

EXAMINING THE SELF-REPORTED PSYCHOLOGICAL FUNCTIONING OF  
PARENTS OF CHILDREN WITH CYSTIC FIBROSIS

Honours Thesis

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### Abstract

Cystic Fibrosis (CF) is the most common genetic, life-threatening disease among Caucasians, which impacts multiple organs and requires extensive therapies. Although adults with CF can typically care for their medical needs independently, children and adolescents with CF require considerable assistance from caregivers. Previous research has indicated that parents who have children with CF are at increased risk for psychopathology (i.e., depression and anxiety). However, there is extant research examining the psychological functioning of Canadian parents of children and adolescents with CF. Therefore, the purpose of this study was to extend the current literature by examining psychological functioning (i.e., anxiety, depression, health anxiety, anxiety sensitivity, and intolerance to uncertainty) in Canadian parents who have children and adolescents with CF. Ten parents of children with CF, ages 37-49 ( $M = 43.10$ ,  $SD = 4.012$ ) completed a battery of measures designed to assess anxiety and associated constructs. Results demonstrated that the majority of constructs of interest were significantly associated, with the exception that both health anxiety and intolerance of uncertainty were not significantly associated with all constructs. Results also showed a statistically significant difference between ratings of health anxiety by parents in the current sample and a normative sample. The current study is the first of its kind to explore anxiety, depression, health anxiety, anxiety sensitivity, and intolerance to uncertainty in a population of Canadian parents of children and adolescents with CF. Information gleaned from this study will improve our understanding of the functioning of this group of parents. The knowledge obtained is essential to facilitate early identification of psychological distress in these parents leading to the development of tailored psychological interventions.

Keywords: parents, cystic fibrosis, psychopathology

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## Examining the Self-reported Psychological Functioning of Parents of Children with Cystic Fibrosis

Over the past two decades numerous medical advancements have lead to a rapid incline in the number of children with chronic health conditions living into later life (Mokkink et al., 2008; Perrin, Bloom, & Gortmaker, 2007). As a direct result, there has also been a dramatic increase in the number of parents caring for chronically ill children. Pediatric illnesses impact the whole family, especially the parents (Grootenhuis & Bronner, 2009). Understandably, many parents experience great distress when faced with the diagnosis of their child's illness, especially when the illness is associated with functional limitations (Cohen, 1999). While some parents show great resilience after the diagnosis, many parents fall victim to psychological distress, therefore the mental well being of the parents should not be overlooked.

Research has shown that parents of chronically ill children are at significantly greater risk for psychopathology (i.e., depression and anxiety) than parents of children who do not have a chronic illness (Fauman et al., 2011; Stremmer, Haddad, Pullenayegum, & Parshuram, 2017; van Oers et al., 2014). A recent study done by Stremmer, Haddad, Pullenayegum and Parshuram (2017) found that over a quarter of parents with ill children experienced severe depression, and over one half showed symptoms associated with major depression. These finding indicate that parents of chronically ill children are a relatively vulnerable population, experiencing high levels of psychological distress. In fact, many parents with a chronically ill child can experience the same level of overall distress as adults experiencing a severe illness themselves (Haverman et al., 2013). Increased levels of distress could be attributed to concern for the child's well-being, increased financial strain, and extra time required to care for a chronically ill child (Grootenhuis & Bronner, 2009).

An increased level of distress in parents is a major concern in terms of the parent's well being in general but also because it can negatively affect their chronically ill child. Specifically, parental distress can increase a child's psychological discomfort (Grootenhuis & Bronner, 2009), lead to a child's maladjustment to the illness (Lim, Wood, Miller, & Simmens, 2011), and affect a child's compliance to therapy (Bartlett, Krishnan, Riekert, & Butz, 2004). Therefore, an improved understanding of parental functioning is not only important for this group of parents, but it may also be considerably beneficial for the ill children. This is especially true for children with cystic fibrosis (CF), as they perform fewer self-care behaviours and demonstrate poorer adherence to treatment regimen when their parents show high levels of psychological distress (Cousino & Hazen, 2013).

### **Cystic Fibrosis**

CF is currently the most common genetic, life-threatening disease among Caucasians, with approximately 70,000 to 100,000 patients worldwide (Cystic Fibrosis Worldwide (CFW); Sawicki et al., 2011). CF is a multi-system disease that causes complications such as difficulty digesting fats and proteins, malnutrition, and sinus infections (Cystic Fibrosis Canada). However, the leading cause of death in the majority of people with CF is recurrent lung infections that leads to progressive airway damage (Faint, Staton, Stick, Foster, & Schultz, 2017). Regardless of age and severity, CF patients must undergo extensive treatment activity daily to help manage the disease. In order to slow the progression of the disease patients must take pancreatic enzymes, carefully track their nutritional intake, and frequently take a variety of oral medications (Fitzgerald, George, Somerville, Linnane, & Fitzpatrick, 2018). Although there is currently no cure for CF the life-expectancy of patients is increasing, with the majority of CF patients living into adulthood (Stephenson et al., 2017). Specifically, the median life expectancy

for Canadians with CF is 50.9 years (Stephenson et al., 2017). Fortunately, adults with CF show a high level of functioning and can generally care for their medical needs independently. However, young children and adolescents require extensive assistance from their caregivers (Fitzgerald et al., 2018).

### **Parents of Children with Cystic Fibrosis**

Research has demonstrated that parents of children with cystic fibrosis typically experience significantly higher levels of psychological distress than community samples (Fitzgerald et al., 2018; Quittner et al., 2014; Smith, Modi, Quittner, & Wood, 2010). In fact, research suggests that having a child with CF makes parents two to three times more likely to experience clinically elevated depression and anxiety (Quittner et al., 2014). These findings are especially concerning because depressive symptoms in parents have been demonstrated to affect adherence of airway clearance in patients with CF (Smith et al., 2010). As such, it is not surprising that there is a growing concern regarding the mental health of parents who have children with CF.

The large epidemiological study by Quittner et al. (2014), noted above, has greatly contributed to the understanding of psychological functioning in parents of children with CF. The study examined the rates of anxiety and depression in 4,102 parents of youth (ages 12-18 years) with CF. Participants were recruited from nine countries: Belgium, Germany, Italy, Spain, Sweden, The Netherlands, Turkey, the United Kingdom, and the United States of America. Canada was not included in this study. The results demonstrated that 20% to 34% of mothers and 18% to 25% of fathers experienced elevated levels of depression. In addition, elevated levels of anxiety were found in 48% of mothers and 36% of fathers. The study also had

other important findings such as anxiety or depression in parents doubled the risk that the adolescent with CF would experience psychological distress.

Although the study by Quittner et al. (2014) has numerous strengths (i.e., large sample size), there are also a number of notable limitations. First, the Quittner et al. study focuses solely on anxiety and depression. It would be advantageous to examine additional related constructs such as health anxiety, anxiety sensitivity and intolerance of uncertainty (see definitions in section 1.3). In fact, research suggests that intolerance of uncertainty may be a fundamental component of all anxiety disorders (i.e., anxiety, health anxiety, and anxiety sensitivity; Nicholas Carleton, Sharpe, & Asmundson, 2007) and depression (Carleton et al., 2012). Therefore, examining the additional related constructs could be beneficial to facilitate a more thorough understanding of the psychological functioning in this population of parents. Second, the Quittner et al. study examined a CF population of youth ages 12-18 years and their parents. Their sampling does not include children under the age of 12 years. Examining psychological functioning in children is important as anxiety is a very common type of psychopathology in children (Chavira, Stein, Bailey, & Stein, 2004) and untreated anxiety in childhood is associated with treatment resistant anxiety in adolescence and adulthood (Benjamin, Harrison, Settapani, Brodman, & Kendall, 2013). As such, examining psychological functioning in children under the age of 12 years with CF is particularly timely. That said, the focus of the proposed study is on the parents' psychological functioning but by not sampling parents of children with CF under the age of 12 years we are missing a parent group who may have specific psychological needs. Third, considering Canada was not one of the nine countries included in the Quittner et al. study it is unknown if the findings are generalizable to the Canadian context. Regardless of Canada's geographical proximity to the United States there is a large gap between survival rates in CF

patients between countries. As noted above, in Canada the median age of survival for CF patients was found to be 50.9 years, which is ten years higher than the United States Survival rate (i.e., 40.6%; Stephenson et al., 2017). As a result, it is possible that Canadian parents who have children with CF have a qualitatively different experience and different rates of psychological distress than parents of children with CF from the United States.

### **Additional Constructs of Interest**

**Health Anxiety (HA).** Health anxiety refers to fear that arises when bodily changes are believed to be suggestive of a serious disease or illness (Asmundson, Abramowitz, Richter, & Whedon, 2010; Marcus, Gurley, Marchi, & Bauer, 2007). Unfortunately, worry and anxiety about one's health are not uncommon among medically ill patients attending clinics, especially those attending neurology clinics (Tyrrer et al., 2011). When diagnosed with a chronic physical illness (i.e. fibromyalgia) adults demonstrate notably higher levels of HA than relatively healthy populations. Therefore, it is well established in the literature that HA is more frequent and severe among medically ill individuals. In fact, people with at least one physical illness are an astounding 5 times more likely to have HA compared to healthy individuals (Uçar et al., 2015). However, even through there is extensive research regarding HA among medically ill adults, there is little known about HA in parents of medically ill children, in particular for parents of children with CF.

**Anxiety Sensitivity (AS).** Anxiety sensitivity is the tendency to respond to anxiety related symptoms (i.e. irregular breathing, heart palpitations, trembling) with fear (Bartel, Sherry, Smith, Vidovic, & Stewart, 2018; McNally, 2002; Taylor et al., 2007). AS can play a salient role in the development and maintenance of multiple anxiety disorders (Mcleish, Luberto, & O'bryan, 2016; Wheaton, Deacon, McGrath, Berman, & Abramowitz, 2012). There is also

considerable evidence to suggest that AS is a predictor variable for HA, as individuals with HA tend to fear physical anxiety related symptoms (Wheaton, Berman, Franklin, & Abramowitz, 2010; Wheaton et al., 2012). For adults with health disorders (i.e. asthma) AS can worsen the physical symptoms of their disease and increase the severity of their health disorder (McLeish et al., 2016). Unfortunately, there is limited research on how AS can present in parents of chronically ill children, in particular for parents of children with CF.

**Intolerance of Uncertainty (IU).** Intolerance of uncertainty is the propensity for an individual to consider the possibility of a negative event occurring as threatening regardless of how low the probability is that the event will transpire (Holaway, Heimberg, & Coles, 2006; Carleton et al., 2007). Previous research has demonstrated that IU and anxiety sensitivity are independent and moderately related constructs (Carleton et al., 2007). However, discrepancies have been found when examining the relationship between IU and health anxiety. Previous research regarding the psychological functioning of parents of ill children found IU to be significantly correlated with both anxiety and depression (Haegen & Etienne, 2018). However, there is limited research regarding IU in parents of chronically ill children, in particular for parents of children with CF.

### **Purpose**

Given the above review, the purpose of this study was three-fold: (1) to examine self-reported psychological functioning (i.e., anxiety, depression, HA, AS, and IU) in Canadian parents of children and adolescents with CF (ages 8-18); (2) to compare data from the current study to community/normative data across the constructs of anxiety, depression, health anxiety, AS, and IU; and (3) to explore whether parental (i.e., demographics) or child (i.e., demographic or medical characteristics) characteristics were associated with parental anxiety and depression.

**Hypotheses:**

The hypotheses were two-fold:

- 1) It was hypothesized that significant, positive associations would exist between self-report parent psychological functioning as it pertains to the constructs of interest (i.e., anxiety, depression, health anxiety, AS, and IU);
- 2) It was hypothesized that parents of children with CF would have significantly higher scores on the measures of interest compared to existing community/normative data.

No specific hypotheses were made regarding the third purpose as this purpose was exploratory.

**Method****Participants**

Participants consisted of 10 parents ( $\text{mean}_{\text{age}} = 43.10$  years;  $SD = 4.012$ ; range = 37-49 years). For parent demographic characteristics see Table 1. The majority of parents self-identified as female (90%,  $n = 9$ ). All participants self-reported as Caucasian (100%,  $n = 10$ ), but they differed in geographical location. The majority of participants resided in Ontario (50%,  $n = 5$ ) and Alberta (20%,  $n = 2$ ). In addition, the majority of parents had more than one child (80%,  $n = 2$ ) and were married (90%,  $n = 10$ ). One parent reported receiving an intervention for an existing mental health condition. Three parents did not complete the entire battery of measures therefore the primary analyses were completed with 7 parents.

Participants also consisted of 10 children and adolescents ( $\text{mean}_{\text{age}} = 11.22$  years;  $SD = 3.35$ ; range = 8-21 years). For child demographic characteristics see Table 2. The majority of child participants were male (60%,  $n = 6$ ), and did not have haemoptysis or pneumothorax in the last 6 months (80%,  $n = 8$ ). Demographic information was also collected for children and

Table 1

*Descriptive Statistics for Parent Demographic Information*

Demographic	Totals Sample	
	<i>n</i>	%
Gender		
Male	1	10
Female	9	90
Province of residence		
Ontario	5	50
Alberta	2	20
British Columbia	1	10
Saskatchewan	1	10
Newfoundland and Labrador	1	10
Ethnicity		
White/Caucasian	10	100
Relationship Status		
Married	9	90
Single	1	10
Employment Status		
Employed Full-Time	7	70
Employed Part-Time	1	1
Homemaker	2	20
Highest Level of Education		
Grade 12	2	20
Some University	1	10
University Diploma	3	30
University Degree	1	10
Trade School	1	10
M.A.	2	20
Existing Mental Health Condition		
Yes	1	10
No	9	90
	<i>M</i>	<i>SD</i>
Age	43.10	4.012

Table 2

*Descriptive Statistics for Child Demographic Information*

Demographic	Totals Sample		Males		Females	
	<i>n</i>	%	<i>n</i>	%	<i>N</i>	%
Child Age						
8-12	6	60	4	80	2	50
13-21	4	40	1	20	2	50
Province of residence						
Ontario	5	50	2	33.3	3	75
Alberta	2	20	1	16.7	1	25
British Columbia	1	10	1	16.7	0	0
Saskatchewan	1	10	1	16.7	0	0
Newfoundland and Labrador	1	10	1	16.7	0	0
Ethnicity						
White/Caucasian	10	100	6	100	4	100
Haemoptysis or pneumothorax in 6 months						
Yes	2	20	1	16.7	1	25
No	8	80	5	83.8	3	75
Currently on intravenous antibiotics	1	10	0	0	1	10
Mental health condition						
Yes	1	10	1	16.7	0	0
No	9	90	5	83.3	4	100
If yes, what condition						
Anxiety	1	100	1	100	0	0
Depression	0	0	0	0	0	0
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Age	11.22	3.346	10.00	2.449	12.75	4.031
FEV <sub>1</sub> , percent predicted	75.14	19.5	88.0	9.8	58.0	15.13
BMI	17.3	2.0	16.3	1.5	19.2	1.3

Note. FEV<sub>1</sub> = Forced expiratory volume in 1 second.

adolescent's FEV<sub>1</sub> percent predicted (forced expiratory volume in 1 second;  $M = 73.6$ ;  $SD = 18.6$ ).

### **Procedure**

As part of a larger on-going study ethics approval was granted from the University of Regina Ethics Board. After approval was obtained, Nurse Coordinators from CF clinics and Cystic Fibrosis Canada Chapter Presidents across Canada were sent an introductory recruitment email and link to an anonymous, online-hosted survey (SurveyMonkey). The Nurse Coordinators and Chapter Presidents were asked to forward the email to potentially eligible participants. In order to be eligible to participate inclusion criteria required participants to be the parent of a child with a confirmed diagnosis of CF. Consent was obtained from the participant before the survey was completed via SurveyMonkey. Each parent participant completed demographic questionnaire and medical information forms for themselves and their child or adolescent (See Appendix A). The participating parents were asked to complete self-report measures assessing the constructs of anxiety, depression, health anxiety, anxiety sensitivity, and intolerance of uncertainty [i.e., State-Trait Anxiety Inventory (STAI; Spielberger, Gorsuch, & Lushene, 1970); Center for Epidemiologic Studies Depression Scale (CESD; Radloff, 1977); Short Health Anxiety Inventory (SHAI; Salkovskis, Rimes, & Warwick, 2002); Anxiety Sensitivity Index-3 (ASI-3; Taylor et al., 2007), and the Intolerance of Uncertainty Scale-Short Form (IUS-12; (Carleton, Norton, & Asmundson, 2007))].

### **Measures**

**State-Trait Anxiety Inventory (STAI; Spielberger et al., 1970; See Appendix B)** The STAI is a 40-item self-report questionnaire for adults 18 and older that measures two types of anxiety (i.e., state and trait anxiety). Half of the questions measure state anxiety (i.e., unpleasant

feeling that people are feeling right now). The other half of the questions measure trait anxiety [i.e., a person's stable tendency to experience, attend to and report negative emotions (i.e., fear and worry)]. Each item is rated on a 4-point scale: 1-not at all, 2-somewhat, 3-moderately so, and 4-very much so. The total score for each version of the measure ranges from 20-80, with higher scores indicate greater levels of anxiety. The STAI has demonstrated good psychometric properties, especially good internal consistency ( $\alpha > .89$ ) and test-retest reliability ( $r = .88$ ) (Barnes, Harp, & Jung, 2002). In the current study, both state and trait subscales demonstrated excellent internal consistency ( $\alpha = .97$ ,  $\alpha = .98$ , respectively).

**Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977; See Appendix C)** The CES-D is a 20-item self-report questionnaire used to measure symptoms of depression. All items are rated on a 4-point scale: 0-rarely or none of the time, 1-some or a little of the time, 2-ocasionally or a moderate amount of time, and 3-most or all of the time. The CES-D total score ranges from 0-60, with higher scores indicating greater symptomology. The CES-D has been found to have good convergent validity ( $\alpha = .78$ ) and excellent test-retest reliability ( $r = .91$ ; Chin, Choi, Chan, & Wong, 2015). In the current study, the CES-D total score demonstrated excellent internal consistency ( $\alpha = .97$ ).

**Short Health Anxiety Inventory (SHAI; Salkovskis et al., 2002; See Appendix D)** The SHAI is an 18-item self-report questionnaire designed to assess health anxiety. Each of the 18-items consists of four statements and participants are instructed to pick the statement that best applies to them over the last six months. All items are rated on a 4-point scale: 0-no symptomology, 1-mild symptomology, 2-severe symptomology, and 3- very severe symptoms. The measure is comprised of two components: illness likelihood (IL) and negative consequences of illness (NC). For the purpose of this study we will employ the 14-item version. The 14-item

SHAI total score ranges from 0-42, with higher scores reflecting greater levels of health anxiety. Research suggests that the SHAI is a psychometrically sound tool with good internal consistency ( $\alpha = .74-.96$ ) and good test-retest reliability ( $r = .87$ ) over a three-week period (Alberts, Hadjistavropoulos, Jones, & Sharpe, 2013). In the current study, the SHAI total score demonstrated excellent internal consistency ( $\alpha = .95$ ).

**Anxiety Sensitivity Index-3 (ASI-3; Taylor et al., 2007; See Appendix E)** The ASI-3 is an 18-item self-report assessment that measures anxiety sensitivity (AS). AS consists of three factors: fear of physical symptoms, fear of lack of cognitive control, and fear of social concerns. All items are rated on a 5-point scale: 0-very little, 1-a little, 2-some, 3-much, and 4-very much. For the current study we will employ the total score. The ASI-3 total score ranges from 0-54, with a higher score indicating a greater level of anxiety sensitivity. The ASI-3 demonstrates good to excellent validity and reliability (Rifkin, Beard, Hsu, Garner, & Björgvinsson, 2015). More specifically, the measure has great internal consistency ( $\alpha = .84-.89$ ) and good test-retest reliability with scores ranging from .60 to .82 (Farris et al., 2015). In the current study, the ASI-3 total score demonstrated excellent internal consistency ( $\alpha = .94$ ).

**Intolerance of Uncertainty Scale-12 (IUS-12; Carleton et al., 2007)** The IUS is a 12-item self-report questionnaire that measures IU across the lifespan. This measure is a shortened version of the original 27-item IUS (Freeston et al., 1994). The IUS-12 is a 2-factor model consisting of 7 statements regarding prospective anxiety and 5 questions regarding inhibitory anxiety. All questions are rated on a 5-point likert scale: 1-not at all characteristic of me, 2-a little characteristic of me, 3-somewhat characteristic of me, 4-very characteristic of me, and 5-entirely characteristic of me. This measure consists of two subscales (i.e., prospective IU and inhibitory IU) and total scores range from 12-60, with higher scores reflecting greater levels of

IU. Research indicates that the IUS-12 has excellent internal consistency with an alpha coefficient of .91 (Carleton et al., 2007) and adequate test-retest reliability ( $r = .77$ ; Khawaja & Yu, 2010). In the current study, the IUS-12 total score demonstrated very good internal consistency ( $\alpha = .89$ ).

### **Analyses**

A series of statistical analyses were performed using the IBM SPSS Statistics software package (SPSS: version 24). Descriptive statistics were computed for the parent and child's demographic information as well as child's medical information, as well as for total and subscale scores for the measures of self-reported psychological functioning (i.e. STAI, CES-D, SHAI, ASI-3, and IUS-R). Three primary analyses were completed: (1) bivariate correlations were computed to examine the association between the constructs of interest, (2) a series of one sample t-tests were computed to examine the potential differences between levels of the constructs of interest in the current sample compared to community/normative data; and (3) a series of bivariate correlations were computed to examine whether any parental characteristics (i.e., demographics) or child characteristics (i.e., demographic or medical characteristics) were associated with variance in parental anxiety and depression. The latter analysis was completed to facilitate comparison to the existing epidemiological findings (Quittner et al., 2014) that only looked at parental anxiety and depression.

### **Results**

#### **Descriptive Statistics**

A series of descriptive statistics were computed for demographic information and for total scores and (where appropriate) subscale scores of the measures (see Tables 1-3). As stated above 10 parents ages 37-49 ( $M = 43.10$ ,  $SD = 4.012$ ) completed the demographic questionnaire

Table 3

*Descriptive Statistics for Measures of Constructs of Interest*

Measures	M (SD)	Score Range
STAI		
State subscale	43.9(17.4)	23.0-75.0
Trait subscale	41.1(14.9)	25.0-63.0
CES-D	14.6(15.4)	3.0-49.0
SHAI	24.3(7.5)	15.0-39.0
ASI-3	17.4(14.3)	5.0-42.0
IUS-12	25.6(7.9)	16.0-41.0

*Note.* STAI = State-Trait Anxiety Inventory; CES-D = Center for Epidemiologic Studies Depression Scale; SHAI= Short Health Anxiety Inventory; ASI-3 = Anxiety Sensitivity Index-3; IUS-12 = Intolerance of Uncertainty Scale-12.

(9 females and 1 male). Bivariate correlations were computed between age and total scores on measures of state and trait anxiety, depression, health anxiety, anxiety sensitivity, and intolerance of uncertainty to examine potential association between age and constructs of interest. No statistically significant associations were observed between age and constructs of interest. We did not examine potential sex differences across constructs of interest as our sample was comprised of primarily females.

### **Associations Between Constructs of Interest**

It was hypothesized that significant, positive associations would exist between self-report parent psychological functioning as it pertains to the constructs of interest (i.e., anxiety, depression, HA, AS, and IU). A series of bivariate correlations were computed to examine the potential associations between the constructs of interest. Results demonstrated that the majority of constructs of interest were significantly associated, with the exception that both health anxiety (SHAI) and intolerance of uncertainty (IUS-12) were not significantly associated with all constructs (see Table 4). Statistically significant associations were not found between the SHAI and the STAI state subscale, the STAI trait subscale or the IUS-12. An association was also not present between the STAI trait subscale and the IUS-12. All other associations were statistically significant.

### **Comparison of Psychological Functioning for CF Parents vs Normative Samples**

It was hypothesized that parents of children with CF would have significantly higher scores on the measures of interest compared to existing community/normative data. Total and (where appropriate) subscale score for measures of interest in the current study were compared to community/normative data using a series of one-sample t-tests (see Table 5 & Figure 1). Results demonstrated one statistically significant difference between the current sample and the

Table 4

*Associations Between Measures of Constructs of Interest*

Measures	Parent age	STAI State	STAI Trait	CES-D	SHAI	ASI-3	IUS-12
Parent age	---	.390	.079	.307	.241	.336	.608
STAI State		---	.922**	.924**	.679	.900**	.922**
STAI Trait			---	.861**	.621	.890**	.801
CES-D				---	.864**	.95**	.857*
SHAI					---	.882**	.309
ASI-3						---	.808*
IUS-12							---

*Note.* STAI = State-Trait Anxiety Inventory; CES-D = Center for Epidemiologic Studies Depression Scale; SHAI= Short Health Anxiety Inventory; ASI-3 = Anxiety Sensitivity Index-3; IUS-12 = Intolerance of Uncertainty Scale-12. \*\* $p < .01$ , \*  $p < .05$ .

Table 5

*Comparison of Psychological Functioning in CF and Community/Normative Samples*

Measures	CF Sample	Community/ Normative Samples	<i>t</i>	<i>P</i>
	M (SD)	M (SD)		
STAI total score <sup>a</sup>				
State subscale	43.9(17.4)	36.4(10.6)	1.294	0.232
Trait subscale	41.1(14.9)	41.9(8.6)	0.159	0.878
CES-D total score <sup>b</sup>	14.6(15.4)	13.9(7.4)	0.135	0.896
SHAI total score <sup>c</sup>	24.3(7.5)	9.19(4.9)	5.969	0.001*
ASI-3 total score <sup>d</sup>	17.4(14.3)	19.14(14.4)	0.349	0.737
IUS-12 total score <sup>e</sup>	25.6(7.9)	29.5(10.9)	1.327	0.233

*Note* STAI = State-Trait Anxiety Inventory; CES-D = Center for Epidemiologic Studies Depression Scale; SHAI= Short Health Anxiety Inventory; ASI-3 = Anxiety Sensitivity Index-3; IUS-12 = Intolerance of Uncertainty Scale-12. <sup>a</sup>Vardar et al, 2006. <sup>b</sup>Shean, 2008. <sup>c</sup>Alberts et al., 2011. <sup>d</sup>Carleton et al., 2010. <sup>e</sup>Carleton et al., 2012. \* $p < .001$

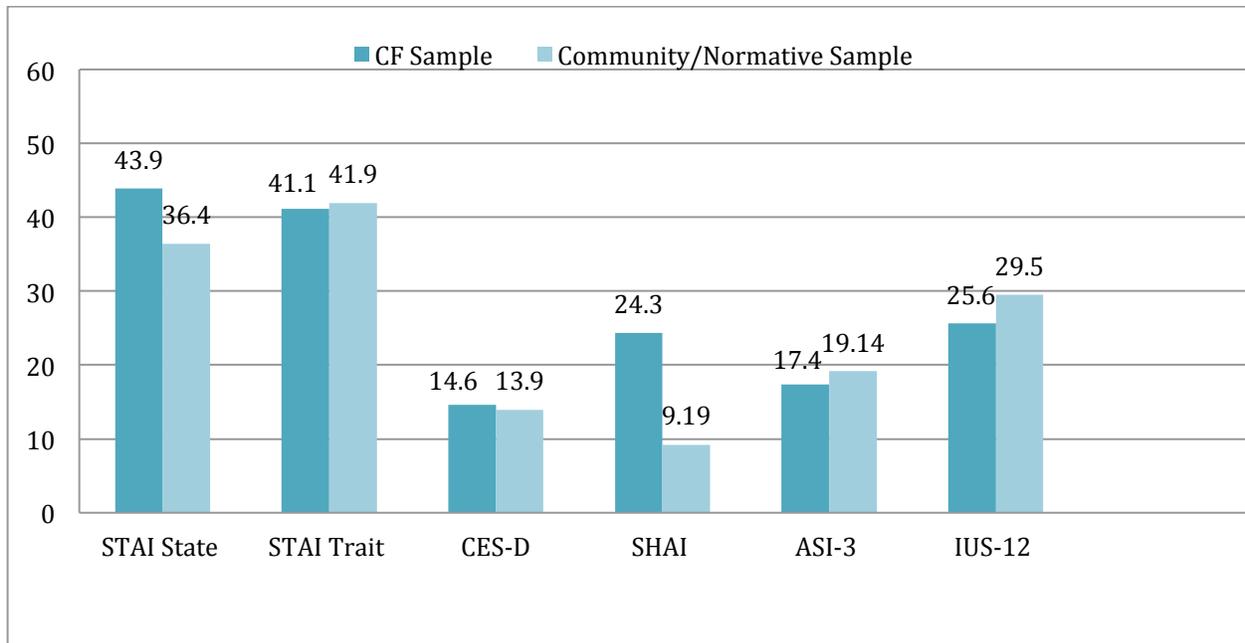


Figure 1. Comparison of Psychological Functioning in Current and Community/Normative Samples

community/normative sample. Parents of children and adolescents with CF had significantly higher SHAI total scores than SHAI total scores in a community/normative sample,  $t(8) = 5.97$ ,  $p < .001$ . The mean SHAI total score for parents of children and adolescents with CF was 24.3 ( $SD = 7.5$ ) and the mean for the community/normative sample total score on the SHAI was 9.19 ( $SD = 4.9$ ). No other statistically significant results were found between the current parent sample and community/normative sample.

### **Variables associated with Self-reported Parent Anxiety and Depression**

The purpose of the final data analysis was to explore whether any parental characteristics (i.e., demographics) or child characteristics (i.e., demographic or medical characteristics) were associated with parental anxiety and depression. No specific hypotheses were made as this purpose was exploratory. A series of bivariate correlations were computed between parent/child characteristics and parent total score on anxiety and depression.

Parent age was not significantly associated with parent anxiety or depression (see Table 4). Potential sex differences in the experience of parent anxiety and depression were not explored, as there was only one father who participated. With respect to child variables, child age was not associated with parent anxiety, STAI-S,  $r(6) = -.22$ ,  $p = .610$ , STAI-T,  $r(6) = -.52$ ,  $p = .184$ , or depression, CESD,  $r(6) = -.26$ ,  $p = .535$ . No association was observed between FEV<sub>1</sub> percent predicted scores (forced expiratory volume in 1 second) and parent anxiety, STAI-S,  $r(5) = -.45$ ,  $p = .309$ , STAI-T,  $r(5) = -.32$ ,  $p = .478$ , or depression, CESD,  $r(5) = -.30$ ,  $p = .509$ . No significant differences in parent anxiety were observed for parents of male versus female children or adolescents, STAI-S,  $t(7) = -0.98$ ,  $p = .360$ , STAI-T,  $t(7) = -0.41$ ,  $p = .696$ , respectively. No significant differences in parent depression were observed for parents of male versus female children or adolescents, CESD,  $t(7) = -0.66$ ,  $p = .529$ . No significant differences

in parent anxiety were observed between parents of children or adolescents who had/did not have haemoptysis or pneumothorax in the last 6 months, STAI-S,  $t(7) = -0.43, p = .682$ , STAI-T,  $t(7) = -0.92, p = .390$ , respectively. No significant differences in parent depression were observed between parents of children or adolescents who had/did not have haemoptysis or pneumothorax in the last 6 months, CESD,  $t(7) = -1.05, p = .327$ .

### Discussion

Numerous medical advancements have led to a greater number of parents caring for chronically ill children as they age (Mokkink et al., 2008; Perrin et al., 2007). An abundance of research suggests parents of chronically ill children are at significantly greater risk for psychopathology (i.e., depression and anxiety) than parents of children who do not have a chronic illness (Fauman et al., 2011; Stremmler et al., 2017; van Oers et al., 2014). This finding is especially concerning in regards to CF (a chronic health condition that requires extensive treatment activity daily to help manage the disease), because depressive symptoms in parents have been demonstrated to affect adherence of airway clearance in patients with CF (Smith et al., 2010). When examining the psychological functioning of parents of children with CF there is no existing literature regarding Canadian parents. Quittner et al. (2014) examined anxiety and depression in parents of children with CF among 9 countries (excluding Canada). The results demonstrated that parents of children with CF are two to three times more likely to experience elevated levels of anxiety and depression. While this epidemiological study has greatly contributed to the understanding of psychological functioning of parents with CF, it is unknown if the results accurately represent Canadian parents of children with CF. Further, the Quittner et al. study only explored anxiety and depression in parents of children with CF, and only included a youth sample of adolescents 12-17 years, excluding children 8-11 years of age. Therefore, the

current study sought to address the limitations of the Quittner et al. study in a number of ways. Specifically, the purpose of the current study was three-fold: (1) to examine self-reported psychological functioning [i.e., anxiety, depression, health anxiety (HA), anxiety sensitivity (AS), and intolerance of uncertainty (IU)] in Canadian parents of children and adolescents with CF (ages 8-18); (2) to compare data from the current study to community/normative data across the constructs of anxiety, depression, HA, AS, and IU; and (3) to explore potential associations between parental (i.e., demographics) or child (i.e., demographic or medical characteristics) characteristics were and parental anxiety and depression. Each of the hypotheses and the associated findings will be discussed below in succession.

It was hypothesized that significant, positive associations would exist between self-report parent psychological functioning as it pertains to the constructs of interest (i.e., anxiety, depression, HA, AS, and IU). This hypothesis was partially supported. Specifically, the majority of parent-reported constructs of interest were significantly associated, however there was a lack of association between health anxiety and intolerance of uncertainty. This result is inconsistent with previous literature, as HA and IU are typically associated (Carleton, Norton, & Asmundson, 2007; Wheaton, Deacon, McGrath, Berman, & Abramowitz, 2012). Data collection is ongoing and it is anticipated that a larger sample size will allow us to explore this discrepancy.

It was also hypothesized that parents of children with CF would have significantly higher scores on the measures of interest compared to existing community/normative data. This hypothesis was partially supported, as results were only significant across one construct. Our findings demonstrated that parents of children with CF had statistically significant higher levels of health anxiety than a community/normative sample. This finding may be intuitive given that CF is a life-limiting health condition where parents are required to provide care daily and be

vigilant for changes in the health status of their child, in turn possibly becoming much more aware of and concerned for changes in their health. In addition, although not statistically significant, the current sample of parents reported greater levels of state anxiety and depression. A larger sample size will allow for us to investigate these potential differences further.

No major parent or child/adolescent demographics were associated with parent-reported anxiety or depression. This finding is inconsistent with previous literature. For example, Quittner et al. (2014) found that elevated parent anxiety was associated with having younger aged children with CF. However, our analyses were limited due to our current small sample size. Further data collection will allow us to examine these associations more thoroughly.

### **Limitations**

The current study had a number of limitations that require attention. First, sample size is one major limitation of the current study. We anticipated having 100 participants complete the survey including the demographics questionnaires and the battery of measures. Unfortunately, only 10 parents provided the demographic information and 7 parents completed all of the measures. One possible explanation for the small sample size is that the survey can be considered time consuming. Parents and children were both required to fill out five measure, which takes approximately 2 hours total. Parents may have deemed the time and effort required to fill out the self-report questionnaires too much to schedule into their already busy lives. Therefore, having a small sample size may impact the current findings generalizability. Another possible explanation for the small sample size is that the current study relied solely on internet-based technology for correspondence, recruitment, and data collection. It is possible that if parents were recruited face-to-face they may have felt more accountable and willing to complete the measures. Since data collection is ongoing, moving forward recruitment will also be conducted in person as well as

online. Ideally, adapting the recruitment methods will increase response rates and allow participants to better understand how this research can benefit them personally.

Second, data collected relied solely on self-report questionnaires, which can be subject to response biases (Mundia, 2011). There is a lot of pressure in today's society for parents to have every aspect of their lives under control. Mental health can be a sensitive topic, and parents of ill children may be hesitant to open up about struggling with their mental health. Therefore, the socially desirable response bias may have influenced the results of this study through parents reporting fewer symptoms than they were actually experiencing (Näher & Krumpal, 2012). Fortunately, as part of the larger study psychological measurement will involve both self-report measures and qualitative interviews to allow for a better understanding of the psychological needs of this population.

### **Future Directions**

The current study was the first of its kind to explore anxiety, depression, health anxiety, anxiety sensitivity, and intolerance to uncertainty in a population of Canadian parents of children and adolescents with CF. Improved understanding of this population is essential in order to facilitate early identification of psychological distress in these parents, and ideally inform the development of tailored psychological interventions. In order to broaden the understanding of parents of children with CF, further research may aim to examine psychological distress in fathers of children with CF. Only one father participated in the current study; however including fathers is necessary because previous research has indicated that fathers of chronically ill children also experience psychological distress when raising an ill child (van Oers et al., 2014). In addition, it would be beneficial to examine psychological distress in sibling of children with CF in a Canadian sample. Chronic illnesses impact the entire family, and research has

demonstrated that having a sibling with CF can negatively impact one's psychological well-being (Hartling et al., 2014). Furthermore, future research may examine self-reported psychological function of parents of children with CF using a longitudinal study design. A longitudinal study would be beneficial, because it would allow researchers to better understand the trajectory of psychological distress in this population of parents.

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## Appendix A

**Parent/Child Demographic Questionnaire:****Parent**

1. What is your sex?

Male       Female

2. How old are you?

Age: \_\_\_\_\_

3. What is your ethnicity?

White/Caucasian       Black/African       Hispanic  
 Asian       Aboriginal/First Nations       Middle Eastern  
 Mixed Ethnicity       Other (please specify)

4. What is your HIGHEST level of education?

<input type="checkbox"/> Some elementary school	<input type="checkbox"/> Some University
<input type="checkbox"/> Grade 8	<input type="checkbox"/> University Diploma
<input type="checkbox"/> Grade 9	<input type="checkbox"/> University Degree
<input type="checkbox"/> Grade10	<input type="checkbox"/> Trade School
<input type="checkbox"/> Grade11	<input type="checkbox"/> M.A.
<input type="checkbox"/> Grade12	<input type="checkbox"/> Ph.D.

5. What is your current relationship status?

<input type="checkbox"/> Single	<input type="checkbox"/> Divorced	<input type="checkbox"/> Common law/cohabiting
<input type="checkbox"/> Married	<input type="checkbox"/> Separated	<input type="checkbox"/> Dating
<input type="checkbox"/> Widowed	<input type="checkbox"/> Other (please specify)	

6. What is your current employment status? (Select all those that currently apply)

Employed-full time     Employed part-time  
 Student     On disability     Other (please specify)

8. What is your current family size?

\_\_\_\_\_ number

9. What is your current household income?

Less than 30,000     30,000-49,999     50,000-99,999  
 100,000-499,000     greater than 500,000

9. Where do you live?

urban setting     rural setting

10. Do you have an existing health condition?

YES            NO

11. If YES, please list:

12. Do you have an existing mental health condition (e.g., attention deficit/hyperactivity disorder, depression, panic disorder, schizophrenia)?

YES            NO

13. If YES, please list:

14. Are you receiving any intervention for an existing mental health condition?

YES            NO

If YES, please check as appropriate

psychiatric medication     psychotherapy     other

**Child**

1. What is your child's sex?

\_\_\_\_\_ Male      \_\_\_\_\_ Female

2. How old is your child?

Age: \_\_\_\_\_

3. What is your child's date of birth? (Month, Day, Year)

Birthday :    \_\_\_\_\_  
                  MM    DD    YY

4. What is your child's ethnicity?

\_\_\_\_\_ White/Caucasian      \_\_\_\_\_ Black/African      \_\_\_\_\_ Hispanic  
\_\_\_\_\_ Asian      \_\_\_\_\_ Aboriginal/First Nations      \_\_\_\_\_ Middle Eastern  
\_\_\_\_\_ Mixed Ethnicity      \_\_\_\_\_ Other (please specify)

5. What grade is your child in?

\_\_\_\_\_ Grade 2      \_\_\_\_\_ Grade 3      \_\_\_\_\_ Grade 4      \_\_\_\_\_ Grade 5      \_\_\_\_\_ Grade 6  
\_\_\_\_\_ Grade 7      \_\_\_\_\_ Grade 8      \_\_\_\_\_ Grade 9      \_\_\_\_\_ Grade 10

Responses from the following two questions allow us to calculate your child's body mass index (BMI)

6. What is your child's height?

\_\_\_\_\_ feet    \_\_\_\_\_ inches

\_\_\_\_\_ Do not know

7. What is your child's weight?

\_\_\_\_\_ lbs

\_\_\_\_\_ Do not know

8. What is your child's FEV<sub>1</sub> percent predicted (forced expiratory volume in 1s as a percentage of predicted)?

\_\_\_\_\_

\_\_\_\_\_ Do not know

10. Has your child had haemoptysis or pneumothorax in last 6 months?

YES            NO

11. Is your child currently on intravenous antibiotics?

YES            NO

If YES, for how long

\_\_\_\_\_ months \_\_\_\_\_ weeks \_\_\_\_\_ days

12. Is your child on the national waiting list for lung transplantation?

YES            NO

13. Does your child have an existing mental health condition (e.g., attention deficit/hyperactivity disorder, depression, panic disorder, schizophrenia)?

YES            NO

13. If YES, please list:

14. Is your child currently on psychiatric medication for a mental health condition?

YES            NO

If YES, please list mental health condition and associated prescribed medication

Mental Health Condition

Medication

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

15. Is your child currently receiving psychotherapy for a mental health condition?

YES

NO

Appendix B

**STAI-S**

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you feel *right* now, that is, ***at this moment***. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

		<b>Not at all</b>	<b>Somewhat</b>	<b>Moderately so</b>	<b>Very Much so</b>
1.	I feel calm .....	1	2	3	4
2.	I feel secure.....	1	2	3	4
3.	I am tense.....	1	2	3	4
4.	I feel strained .....	1	2	3	4
5.	I feel at ease .....	1	2	3	4
6.	I feel upset .....	1	2	3	4
7.	I am presently worrying over possible..... misfortunes	1	2	3	4
8.	I feel satisfied .....	1	2	3	4
9.	I feel frightened .....	1	2	3	4
10.	I feel comfortable .....	1	2	3	4
11.	I feel self-confident .....	1	2	3	4
12.	I feel nervous .....	1	2	3	4
13.	I am jittery .....	1	2	3	4
14.	I feel indecisive .....	1	2	3	4
15.	I am relaxed .....	1	2	3	4
16.	I feel content .....	1	2	3	4
17.	I am worried .....	1	2	3	4
18.	I feel confused .....	1	2	3	4

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- |     |                       |   |   |   |   |
|-----|-----------------------|---|---|---|---|
| 19. | I feel steady .....   | 1 | 2 | 3 | 4 |
| 20. | I feel pleasant ..... | 1 | 2 | 3 | 4 |

## STAI-T

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you feel *in general*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	Almost	Never	Sometimes	Often	Almost always
1. I am happy .....	1		2	3	4
2. I am content.....	1		2	3	4
3. I am satisfied with myself .....	1		2	3	4
4. I feel pleasant .....	1		2	3	4
5. I feel secure .....	1		2	3	4
6. I lack self-confidence .....	1		2	3	4
7. I feel inadequate.....	1		2	3	4
8. I feel like a failure.....	1		2	3	4
9. I am a steady person.....	1		2	3	4
10. I wish I could be as happy as others seem to be	1		2	3	4
11. I make decisions easily.....	1		2	3	4
12. I am 'calm, cool, and collected' .....	1		2	3	4
13. I feel rested.....	1		2	3	4
14. Some unimportant thought runs through ..... my mind and bothers me	1		2	3	4
15. I worry too much over something that..... doesn't really matter	1		2	3	4
16. I get in a state of tension or turmoil as I think.. over my recent concerns and interests	1		2	3	4
17. I have disturbing thoughts .....	1		2	3	4
18. I take disappointments so keenly that I can't... put them out of my mind	1		2	3	4
19. I feel that difficulties are piling up so that I..... can't overcome them	1		2	3	4

20. I feel nervous and restless..... 1 2 3 4

## Appendix C

**Center for Epidemiologic Studies Depression Scale (CES-D), NIMH**

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

	<b>During the past week</b>			
	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me.				
2. I did not feel like eating; my appetite was poor.				
3. I felt that I could not shake off the blues even with help from my family or friends.				
4. I felt I was just as good as other people.				
5. I had trouble keeping my mind on what I was doing.				
6. I felt depressed.				
7. I felt that everything I did was an effort.				
8. I felt hopeful about the future.				
9. I thought my life had been a failure.				
10. I felt fearful.				
11. My sleep was restless.				
12. I was happy.				
13. I talked less than usual.				
14. I felt lonely.				
15. People were unfriendly.				
16. I enjoyed life.				
17. I had crying spells.				
18. I felt sad.				
19. I felt that people dislike me.				
20. I could not get "going."				

SCORING: zero for answers in the first column, 1 for answers in the second column, 2 for answers in the third column, 3 for answers in the fourth column. The scoring of positive items is reversed. Possible range of scores is zero to 60, with the higher scores indicating the presence of more symptomatology.

## Appendix D

**SHAI**

**Instructions:** Each question in this section consists of a group of four statements. Please read each group of statements carefully and then select the one which best describes your feelings, over the past week. Identify the statement by choosing the letter next to it, i.e., if you think that statement (a) is correct, choose statement (a); it may be that more than one statement applies, in which case, please choose any that are applicable.

1.     (a) I do not worry about my health.  
       (b) I occasionally worry about my health.  
       (c) I spend much of my time worrying about my health.  
       (d) I spend most of my time worrying about my health.
  
2.     (a) I notice aches/pains less than most other people (of my age).  
       (b) I notice aches/pains as much as most other people (of my age).  
       (c) I notice aches/pains more than most other people (of my age).  
       (d) I am aware of aches/pains in my body all the time.
  
3.     (a) As a rule I am not aware of bodily sensations or changes.  
       (b) Sometimes I am aware of bodily sensations or changes.  
       (c) I am often aware of bodily sensations or changes.  
       (d) I am constantly aware of bodily sensations or changes.
  
4.     (a) Resisting thoughts of illness is never a problem.  
       (b) Most of the time I can resist thoughts of illness.  
       (c) I try to resist thoughts of illness but am often unable to do so.  
       (d) Thoughts of illness are so strong that I no longer even try to resist them.
  
5.     (a) As a rule I am not afraid that I have a serious illness.  
       (b) I am sometimes afraid that I have a serious illness.  
       (c) I am often afraid that I have a serious illness.  
       (d) I am always afraid that I have a serious illness.
  
6.     (a) I do not have images (mental pictures) of myself being ill.  
       (b) I occasionally have images of myself being ill.  
       (c) I frequently have images of myself being ill.  
       (d) I constantly have images of myself being ill.
  
7.     (a) I do not have any difficulty taking my mind off thoughts about my health.  
       (b) I sometimes have difficulty taking my mind off thoughts about my health.  
       (c) I often have difficulty in taking my mind off thoughts about my health.  
       (d) Nothing can take my mind off thoughts about my health.
  
8.     (a) I am lastingly relieved if my doctor tells me there is nothing wrong.

- (b) I am initially relieved but the worries sometimes return later.
  - (c) I am initially relieved but the worries always return later.
  - (d) I am not relieved if my doctor tells me there is nothing wrong.
9. (a) If I hear about an illness I never think I have it myself.  
(b) If I hear about an illness I sometimes think that I have it myself.  
(c) If I hear about an illness I often think I have it myself.  
(d) If I hear about an illness I always think that I have it myself.
10. (a) If I have a bodily sensation or change I rarely wonder what it means.  
(b) If I have a bodily sensation or change I often wonder what it means.  
(c) If I have a bodily sensation or change I always wonder what it means.  
(d) If I have a bodily sensation or change I must know what it means.
11. (a) I usually feel at very low risk for developing a serious illness.  
(b) I usually feel at fairly low risk for developing a serious illness.  
(c) I usually feel at moderate risk for developing a serious illness.  
(d) I usually feel at high risk for developing a serious illness.
12. (a) I never think that I have a serious illness.  
(b) I sometimes think that I have a serious illness.  
(c) I often think that I have a serious illness.  
(d) I usually think that I have a serious illness.
13. (a) If I notice an unexplained bodily sensation I don't find it difficult to think about other things.  
(b) If I notice an unexplained bodily sensation I sometimes find it difficult to think about other things.  
(c) If I notice an unexplained bodily sensation I often find it difficult to think about other things.  
(d) If I notice an unexplained bodily sensation I always find it difficult to think about other things.
14. (a) My family/friends would say I do not worry enough about my health.  
(b) My family/friends would say I have a normal attitude about my health.  
(c) My family/friends would say I worry too much about my health.  
(d) My family/friends would say I am a hypochondriac.

For the following questions, please think about what it might be like if you had a serious illness of a type which particularly concerns you (such as heart disease, cancer, multiple sclerosis and so on). Obviously you cannot know for definite what it would be like; please give your best estimate of what you think might happen, basing your estimate on what you know about yourself and serious illness in general.

15. (a) If I had a serious illness I would still be able to enjoy things in my life quite a lot.  
(b) If I had a serious illness I would still be able to enjoy things in my life a little.  
(c) If I had a serious illness I would still be almost completely unable to enjoy things in my life.  
(d) If I had a serious illness I would be completely unable to enjoy life at all.
16. (a) If I developed a serious illness there is a good chance that modern medicine would be able to cure me.  
(b) If I developed a serious illness there is a moderate chance that modern medicine would be able to cure me.  
(c) If I developed a serious illness there is a very small chance that modern medicine would be able to cure me.  
(d) If I developed a serious illness there is no chance that modern medicine would be able to cure me.
17. (a) A serious illness would ruin some aspects of my life.  
(b) A serious illness would ruin many aspects of my life.  
(c) A serious illness would ruin almost every aspect of my life.  
(d) A serious illness would ruin every aspect of my life.
18. (a) If I had a serious illness I would not feel that I had lost my dignity.  
(b) If I had a serious illness I would feel that I had lost a little of my dignity.  
(c) If I had a serious illness I would feel that I had lost quite a lot of my dignity.  
(d) If I had a serious illness I would feel that I had totally lost my dignity.

## Appendix E

**ASI-3**

For each statement below, please choose the response that best represents how well the statement describes you.

	Agree very little	Agree a little	Somewhat agree	Agree a lot	Agree very much
1. It is important for me not to appear nervous.	0	1	2	3	4
2. When I cannot keep my mind on a task, I worry that I might be going crazy.	0	1	2	3	4
2. It scares me when my heart beats rapidly.	0	1	2	3	4
4. When my stomach is upset, I worry that I might be seriously ill.	0	1	2	3	4
5. It scares me when I am unable to keep my mind on a task.	0	1	2	3	4
6. When I tremble in the presence of others, I fear what people might think of me.	0	1	2	3	4
7. When my chest feels tight, I get scared that I won't be able to breathe properly.	0	1	2	3	4
8. When I feel pain in my chest, I worry that I'm going to have a heart attack.	0	1	2	3	4
9. I worry that other people will notice my anxiety.	0	1	2	3	4
10. When I feel "spacey" or spaced out I worry that I may be mentally ill.	0	1	2	3	4
11. It scares me when I blush in front of people.	0	1	2	3	4
12. When I notice my heart skipping a beat, I worry that there is something seriously wrong with me.	0	1	2	3	4
13. When I begin to sweat in a social situation, I fear people will think negatively of me.	0	1	2	3	4
14. When my thoughts seem to speed up, I worry that I might be going crazy.	0	1	2	3	4
15. When my throat feels tight, I worry that I could choke to death.	0	1	2	3	4
16. When I have trouble thinking clearly, I worry that there is something wrong with me.	0	1	2	3	4
17. I think it would be horrible for me to faint in public.	0	1	2	3	4

## Appendix F

*IUS*

*Please circle the number that best corresponds to how much you agree with each item*

	Not at all characteristic of me	A little characteristic of me	Somewhat characteristic of me	Very characteristic of me	Entirely characteristic of me
1. Unforeseen events upset me greatly.	1	2	3	4	5
2. It frustrates me not having all the information I need.	1	2	3	4	5
3. Uncertainty keeps me from living a full life.	1	2	3	4	5
4. One should always look ahead so as to avoid surprises.	1	2	3	4	5
5. A small unforeseen event can spoil everything, even with the best of planning.	1	2	3	4	5
6. When it's time to act, uncertainty paralyzes me.	1	2	3	4	5
7. When I am uncertain I can't function very well.	1	2	3	4	5
8. I always want to know what the future has in store for me.	1	2	3	4	5
9. I can't stand being taken by surprise.	1	2	3	4	5
10. The smallest doubt can stop me from acting.	1	2	3	4	5
11. I should be able to organize everything in advance.	1	2	3	4	5
12. I must get away from all uncertain situations.	1	2	3	4	5