, being compliant and it was always stressed about good diet, hygiene and activity and so forth.”

Negative transition experiences: “There’s still a lot of discussion about how her transition from paediatrics to adult services was handled… still a lot of bitterness, resent, anger… possibly even some denial about that. I’d still regard it as she was expelled from the paediatrics service… One of my friends described it best “it’s like they are putting your life in the hands of strangers.”

Fight to be diagnosed: “Leading up to my daughter’s diagnosis at 18 months old, I knew that there was something there. [That was one of the most challenging times for me]. I knew there was something wrong, but it took quite some time to find out what was wrong with her. Then we found out what was wrong with her and there we all went.”

Treatment logistics: “When [my daughter] had CF we were in northern Victoria so we were 3 and a half hours from the children’s hospital in Melbourne. So, a lot of times, it was phone call to the hospital, you couldn’t just go in and see your doctor, or go in and say ‘can we come in and see somebody?’, it had to be a phone call as a first port of call anyway.”

7.4 Discussion

The current study aimed to build upon the theoretical framework presented in Studies 1 and 2 of the current research and gain a richer understanding of the psychosocial experiences of adolescents and young adults with CF and their parents. Accordingly, patients and parents were invited to provide written comments describing their CF-related experiences or to participate in an interview examining these experiences. Specifically, patients and parents responded to open-ended questions pertaining to aspects of the social cognitive processing model (Lepore, 2001), common-sense model of illness (Leventhal et al., 1980) and Antonovsky’s (1979) concept of sense of coherence as well as questions which allowed participants to discuss CF-related experiences which were important to them, but not covered in their responses to previous topic areas (i.e., questions derived from the theoretical models). Thematic frameworks of the patients’ and parents’ experiences were derived from the interview data using an inductive qualitative content approach. These thematic frameworks were then validated using a deductive qualitative content approach to the analysis of patients’ and parents’ written data. Finally, the thematic frameworks obtained were also sent back
to the participants of the current study for member checking. While only around a third of participants participated in this stage of the research, all patients and parents who provided feedback reported that the thematic frameworks presented were a good representation of their CF-related experiences.

7.4.1 Patients’ Experiences

Overall, patients’ reported experiences with CF pertained to intra-personal experiences and extra-personal experiences. Within the domain of intra-personal experiences, topics related to patients’ self-acceptance (i.e., seeing oneself as more than a person with an illness) and strong emotions related to CF (e.g., emotional impact of health deterioration) were identified as part of their personal feelings toward CF. Also in this domain, a number of healthcare-related experiences were identified. Specifically, these related to general CF management, positive health outcomes (e.g., feeling as fit as people without CF), and negative health-related experiences (e.g., negative experiences with hospital staff). Within the extra-personal experiences domain, two main topic areas were also identified. Challenges relating to discussing CF in the general community and perceiving a lack of understanding from others were the main aspects of experiences in the wider community reported by patients. Finally, patients also discussed experiences relating to the impact of CF on personal relationships. Patients identified the conditions under which they felt comfortable discussing CF with others. They also highlighted that friends and parents were generally there for them when they needed support, but were approached for different concerns (e.g., parents for treatment assistance, friends for emotional support). Patients described discussing more serious topics related to CF (i.e., its life threatening nature) with parents as challenging. Patients also identified that discussing CF with new people can be challenging, at times, as some individuals find the discussion overwhelming.

7.4.1.1 Comparison of Patients’ Themes to Past Research Findings

Comparing the topic areas identified in the analysis of patient data in the current study to those highlighted in other qualitative studies conducted with CF patients, it was observed that many topics indentified here overlapped with those identified in past research. Regarding personal feelings toward CF, the components of self-acceptance and strong emotions were also identified by a number of authors. Lowton and Gabe (2003) reported that most adults with CF accept that CF is a part of their life and that their treatments can assist in maintaining health which, in turn, facilitates longer term life planning. Berge et al. (2007) also reported that most adult CF patients consider that
they have incorporated CF into their self-identity. Further, Huyard (2008) also reported that, by adulthood, most CF patients attempt to regard their health as not their primary concern. This complements Jessup and Parkinson’s (2010) report that most young adults with CF are planning ways to attain their life goals (i.e., plans for a family and career). These themes directly relate to the topics of ‘acceptance of illness’, ‘future desires’ and ‘CF and identity’ discussed in the results of the current study. Regarding strong emotions related to CF, the topic of ‘realisation of illness severity’ was also highlighted by Carpenter and Narsavage (2004) and a similar topic to ‘parent and child blame’ was also discussed in Jessup and Parkinson’s and Berge et al.’s research findings. Following interviews with parents of children with CF, Carpenter and Narsavage reported that many parents felt ‘powerless’ and ‘guilty’ following the receipt of their child’s CF diagnosis and the information that CF is inherited. Additionally, Jessup and Parkinson noted the emotional impact of losing a friend with CF for CF patients. Berge et al. also noted the emotional impact of health deteriorations of CF patients.

Significant overlap was also noted between topics discussed pertaining to CF patients’ health management and health outcomes in the current study and those reported in past research. Specifically, Miller (2009) reported CF patients’ and parents’ reflections on how collaborative decision making in CF treatment management develops between parents and children. This discussion reflects the current patient samples’ recollections of ‘paediatric parent-direct care’ and their uptake of treatment responsibilities in later years (i.e., ‘child-directed care’). Additionally, Miller also noted that patients and parents will engage each other to facilitate illness management when required, which also related to the topic of ‘physical health’ reported in the current results, being a component of the subcategory of positive health experiences. The other aspect of this subcategory, ‘comparative functioning’, had also been discussed in the results of D’Auria et al. (1997) who noted that, at a young age, CF patients compare their physical functioning to peers. In addition to this, George et al. (2010) reported the reflections of adults with CF who stated that they are more motivated to complete their treatments when they see the positive health benefits. Finally, negative health-related experiences (i.e., ‘feeling different to others’ and ‘negative hospital experiences’) were also highlighted in the results of recent studies. A number of studies reported both children’s and adult’s perceptions of being ‘different’ when considering the impact of their CF treatment regime on their social, academic or vocational pursuits (Berge et al., 2007; D’Auria et al.; Jessup & Parkinson, 2010; Lannon Palmer & Boisen, 2002; Williams et al., 2009). Additionally, Tuchman and Britto (2008) discussed the fear of
the ‘unknown’ and the difficulty of losing relationships with medical staff from paediatric services which many adolescents experience during their transition from paediatric to adult care.

Consistency was also noted between CF patients’ reports of their experiences in the general community in the current study and those reported by patients in past research. Regarding the subcategory of others’ understanding of CF, Gjengedal (2003) discussed the frustration and fear that CF patients experience in the health care system when they perceive that only a small percentage of medical staff have a good understanding of CF. Gjengedal also noted that, within social services, CF patients often perceive that they are not respected by staff members. These themes relate to the topics of ‘low CF awareness’ and ‘others’ perceptions of CF’ indentified in the current study.

Regarding the sub-category of challenges in the wider community, the topic of ‘impact of non-disclosure’ was highlighted in Lowton’s (2004) findings and the topic of ‘interaction of CF and other challenges’ was discussed in D’Auria et al.’s (2000) outcomes. Lowton discussed the fear that CF patients report experiencing when debating whether to disclose their illness to an intimate partner or manager; while this is daunting for patients, they often fear the consequences of non-disclosure if they are ‘discovered’ at a later time (i.e., termination of relationship by partner, loss of job). Additionally, D’Auria et al. highlighted the difficulties faced by teenagers with CF when trying to balance their treatment regime with school, recreational and social commitments.

The comparison of topics discussed in relation to personal relationships and CF in the current study to those reported in past research identified less overlap. While topics discussed in relation to feeling comfortable/understood (i.e., ‘understanding of illness’ and ‘bond for disclosure’) and CF health-related inquiries (i.e., ‘other initiated disclosure’ and ‘health care concerns’ were also identified in past research, only some aspects of emotionality in relationships (i.e., ‘protecting others’ and ‘disclosure response uncomfortable’ not ‘parental avoidance’) and neither topics discussed pertaining to supports for CF-related emotions (i.e., ‘friends’ emotional support’ and ‘crisis support’) had been identified in past research.

With respect to the topics which were discussed by past authors, Lowton (2002) described parents as ‘expert lay carers’ in regards to their CF knowledge and Iles and Lotwon (2010) described parents of children with CF as ‘troubleshooters’ of their children’s treatment management based upon patients’ reflections of their parents’ abilities. Thus, the current patient samples’ discussion of their parents having a thorough understanding of CF relates to these findings. Coates et al. (2007), D’Auria et
al. (1997) and Lowton (2004) also discussed that CF patients are more likely to disclose about their CF to individuals with whom they hold more intimate relationships, in comparison to less intimate acquaintances. Finally, in relation to topics discussed pertaining to CF health-related inquiries, Miller (2009) discussed patients’ reflections of their parents engaging them in CF-related discussions if they had concerns for their health. Further, Jessup and Parkinson (2010) reported that CF patients may discuss their illness in response to inquiries from peers/acquaintances who observed them completing aspects of their CF treatment.

Regarding past research pertaining to emotionality in relationships, Coates et al. (2007) reported that CF patients and their parents may refrain from discussing the diagnosis of CF with wider family members as they want to protect their relatives from the distress of knowing they are carriers of CF. Lowton (2004) also highlighted the concerns of adults with CF about their friends and intimate partners being shocked or surprised by their disclosure about CF.

7.4.1.2 Relationship Between Patients’ Results and the Underlying Theoretical Framework

As noted above, substantial overlap was observed between many of the topics discussed by CF patients in the current study and those highlighted in past qualitative research which did not apply this framework. This suggests two things. Firstly, this finding implies that the theoretical framework used to conceptualise the psychosocial experiences of CF patients in the current study does have particular utility for this population. Secondly, this observation also suggests that, while the questions patients were asked to respond to were based upon a particular theoretical framework, patients were successfully facilitated to discuss other topics relating to their experiences which they felt were important to them. Thus, it appears that authenticity was obtained in the current study (Manning, 1997).

Also noted above, one aspect of emotionality in relationships of CF patients and both topics discussed pertaining to patients’ reflections of supports for their CF-related emotions were not identified in past research. Hence, it can be suggested that these topics are likely to pertain to unique aspects of CF patients’ experiences which relate to concepts presented in the theoretical framework applied in the current research. It can be suggested that patients’ perceptions ‘parental avoidance’ of more serious CF-related topics, such as their child’s mortality, may relate to negativity in parents’ perceptions of CF and the distress that is related to these perceptions of illness. Avoidance of this topic may decrease
distress. This finding provides further evidence that the common-sense model of illness (Leventhal et al., 1980) is appropriate for use with the CF patient and parent population.

In the current study, patients also identified that they will often discuss these more distressing topics pertaining to CF with their friends (relating to the theme of ‘friends emotional support’). Additionally, patients reported that although their parents may avoid the discussion of distressing topics, they are usually very supportive during periods of health crisis (‘crisis support’). The finding that patients approach their friends when they perceive that they cannot comfortably discuss aspects of their illness with their parents appears related to the theoretical concept of social constraints. Thus, talking with friends may be a way of coping with constraints from patients. Accordingly, it is suggested that future research using Lepore’s (2001) social cognitive processing model with the adolescent and young adult population should examine both communication between patient and parents and patients and their close friends. Yet, the finding that parents are supportive of their children appears to be more indicative of parents generally being concerned for their child’s well-being, as identified in many families coping with chronic illness (e.g., Cappelli et al., 1989, Seligman & Benjamin Darling, 2007), more than relating to a specific model applied in the current research.

7.4.2 Parents’ Experiences

Similar to the patient data, parents’ CF-related experiences were centred on their experiences within the family unit, intra-familial experiences, and extra-familial experiences. Parents’ experiences within the family related to their ability to manage their child’s CF (i.e., monitoring child’s care while encouraging independence), their personal reactions to their child’s illness (i.e., adaptive and maladaptive coping styles, coping with CF treatment skill management), their ability to engage a close relationship with their child with CF and with other family members, as well as their ability to manage CF in the context of other life events (e.g., financial concerns, illnesses of other family members). Within the extra-personal experiences domain, two main topic areas were identified. One related to parents’ interactions with their child’s health practitioners which could be both supportive and challenging (i.e., transition from paediatric to adult care; difficulties getting a CF diagnosis before the implementation of the heel-prick test). Finally, parents also discussed their experiences in the wider community. These pertained to parents perceiving a low level of understanding of CF by members of the general public, and parents being supportive of their child’s discussion of CF with others. Parents also noted the positive role of their state CF
organisations and the benefits and challenges of their children interacting with other individuals with CF.

7.4.2.1 Comparison of Parents’ Themes to Past Research Findings

Some overlap was also observed between the topics identified by the parent sample in the current study and topics identified in past qualitative research with parents of children with CF. However, less thematic overlap was observed for parents’ results than was observed for the patients’ results. Further, the topics discussed by parents within the intra-personal domain were more consistent with previous research than topics pertaining to parents’ extra-familial experiences. Regarding parents’ personal experiences relating to CF all aspects of positive coping and adaptation (i.e., ‘positive life experiences’, ‘adaptive coping’, and ‘recognising genetic contributions’), challenges in coping (‘diagnosis information over-whelming’, ‘CF-related personal distress’, and ‘extreme emotional distress’) and skills in CF management (‘confidence in CF care’, ‘parent illness understanding’, and parental decision doubt) have been discussed in past qualitative studies.

Regarding positive adaptation and coping, Grossoehome et al. (2010) reported that a number of parents of children with CF used religion as a coping mechanism when processing the impact of CF on their personal and family life, which was also identified as a positive coping mechanism by some parents in the current study. In addition to this, Hodgkinson and Lester (2002) also reported that most parents engage in problem-focused coping to overcome CF-related challenges, which was also reported by the current parent sample. Also similar to current parent reports, Jessup and Parkinson (2010) discussed that many parents of children with CF identify some positive impacts of CF on their life, such as becoming a ‘stronger’ person. Finally, Coates et al. (2007) reported that some CF patients and parents do not discuss CF with individuals in the wider family as they perceive that this information will cause distress. This finding is similar to current parents’ reports which suggested that acceptance of the genetic basis of CF is a sign of illness acceptance and positive adaptation.

In addition, the results of Hayes and Savage’s (2008) interviews with fathers of children with CF identified that many fathers found it difficult to process their child’s CF diagnosis and experienced ‘constant’ anxiety about their child’s health. The parent reports of perceiving the diagnosis information as overwhelming, their experience of CF-related distress, and extreme emotional distress from the current study resemble similar themes to those reported by Hayes and Savage. Regarding the final domain of
parents’ personal experiences with CF, skills in CF management, a number of authors have reported parents’ reflections that, while they found the diagnosis of CF and learning skills for CF management challenging, they were often surprised and proud of how quickly their skill base developed (Carpenter & Narsavage, 2004; Iles & Lowton, 2010; Lotwon, 2002). Prior research also identified that many parents take initiatives outside of their child’s CF clinic visits to increase their CF knowledge base, such as keeping up to date with CF research (Iles & Lowton; Lowton). Similarly, the topic of parent decision doubt from the current study is also consistent with Hodgkinson and Lester’s (2008) findings that decision making can be difficult regarding CF treatment when only one parent in a two-parent household participates in this process.

In the domain of illness management, most topics discussed by parents in the current study were also reported previously. For example, in the subcategory of parents protecting their children with CF, two studies identified strategies that parents use to assist their children in developing a view that CF is only one aspect of ‘who they are’ (Carpenter & Narsavage, 2004; Gjendedal, 2003). Similarly, in the current study, parents highlighted their efforts to assist their children in developing a balanced identity. Hayes and Savage (2008) acknowledged fathers’ reports of tenaciously attempting to keep their children with CF healthy. Thus, parents’ reports of being an advocate for their child and their discussion of their ‘fear of infection’ in the current results are similar to the concerns reported by fathers in Hayes and Savage’s research.

A number of qualitative studies have reported themes pertaining to parents’ efforts to encourage their children’s independence (e.g., Iles & Lowton, 2010; Miller, 2009). Similar themes were also identified in the current study. Miller discussed parents’ explanations of how they engaged their children in discussions about CF management and decision making as they grew older, which highlights parents’ attempts to increase the frequency and depth of these discussions as their child’s knowledge and treatment skill-base grew. Thus, the topics of ‘facilitating independence’ and ‘development in child’s coping’ identified in the current parent sample were similar to these themes. Iles and Lowton also reported parents reflections on the difficulties experienced during this treatment process; thus, pertaining to ‘challenge of letting go’ in the current study. Iles and Lowton reported that parents’ were often concerned about causing their child distress and only gave them information about CF ‘as needed’.

Regarding the final domain of illness management, parent-child discussions, only two of the three topics discussed by parents in the current study had been emphasized in the results of past qualitative investigations of parents’ experiences with
CF. Miller (2009) discussed how both CF patients and their parents engage each other in conversations around strategies for CF management. This theme resembles parents' discussion of ‘illness monitoring’ in the current study. Additionally, both Iles and Lowton (2010) and Hafetz and Miller (2010) discussed how CF patients’ perceive their parents as having specialist knowledge about their illness and as being a person they can approach when they have difficulties with their CF management. These themes relate to the topic of ‘assistance in illness management’ discussed by parents in the current study. However, regarding current parents’ discussions of ‘illness severity and mortality’, this topic was not identified in past qualitative research with parents of children with CF.

In the final category of intra-familial experiences, managing activities and relationships several topics were highlighted in parent reports from earlier research. These include: of ‘sibling management’ and ‘interaction of CF and other life occurrences’ from the subcategory of balancing CF and other commitments, and the topic of ‘parent-child bond’ from the positive relationships subcategory. However, ‘pride in children’, which pertained to positive relationships in the current study had not been identified in past qualitative research. Hodgkinson and Lester (2002) identified that mothers of children with CF often feel that they spend less time with their children who are not ill than their child with CF, especially when CF flares or a clinic visit is required. Additionally, Hodgkinson and Lester also reported that mothers note that CF-related treatment impacts on their ability to meet other family, work, and social commitments. Eiser et al. (1995) also discussed parents’ concerns that their children without CF receive less attention than their ill child(ren). Regarding positive parent-child relationships, as discussed previously, Iles and Lowton (2010) identified that adult CF patients perceive their parents as ‘troubleshooters’ when they experience CF-related concerns; this also exemplifies positive aspects of the bond between CF patients and their parents highlighted in the current study.

Regarding current parents’ extra-familial CF-related experiences, many topics discussed pertaining to the category of health professionals were identified in past research. However, only one of six topics relating to parents’ experiences in the general community were also identified in past research. This consisted of ‘barriers to interactions’, within the interactions in the CF community in the sub-domain of general community. Thus, ‘need for interaction’ and ‘support from state organisations’ from this subcategory were not identified in previous research. Further, the topics of ‘supporting child’s disclosure decision’, ‘encouraging education about CF’ and ‘limited CF awareness in community’ from the subcategory of discussion of CF were unique to
parents’ reports from the current study. Regarding ‘barriers to interactions’, Jessup and Parkinson (2010) discussed the emotional impact of losing a friend with CF on other children with CF; which reflected parents’ concerns in the current study. Additionally, Iles and Lowton (2010) also discussed parents’ attempts to protect their children from emotional distress.

Pertaining to the current parent samples’ discussion of the support they have received from their children’s practitioners, Hodgkinson and Lester (2002) also highlighted parents’ appreciation of the supportive and understanding nature of their child’s health management staff. As discussed previously, Tuchman and Britto (2008) reported CF patients’ experiences relating to their transition from paediatric to adult care, specifically highlighting the difficulty of ending relationships with staff from paediatric care services. This is similar to parents’ reports of comfort in paediatric services in the current study, as well as parents’ reports of negative transition experiences from the challenges of illness management domain. Further to this, Kepreotes, Keatinge and Stone (2010) noted parent’s perceptions of inadequacy of the support received from some practitioners in relation to their children’s chronic illness. This may also contribute to negative transition experiences for families. Finally, similar to parent reports from the current study, two studies also identified that some parents of children with CF experienced difficulty obtaining a diagnosis for their child, especially when their child had an atypical CF presentation (Gjengedal, 2003; M. Kharrazi and L. Kharrazi, 2005).

### 7.4.2.2 Relationship Between Parents’ Results and the Underlying Theoretical Framework

Similar to the observations made from the comparison between topics discussed by CF patients in the current study and those reported in past qualitative research, overlap was also noted between a number of topics discussed by parents of children with CF in the current study and those identified by parents in past research. This again suggests that the theoretical framework applied in the current study was appropriate for the examination of parents’ psychosocial experiences with CF, as well as that of patients. Further, parents’ discussion of topics which were not directly related to the theoretical framework also highlights that authenticity was obtained in the qualitative investigation of parents’ CF-related experiences in the current study (Manning, 1997).

It is noted, however, that less overlap was observed between the themes identified in the current research for parents and those of past research than was
observed between the themes identified by the current CF patient sample and participant reports from previous research. It appears that the majority of qualitative studies previously conducted with parents of children with CF have either focused on parents’ individual coping and ability to manage treatment demands or parents’ experiences managing the entire family unit. Fewer studies have examined specific aspects of the bond between CF patients and their parents, and parents perceptions of the understanding of CF in the general community. Thus, it appears that Lepore’s (2001) social cognitive processing model and that the extension of dyadic illness perceptions from Leventhal et al.’s (1980) common sense model of illness had particular utility in investigating this aspect of functioning in families with adolescents and young adults with CF.

Specifically, the topic of ‘illness severity and mortality’, which was unique to the current study, appears to be related to negativity in illness perceptions between CF patients and their parents. Additionally parents’ discussion of ‘pride in children’, if expressed to CF patients, may be a factor which would facilitate parent child communication, and thus, potentially decrease patient perceptions of social constraints. However, measurement of this element of the parent-child relationship and its relationship to social constraints may be best suited to a quantitative study, and is a potential direction for future research with the social cognitive processing model.

Regarding other topics discussed by parents which are unique to the current study, ‘supporting child’s disclosure decision’, ‘encouraging education about CF’ and ‘limited CF awareness in the community’ appear to relate to the examination of CF knowledge and the illness perceptions of CF of members of the general community examined in Study 2. Thus, it appears that parents also perceive that CF is not well understood by members of the general public, similar to current patients’ reports. Conversely to this, parents also identified that their state CF organisations were supportive of their experiences and that support and understanding could also be obtained from other families coping with CF. These pertain to examples of individuals whom parents perceive as having a good understanding of CF. Finally, parents’ discussion of ‘treatment logistics’ in the current study appears to highlight a more practical issue than one pertaining to the psychosocial experience of CF as explained by models applied in the current study. However, given the impact that CF treatments can have on relationships between CF patients and parents with other members of the family, this appears to be an aspect of functioning which should also be considered in future research with families with CF, especially if recruiting families from rural or remote areas.
7.4.3 Implications of Patients’ and Parents’ Results

A number of suggestions can be made regarding the implications of the current results for the management of families coping with CF. Firstly, the current study highlighted CF patients’ and parents’ observations that CF is not well recognised in the general community. Thus, it appears that educational campaigns, facilitated by the media, focusing on what CF is, its impact on individual’s lives, and also the fact that, for many individuals, CF is a well-managed condition which may not severely limit their capabilities may assist in developing awareness of CF in the general community and help lay individuals to develop more positive perceptions of those with CF. However, the development of such campaigns would depend on the availability of appropriate funding, which may be difficult to obtain.

Secondly, the negative impact of transitions from paediatric to adult care which are not well managed was also identified by both CF patients and their parents. This finding highlights the need for the implementation of more well-structured transition programs in some Australian adult CF clinics. The finding also gives merit to the recent research of Wang et al. (2010) and Wedgwood et al. (2008) who have begun to identify the barriers which prevent a smooth transition process and make recommendations regarding approaches to overcoming these barriers.

Regarding the identification of challenges within the parent-child relationship in families coping with CF, which had not been identified in previous research, both patients and parents spoke of the difficulties of discussing more serious implications of CF, such as its life threatening nature, in this dyad. Thus, it would be beneficial for future research to identify both parents’ and patients’ specific reservations about having such discussions, and identify approaches which may assist in facilitating these conversations. As discussed in Study 1, it is possible that future psychological interventions may benefit from incorporating an assessment of patients’ and parents’ individual and dyadic cognitive representations of CF.
CHAPTER 8 – GENERAL DISCUSSION AND CONCLUSIONS

In the last two decades, major advances in the medical understanding of CF and the availability of effective treatments to manage the symptoms of CF have resulted in a more positive outlook for the longevity of individuals with CF (Crosier & Wise, 2001). The review of the psychosocial literature pertaining to the experiences of individuals with CF and their families in the current research, however, identified a number of important issues that need to be addressed. These involve gaps in the current understanding of individuals’ psychological adjustment to CF, the overall functioning of families with adolescents and young adults with CF, and the understanding of CF in the wider community which impacts the social experience of individuals and families with CF. It was also apparent from the literature review that few studies which had examined the psychological adaptation of individuals and families with CF had applied a strong theoretical framework using well-established psychological models as a basis for the research. Yet, it was also noted that for a range of other chronic illnesses (e.g., cancer, diabetes, heart disease), psychological theory had been applied to the study of the psychosocial experiences of these patient groups, which, in turn, has lead to the development of theoretically-based psychological interventions for patients and families who were not coping well with the diagnosis of their illness or the experience of their illness (e.g., Broadbent et al., 2009; Keogh et al., 2007). Thus, it was the overall aim of the current study to apply well-tested psychological theory to the examination of CF patients’ personal, family-based, and social experiences to provide a preliminary framework for tailored psychological interventions with this population.

To achieve this aim, two broad psychological models which examine aspects of psychological adaptation to chronic illness were applied; Lepore’s (2001) social cognitive processing model of emotional adjustment to illness and Leventhal et al.’s (1980) common-sense model of illness. Further to this, the construct of sense of coherence from Antonovsky’s (1979) salutogenic model of health and illness was applied as an outcome measure in addition to more traditional psychological adjustment indicators (e.g., depression, anxiety) to examine the adaptation of CF patients and their parents. These models were applied across three studies in the current research.

Study 1 recruited a sample of adolescents and young adults with CF and their parents and examined their cognitive representations of CF, communication styles within the family and each party’s psychological adjustment at two points in time, 6 months apart. Study 2 utilised a non-health based student sample and examined their
awareness, knowledge and cognitive representations of CF; thus, this study only applied
the common-sense model of illness. Using a subset of patients and parents from Study
1, Study 3 then examined individual, family-based, and social experiences of this
sample using a qualitative approach. This allowed a richer understanding of patients’
and parents’ experiences as they related to concepts from each of the psychological
models applied in the earlier studies to be obtained, but also allowed other themes
important to this population to be identified. Overall, the results of the current research
demonstrated strong support for the application of the above-mentioned psychological
models in the examination of psychosocial experiences of CF patients and their parents.
The key findings, implications and limitations of these studies are reviewed in this
chapter, and future directions for further theoretically-based psychological research and
intervention with the CF population are identified.

8.1 Major Contributions of the Current Research and Directions for Future
Research

8.1.1 The Social Cognitive Processing Model

The current research was the first study to apply the social cognitive processing
model to both the examination of parent-child communication patterns and the
perceptions of social constraints of CF patients. This extended past research with other
chronic illness and trauma-affected populations which identified that when individuals
perceive that their partner is not comfortable participating in conversations about their
illness/experience of trauma, the cognitive processing of these concerns is negatively
impacted and the likelihood of experiencing psychological distress increases (e.g.,
Braitman et al., 2008; Lepore & Helgeson, 1998). This finding was also replicated in
the current research; patients’ ratings of social constraints in conversations with their
parents about CF were positively related to patients’ ratings of depression, anxiety, and
stress and were negatively related to patient reports of positive affect and sense of
coherence. These findings also extended research with the social cognitive processing
model by demonstrating relationships between social constraints and reductions in
measures of positive adaptation. Past studies with this model have predominantly
applied measures of distress to examine patient outcomes (Lepore & Kernan, 2009).

Regarding the role of cognitive intrusions and cognitive avoidance in the social
cognitive processing model, the results of the current research presented further evidence
for what appears to be a robust finding, that the associated increase of cognitive
intrusions related to the presence of social constraints, accounts for some unique
variance in patient ratings of distress (e.g., Clarke, 1993; Lepore, 1997; 2001). It also was predicted in the current research that the use of cognitive avoidance related to social constraints may protect CF patients from distress in the short term, but lead to increased distress in the long term. While cross-sectional results presented in Study 1 supported the conceptualisation of avoidance as a short term distress buffer, the longitudinal results of Study 1 did not support the latter prediction. It was suggested though, that given the small patient sample retained at T2 of Study 1, the statistical power of this study to detect the longitudinal relationship between avoidance and distress may have reduced. Thus, future research with larger CF samples and other chronic patient groups is needed to clarify the relationships between social constraints, avoidance and patient outcomes.

Regarding results relating to this model which were identified in the qualitative component of the current research, both patients and parents identified factors which facilitated the discussion of CF in the family unit. Patients discussed that they feel most comfortable discussing CF with others who have a good knowledge and understanding of their illness and with those to whom they feel close or similar, and those they feel are trustworthy. Further, both patients and parents identified that discussions pertaining to more serious topics such as the fatal nature of CF are particularly confronting. From this, patients identified that they may approach friends to discuss topics that are uncomfortable to discuss with parents. This would suggest that if patients perceived social constraints within interactions with friends, their opportunity to discuss and process concerns that are important to them would be severely restricted and may further compromise patients’ adjustment. Thus, it is considered that future research should also examine perceptions of social constraints from friends of patients with CF as well, as this has the potential to be a particular area of concern for some patients.

8.1.2 The Common Sense Model of Illness

Extending upon the work of Sawicki et al. (2011) who identified a relationship between adult CF patients’ cognitive representations of CF and their reports of adjustment in the psychological domains of health-related quality of life, the current research demonstrated that the cognitive representations of adolescent and young adult CF patients are also associated with clinical measures of psychological functioning. Further to this, the current research was also the first to demonstrate that parents’ psychological adjustment is also related to their perceptions of their child’s CF. For both patients and parents, negative perceptions of CF were associated with reduced psychological adjustment. Additionally, extending the work of Olsen et al. (2008) who
compared illness perceptions of adolescent diabetes patients and their parents, and studies which have examined the impact of the match between patients’ and partners’ illness perceptions on patients’ psychological adjustment for other chronic illness groups (e.g., Figueiras & Weinman, 2003; Sterba et al., 2008), the current research was the first to examine dyadic illness representations within the CF patient and parent population. This investigation identified a trend for patients who shared negative perceptions of CF with their parents to report less adaptive psychological functioning when compared to patients in dyads who shared positive perceptions of CF. Moreover, the current study was the first to present data pertaining to the cumulative effect of illness perception discrepancy within a dyad affected by chronic illness and its impact on patient outcomes. Given that significant relationships were identified, future studies examining dyadic illness perceptions in both CF and other patient groups may also benefit from examining this aspect of patients’ and parents’ (or partners’) perceptions of illness.

Regarding the results pertaining to perceptions of CF in the general community, the current study identified that CF is not well understood in this group. This finding was also noted in the qualitative data obtained from CF patients and parents in Study 3 in response to questions examining their social experiences relating to CF. While the genetic basis of CF appeared to be recognised in the student sample examined in the current research, the symptoms related to CF and the general experiences of this population were not well understood. Further, similar to the results of Anagnostopoulos and Spanea (2005) and Vollman et al. (2010) who examined lay perceptions of breast cancer and depression, the current research identified that the student sample reported more negative perceptions of CF than the CF patients and their parents. However, it was also identified that students rated individuals who coughed frequently and took medications with meals as more likeable and less contagious when the reason given for symptoms was CF, as opposed to allergies or a cause not being given. The implications of these findings for interventions with individuals in the general community, CF patients and their parents are discussed later.

8.1.3 Sense of Coherence

The current research is the only study in the last decade which has applied aspects of the salutogenic model of health and illness within a CF population. While Baker (1998) examined the role of sense of coherence (SOC) in adolescent CF patients’ treatment adherence, the current research examined the relationships between patients’ SOC and other psychological adjustment measures, as well as the relationships between
illness perceptions of CF, social constraints and SOC. A review of the latter relationships is presented in the next section. The relationships between SOC and other psychological adjustment measures were also investigated with the parent sample in the current research. Regarding the interrelationships between SOC and other psychological outcome measures, the cross-sectional data obtained for patients and parents identified that individuals’ ratings of SOC were negatively related to concurrent depression, anxiety and stress ratings, and positively related to ratings of positive affect. This was consistent with past research with other chronic illness and trauma populations (e.g., Henje Blom et al., 2010; Oztekin & Tezer, 2009) and theoretical predictions of Antonovsky (1979; 1987; 1990) who conceptualised that having a strong SOC would protect individuals from experiencing distress following adverse health-related events. The results of the qualitative examination of patients’ and parents’ experiences with CF also identified that, overall, patients and parents attempted to take an active and positive approach to coping with illness-related concerns. As this is consistent with behaviours which may indicate that an individual has a strong SOC, this further demonstrates that this construct is of particular relevance for the CF population.

For parents, however, it was also observed in the longitudinal quantitative investigation that their ratings of depression, anxiety, stress and positive affect at T1 were predictive of their SOC ratings at T2. As SOC was conceptualised by Antonovsky (1979) to crystallize by adulthood, it would not be expected that distress would predict an adult’s SOC over time. Thus, this finding appears to support more recent suggestions that SOC may also be influenced in adulthood following the experience of a challenging event (Geyer, 1997; Margalit et al., 1989; Olsson et al., 2008; Pisula & Kossakowska, 2010). Thus, future research examining factors which help to maintain a high SOC in adulthood is warranted.

8.1.4 Relationships Between the Models

In addition to applying the common-sense model of illness, the social cognitive processing model and SOC to the study of CF patients’ and parents’ psychosocial adjustment, theoretical predictions were made regarding the relationships between these models for the CF population. These predictions had not been previously tested with any chronic illness group. Consistent with predictions, dyadic illness representations were found to predict patients’ ratings of social constraints with parents which, in turn, were found to predict patients’ SOC ratings.

Specifically, the current research demonstrated both cross-sectionally and longitudinally that patients in dyads with mutually positive perceptions of CF report less
social constraints than patients in dyads reporting mutually negative perceptions of CF. This finding extends the research of Benyamini et al. (2007) who demonstrated that discrepancies in patients’ and partners’ views of heart disease negatively impact patients’ perceptions of social support from their partner, and partners’ social support provision. However, as this is the first study to identify the role of dyadic illness representations in the development of social constraints in a dyad, replications of this research are needed within both the CF population and with other chronic illness groups in order to allow a strong framework for possible interventions which may develop from this finding.

Regarding the relationship between patients’ reports of social constraints with their parents and their ratings of SOC, the results demonstrated that the SOC ratings of adolescents and young adults are positively influenced by having a relationship with their parent which promotes open communication. While the current research is the first to report data pertaining to this relationship, this finding builds upon past research which demonstrated that an emotionally supportive environment can assist in restoring an individual’s SOC after a traumatic event or illness (Nilsson et al., 2000; Skarsater et al., 2005). Additionally, this finding is also consistent with Antonovsky’s (1979; 1987) proposition that when supportive environments are experienced in childhood this promotes the development of a strong SOC.

8.2 Limitations

While the current study has substantially contributed to the understanding of the experiences of individuals and families coping with CF, some limitations of the current research are noted. As previously highlighted, the patient and parent sample who participated in Studies 1 and 3 were a relatively small and well-adjusted group. Further to this, following attrition from T1 to T2, the power of the statistical analyses conducted for the cross-sectional T2 data and longitudinal assessment of T1 predictors on T2 outcomes was limited. Accordingly, had a larger sample size been obtained, it is possible that a different pattern of results may have been obtained for the T2 cross-sectional analyses and the longitudinal analyses. Thus, replication of Study 1 with a larger sample is suggested to further examine psychosocial predictors of patient and family adjustment over time.

Regarding the impact of a well-functioning sample being recruited in the current study, it is possible that some of the results obtained may not be representative of the wider CF patient and parent population. Specifically, the reduction analyses of the Brief COPE obtained two coping factors for patients and parents which appeared to represent
different aspects of an active coping style. While it was suggested in Chapter 5 that it is likely that the use of avoidant coping may lead to detrimental health outcomes for individuals with CF, and therefore may be unlikely to be utilised by this group; it is also possible as the current sample were experiencing little distress that they had a reduced need for avoidant coping. Thus, replications of the current results for patient and parent coping styles are needed to confirm the suggestion that an active coping style is a common attribute of this population.

Another limitation of Study 1 pertains to the measure of patients’ actual frequency of discussion with their parents about CF-related emotional concerns. It was expected that patients’ reports of social constraints would be negatively related to patients’ reports of the frequency of discussion with their parents. However, a significant relationship was not identified. Given that many patients reported in Study 3 that they still discussed some aspects of their CF-related care with their parents following their transition to adult care, it is possible that patients may have responded to the item assessing discussions of CF-related emotional concerns with their parents by reflecting on their discussions about CF more generally. Thus, it is suggested that in future research, two items examining discussions with parents, one assessing frequency of discussions about CF treatment management and one assessing CF-related emotional concerns, be included. This would allow the identification of the frequency of discussions in each of these areas independently and may allow for the expected relationship between social constraints and discussion of emotional concerns to be identified.

Limitations are also identified when reviewing the sample utilised in Study 2. Given that a university sample was recruited, the education level of this sample would exceed that of the general Australian population. Additionally, it was also noted that nearly one-quarter of the sample was of Asian ethnicity which also exceeds that of the wider Australian population. Further, it was also noted in Study 2 that participants of Asian ethnicity perceived CF to have fewer consequences and to be less chronic than Caucasian and Indigenous participants. The implication of these differences is that it is possible that the combined data may have reflected more positive perceptions of CF than would be obtained in the wider Australian population. Thus, given that significant differences were identified between students’, patients’ and parents’ perceptions of CF in the current sample, it is possible that these differences are even larger in the general community; that is, the general population may perceive CF substantially more negatively than CF patients and parents. Thus, replication of Study 2 with a more representative sample of the general Australian population is recommended.
8.3 Clinical Implications of Overall Findings

8.3.1 Implications for Health Practitioners

Although the current research adopted a specific theoretical approach to the examination of the psychosocial experiences of individuals and families coping with CF, and support was found for the adopted approach, the results of the current research also have more general implications for practitioners who work with the CF population. In Study 1, indicators of physical health status, as well as indicators of the burden stemming from CF treatment regimes were obtained from CF patients, and the impact of these variables on patients’ psychological adjustment was assessed. Of these medical and treatment-related predictor variables, only the impact of treatment on patients’ functioning in their usual roles (e.g., ability to participate in school/work) had a significant relationship with any patient outcome measures. Additionally, throughout Study 1, the majority of effect sizes obtained when examining the relationships between psychosocial predictor variables and psychological outcomes for patients were medium or large.

While it is noted that a more conservative alpha level was used in the analyses of the impact of medical and treatment-related variables on patients’ outcomes in Study 1 (given the number of potential control variables examined), overall, these findings suggest that psychosocial factors are particularly important in the examination of CF patients’ psychological adaptation. Further to this, given that these results were obtained with a sample where the majority of patients and parents reported minimal distress, it is likely that the psychosocial variables which were predictive of adjustment for the current sample would be particularly important to assess in individuals who are experiencing severe distress. Thus, the current results are consistent with a biopsychosocial approach to the examination of CF patient adjustment, and provide further evidence that a purely biomedical approach to patient adjustment would not obtain the best outcomes for CF patients and their families (Morrison, Bennett, Butow, Mullan, & White, 2008).

As reviewed in Chapter 2, hospital protocols state that assessment of patients’ psychosocial adjustment is incorporated as an aspect of patients’ annual CF tune-ups (e.g., Royal Children’s Hospital Melbourne, 2005). Yet, when patients and parents discussed their experiences in the hospital system in the interviews conducted in Study 3 (Chapter 7), most reflections pertained to medical and treatment-related experiences as well as positive and negative interpersonal experiences with medical staff. It is possible that patients and parents did not feel comfortable discussing experiences with
their with social workers or psychologists in these interviews. These findings could also indicate that the assessment of psychosocial factors impacting patients’ adjustment is still only a small part of patients’ tune-ups and may only be conducted when it appears evident to the individual’s health practitioners that they are experiencing distress. If this is the case, it would appear that, at present, there are gaps between what may be considered best practice for health practitioners who work in CF teams and the care that patients and their families actually receive.

8.3.2 Cystic Fibrosis, the Self and the Family

As a part of the psychosocial assessment to be conducted at tune-ups for adolescents and young adults with CF, it appears from the current research that assessment of patients’ comfort with, and frequency of, conversations with parents regarding their CF-related and more general physical and emotional concerns are particularly important for this group. The current results also suggest that it would be particularly important for practitioners to note areas in which patients and parents hold negative views of CF-related experiences, given their potential detrimental impact on patients’ psychological adjustment. Furthermore, given the emotional impact of CF patients’ transition from paediatric to adult care on families noted in both the current study and past research (e.g., Conway, 2004; Tuchman et al., 2008), it is suggested that assessment of the psychosocial adjustment of families is crucial at this time.

It is noted that a strong rapport between patients and their health practitioners would be needed to facilitate this psychosocial assessment, and potential interventions which may stem from this. However, in addition to changes in CF patients’ relationships with their family at the time of transition, it was also highlighted in the current study and in past research that the loss of longterm relationships with paediatric care staff and the formation of new working alliances with adult care staff is also a particularly challenging aspect of the transition process (e.g., Tuchman et al., 2008). Thus, it is unlikely that patients would feel comfortable discussing any concerns they may have with the support received from their family and friends with a social worker or psychologist with whom they have had limited contact. Thus, regarding implications of the current research on the transition process, it is suggested that access to a psychologist or social worker from a patient’s chosen adult clinic before their care at the paediatric service is terminated may help to facilitate patients’ transition. With this approach, patients would have time to build a rapport with at least one member of their
new team before beginning their transition. From this, patients may then feel more comfortable accessing support, if required, during transition.

Regarding the implications of the current research for potential interventions for patients and families who do report experiencing emotional distress, it appears that cognitive-behavioural programs incorporating assessment of, and intervention tailored to, patients’ perceptions of their CF, and the perceptions of their support network, may be particularly useful for this group. As reviewed earlier, interventions of this nature have begun to be assessed with other chronic illness populations and have reported encouraging results (e.g., Broadbent et al., 2009; Keogh et al., 2007). Such interventions are particularly relevant as it was also noted in the current research that a number of the relationships between both individual and dyadic illness representations and participant outcomes were maintained longitudinally. This suggests that interventions based upon this theoretical framework may impact patients’ psychological adjustment not only in the short term, but also many months post-intervention. Thus, it appears that the current study has identified a strong theoretical basis upon which psychosocial assessments and intervention with individuals and families coping with CF can be developed.

8.3.3 Cystic Fibrosis and the Social World

In addition to the implications identified for the provision of care for CF patients in the hospital system, implications for the promotion of positive experiences for CF patients in the general community can also be drawn from the results of the current research. The results of Study 2 (Chapter 6) demonstrated that the understanding of CF in the general community is quite limited. This concern was also highlighted directly by CF patients and their parents in the interviews conducted in Study 3.

Given that CF patients now have a life-expectancy of 40 years and beyond, the current generation of CF patients and their parents are likely to experience challenges relating to limited understanding of CF in the general community that generations before them would not have experienced. For a number of previous decades, primary and possibly high school teachers would have been likely to have been aware of CF due to their involvement with children and adolescents. However, individuals in the community who predominantly interact with adults, such as those who work in social services, universities and other more general work places would have been unlikely to interact with individuals with CF. Now that this population is living well into adulthood it is particularly important that the general public obtain a thorough understanding of CF so that they can be sensitive to both the needs, and abilities, of individuals with CF.
While dependent on the availability of appropriate funding, it is suggested that educational campaigns, facilitated by the media in order to obtain the greatest coverage to the general population, are required to facilitate change in the public’s understanding and perceptions of CF. In particular, the current results suggest that individuals in the general community would benefit from being informed that while CF can have many implications for a person’s life, many cases of CF are well managed. This would promote both a good understanding of the experience of CF, but also promote more positive perceptions of this population. Given the success of recent campaigns promoting breast cancer awareness (Smith, Nazione, LaPlante, Katowski, Atkin, Skubisz, et al., 2009) these suggestions are achievable.

If these suggested ‘CF awareness’ campaigns were initiated and were successful in increasing the general community’s understanding of CF, it is likely that this would have a positive impact on the mental health of CF patients and their parents. Specifically, the frustration which patients and parents often experience when having to explain CF to new individuals would be decreased. More generally, the apprehension which is also, at times, experienced when CF patients are deciding whether or not to disclose their illness to a new individual would also be likely to be decreased, as the shock and discomfort that some individuals have in response to hearing about CF for the first time is likely to have been reduced or eliminated. Hence, more comfortable and free-flowing discussions may then occur. Further to this, an increase of knowledge pertaining to CF may also decrease any stigma held in the community relating to this illness, thus allowing individuals to be more sensitive and supportive to individuals and families coping with CF.

8.4 Final Conclusions

The current research has made significant progress towards providing a theoretical framework for the examination of the psychosocial experiences of adolescents and young adults with CF. While the findings suggest that the majority of the CF population are coping well with managing their illness and other normal developmental experiences, areas for intervention for individuals and families who are experiencing distress have been identified within the current theoretical framework. In particular, it is noted that how the patient and their parents perceive CF is especially important for understanding both individual and family-based indices of adjustment. Further, enhancing awareness of CF in the general community may also assist in facilitating a smooth transition for children and adolescents with CF into the adult world.


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Appendix A

Paired Samples T-Test Results for Patient and Parent IPQ-R Domains from T1 to T2

(Study 1)

Patients

Symptoms Experienced: \( t(30) = .78, p = .442 \)
Symptoms Related to CF: \( t(30) = -1.04, p = .308 \)
Consequences: \( t(30) = -.31, p = .756 \)
Personal Control: \( t(30) = 1.78, p = .086 \)
Treatment Control: \( t(30) = -.27, p = .792 \)
Illness Coherence: \( t(30) = -1.08, p = .290 \)
Timeline-cyclical: \( t(30) = .46, p = .647 \)
Emotional Representations: \( t(30) = .13, p = .896 \)

Parents

Symptoms Experienced: \( t(36) = 1.18, p = .247 \)
Symptoms Related to CF: \( t(36) = 1.53, p = .256 \)
Consequences: \( t(36) = -1.33, p = .193 \)
Personal Control: \( t(36) = -.11, p = .916 \)
Treatment Control: \( t(36) = .22, p = .824 \)
Illness Coherence: \( t(36) = -.53, p = .958 \)
Timeline-cyclical: \( t(36) = -1.66, p = .105 \)
Emotional Representations: \( t(36) = -.91, p = .369 \)

Note: Descriptive data for these analyses are presented in Table 7 (p. 116)
Appendix B

Paired Samples T-Test Results for Patient and Parent Coping Styles from T1 to T2

(Study 1)

Patients
Independent Coping: \( t(36) = 1.73, p = .095 \)
Other-oriented Coping: \( t(36) = .23, p = .823 \)

Parents
Change-oriented Coping: \( t(30) = -.83, p = .412 \)
Management-oriented Coping: \( t(30) = .10, p = .919 \)

Note: Descriptive data for these analyses are presented in Table 7 (p. 116)
Appendix C

Study 2 Vignettes

Female – Condition 1

You work as an administration officer for a small business. Currently, about 20 people work in the office. The newest employee, 21-year old Fiona, arrived about two weeks ago. Over the last two weeks you have been involved in training her in the office procedures and orientating her to the company in general. You and Fiona have been getting along well as colleagues and she appears to be picking up the work at a fair pace. When on lunch breaks with Fiona you notice that she always takes a number of pills with her meal. You have also noticed that Fiona has quite a loud phlegmy-sounding cough.

Male – Condition 1

You work as an administration officer for a small business. Currently, about 20 people work in the office. The newest employee, 21-year old Mark, arrived about two weeks ago. Over the last two weeks you have been involved in training him in the office procedures and orientating him to the company in general. You and Mark have been getting along well as colleagues and he appears to be picking up the work at a fair pace. When on lunch breaks with Mark you notice that he always takes a number of pills with his meal. You have also noticed that Mark has quite a loud phlegmy-sounding cough.

Female – Condition 2

You work as an administration officer for a small business. Currently, about 20 people work in the office. The newest employee, 21-year old Fiona, arrived about two weeks ago. Over the last two weeks you have been involved in training her in the office procedures and orientating her to the company in general. You and Fiona have been getting along well as colleagues and she appears to be picking up the work at a fair pace. When on lunch breaks with Fiona you notice that she always takes a number of pills with her meal. You also noticed that Fiona has quite a loud phlegmy-sounding cough. In a recent conversation with Fiona, she mentioned that she has a lot of trouble with allergies and needs to take a number of medications to control her symptoms.

Male – Condition 2

You work as an administration officer for a small business. Currently, about 20 people work in the office. The newest employee, 21-year old Mark, arrived about two weeks ago. Over the last two weeks you have been involved in training him in the office procedures and orientating him to the company in general. You and Mark have been getting along well as colleagues and he appears to be picking up the work at a fair pace. When on lunch breaks with Mark you notice that he always takes a number of pills with his meal. You have also noticed that Mark has quite a loud phlegmy-sounding cough. In a recent conversation with Mark, he mentioned that he has a lot of trouble with allergies and needs to take a number of medications to control his symptoms.
Female – Condition 3

You work as an administration officer for a small business. Currently, about 20 people work in the office. The newest employee, 21-year old Fiona, arrived about two weeks ago. Over the last two weeks you have been involved in training her in the office procedures and orientating her to the company in general. You and Fiona have been getting along well as colleagues and she appears to be picking up the work at a fair pace. When on lunch breaks with Fiona you notice that she always takes a number of pills with her meal. You have also noticed that Fiona has quite a loud phlegmy-sounding cough. In a recent conversation with Fiona, she mentioned that she has cystic fibrosis and needs to take a number of medications to control her symptoms.

Male – Condition 3

You work as an administration officer for a small business. Currently, about 20 people work in the office. The newest employee, 21-year old Mark, arrived about two weeks ago. Over the last two weeks you have been involved in training him in the office procedures and orientating him to the company in general. You and Mark have been getting along well as colleagues and he appears to be picking up the work at a fair pace. When on lunch breaks with Mark you notice that he always takes a number of pills with his meal. You have also noticed that Mark has quite a loud phlegmy-sounding cough. In a recent conversation with Mark, he mentioned that he has cystic fibrosis and needs to take a number of medications to control his symptoms.

Female – Condition 4

You work as an administration officer for a small business. Currently, about 20 people work in the office. The newest employee, 21-year old Fiona, arrived about two weeks ago. Over the last two weeks you have been involved in training her in the office procedures and orientating her to the company in general. You and Fiona have been getting along well as colleagues and she appears to be picking up the work at a fair pace. When on lunch breaks with Fiona you notice that she always takes a number of pills with her meal. You have also noticed that Fiona has quite a loud phlegmy-sounding cough. In a recent conversation with another colleague, they mentioned that Fiona has cystic fibrosis and needs to take a number of medications to control her symptoms.

Male – Condition 4

You work as an administration officer for a small business. Currently, about 20 people work in the office. The newest employee, 21-year old Mark, arrived about two weeks ago. Over the last two weeks you have been involved in training him in the office procedures and orientating him to the company in general. You and Mark have been getting along well as colleagues and he appears to be picking up the work at a fair pace. When on lunch breaks with Mark you notice that he always takes a number of pills with his meal. You have also noticed that Mark has quite a loud phlegmy-sounding cough. In a recent conversation with another colleague, they mentioned that Mark has cystic fibrosis and needs to take a number of medications to control his symptoms.
Female – Condition 5

You work as an administration officer for a small business. Currently, about 20 people work in the office. The newest employee, 21-year old Fiona, arrived about two weeks ago. Over the last two weeks you have been involved in training her in the office procedures and orientating her to the company in general. You and Fiona have been getting along well as colleagues and she appears to be picking up the work at a fair pace. When on lunch breaks with Fiona you notice that she always takes a number of pills with her meal. You have also noticed that Fiona has quite a loud phlegmy-sounding cough. In a recent conversation with Fiona, she mentioned that she has cystic fibrosis and needs to take a number of medications to control her symptoms. As you had not heard much about cystic fibrosis before you ask Fiona what this is. She gives you a pamphlet with information about this illness. It explains that …. “Cystic fibrosis is a genetic disorder that affects about 1 in every 2500 children. Because this disorder is passed on genetically from parents to children it is not contagious and cannot be passed from person to person. The genes that are affected lead people with cystic fibrosis to have problems with their lungs and digestive system. They have really thick mucus which causes breathing problems and a greater chance of getting chest infections. The problems in their digestive system are also caused by problems with fluids in this area and make it really hard to process food. To be able to do this, these people need to take enzyme tablets when they eat. To manage the lung problems, people with cystic fibrosis also need to have regular physiotherapy on their chest, exercise a lot and often take antibiotics to help with chest infections. Currently, there is no cure for cystic fibrosis and people with this illness are not expected to live past 50, but with good health management people with cystic fibrosis can live quite productive lives up until this time”.

Male – Condition 5

You work as an administration officer for a small business. Currently, about 20 people work in the office. The newest employee, 21-year old Mark, arrived about two weeks ago. Over the last two weeks you have been involved in training him in the office procedures and orientating him to the company in general. You and Mark have been getting along well as colleagues and he appears to be picking up the work at a fair pace. When on lunch breaks with Mark you notice that he always takes a number of pills with his meal. You have also noticed that Mark has quite a loud phlegmy-sounding cough. In a recent conversation with Mark, he mentioned that he has cystic fibrosis and needs to take a number of medications to control his symptoms. As you had not heard much about cystic fibrosis before you ask Mark what this is. He gives you a pamphlet with information about this illness. It explains that …. “Cystic fibrosis is a genetic disorder that affects about 1 in every 2500 children. Because this disorder is passed on genetically from parents to children it is not contagious and cannot be passed from person to person. The genes that are affected lead people with cystic fibrosis to have problems with their lungs and digestive system. They have really thick mucus which causes breathing problems and a greater chance of getting chest infections. The problems in their digestive system are also caused by problems with fluids in this area and make it really hard to process food. To be able to do this, these people need to take enzyme tablets when they eat. To manage the lung problems, people with cystic fibrosis also need to have regular physiotherapy on their chest, exercise a lot and often take antibiotics to help with chest infections. Currently, there is no cure for cystic fibrosis and people with this illness are not expected to live past 50, but with good health management people with cystic fibrosis can live quite productive lives up until this time”.

**Female – Condition 6**

You work as an administration officer for a small business. Currently, about 20 people work in the office. The newest employee, 21-year old Fiona, arrived about two weeks ago. Over the last two weeks you have been involved in training her in the office procedures and orientating her to the company in general. You and Fiona have been getting along well as colleagues and she appears to be picking up the work at a fair pace. When on lunch breaks with Fiona you notice that she always takes a number of pills with her meal. You have also noticed that Fiona has quite a loud phlegmy-sounding cough. In a recent conversation with another colleague, they mentioned that Fiona has cystic fibrosis and needs to take a number of medications to control her symptoms. As you had not heard much about cystic fibrosis before you ask your colleague what this is. They give you a pamphlet with information about this illness. It explains that…. “Cystic fibrosis is a genetic disorder that affects about 1 in every 2500 children. Because this disorder is passed on genetically from parents to children it is not contagious and cannot be passed from person to person. The genes that are affected lead people with cystic fibrosis to have problems with their lungs and digestive system. They have really thick mucus which causes breathing problems and a greater chance of getting chest infections. The problems in their digestive system are also caused by problems with fluids in this area and make it really hard to process food. To be able to do this, these people need to take enzyme tablets when they eat. To manage the lung problems, people with cystic fibrosis also need to have regular physiotherapy on their chest, exercise a lot and often take antibiotics to help with chest infections. Currently, there is no cure for cystic fibrosis and people with this illness are not expected to live past 50, but with good health management people with cystic fibrosis can live quite productive lives up until this time”.

**Male – Condition 6**

You work as an administration officer for a small business. Currently, about 20 people work in the office. The newest employee, 21-year old Mark, arrived about two weeks ago. Over the last two weeks you have been involved in training him in the office procedures and orientating him to the company in general. You and Mark have been getting along well as colleagues and he appears to be picking up the work at a fair pace. When on lunch breaks with Mark you notice that he always takes a number of pills with his meal. You have also noticed that Mark has quite a loud phlegmy-sounding cough. In a recent conversation with another colleague, they mentioned that Mark has cystic fibrosis and needs to take a number of medications to control his symptoms. As you had not heard much about cystic fibrosis before you ask your colleague what this is. They give you a pamphlet with information about this illness. It explains that…. “Cystic fibrosis is a genetic disorder that affects about 1 in every 2500 children. Because this disorder is passed on genetically from parents to children it is not contagious and cannot be passed from person to person. The genes that are affected lead people with cystic fibrosis to have problems with their lungs and digestive system. They have really thick mucus which causes breathing problems and a greater chance of getting chest infections. The problems in their digestive system are also caused by problems with fluids in this area and make it really hard to process food. To be able to do this, these people need to take enzyme tablets when they eat. To manage the lung problems, people with cystic fibrosis also need to have regular physiotherapy on their chest, exercise a lot and often take antibiotics to help with chest infections. Currently, there is no cure for cystic fibrosis and people with this illness are not expected to live past 50, but with good health management people with cystic fibrosis can live quite productive lives up until this time”.
Appendix D

Study 3 Instructions for Obtaining Patients’ and Parents’ Written Reflections

Patients
“In this section I would like to give you the opportunity to discuss your views and feelings on cystic fibrosis and your experiences with your family and friends. You can write about anything related to the questions you have just answered, or you may like to discuss other things that are related to your illness and your relationships with your family and friends. If you need more space feel free to include any other sheets of paper you write on.

Parents
“In this section I would like to give you the opportunity to discuss your views and feelings on your child’s cystic fibrosis and your experiences with them. You can write about anything related to the questions you have just answered, or you may like to discuss other things that are related to your child’s illness and your relationship with them. If you need more space feel free to include any other sheets of paper you write on.”
Appendix E

Study 3 Interview Questions for Patients

1. If you discuss CF with your parents, who usually starts the discussion?
2. What kind of things do you talk about?
3. How comfortable do you feel in these discussions?
4. What about them makes you feel comfortable/uncomfortable?
5. What prevents/helps you to discuss CF with your parents?
6. Have you noticed any changes in the way you and your parent discuss CF since you have transitioned from paediatric to adult support at hospital?
7. What is the most challenging thing about CF for you?
8. How do you cope with this?
9. Where do you see yourself in the future?
10. Do you tell your friends/colleagues about your CF?
11. What kind of things impacts your decision to disclose/not disclose your CF?
12. How do you find disclosing your CF to your friends?
13. How do people usually respond in reaction to this?
Appendix F

Study 3 Interview Questions for Parents

1. If you discuss CF with your child, who usually starts the discussion?
2. What kind of things do you talk about?
3. How comfortable do you feel in these discussions?
4. What about them makes you feel comfortable/uncomfortable?
5. What prevents/helps you to discuss CF with your child?
6. Have you noticed any changes in the way you and your child discuss CF since you have transitioned from paediatric to adult support at hospital?
7. What is the most challenging this about raising a child with CF for you?
8. How do you cope with this?
9. How did you find out that your child has CF?
10. Did you notice any changes in the way you look at life after you found out your child has CF?
11. How do you feel about your child discussing CF with people outside of the family?
12. How would you respond if your child asked you for advice with this – to discuss CF or not?