EDUCATIONAL AND PSYCHOLOGICAL EFFECTS OF CHILDHOOD CHRONIC ILLNESSES

by

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Abstract

The numbers of children affected by a chronic physical illness have steadily increased over the last few decades with current prevalence estimates at as many as 20% of school-aged children affected. For children with a chronic illness, the prevalence of educational and psychological problems is nearly doubled in comparison to the general population. The purpose of this research is to investigate the educational and psychological effects of childhood chronic illness among Canadian children. This project will be a retrospective analysis using data from the National Longitudinal Survey of Children and Youth (NLSCY), taking a cross-sectional look at the relationships between childhood chronic illnesses, performance on a Mathematics Computation Exercise (MCE), and ratings on an Emotional Disorder – Anxiety scale (EDA). A total of 1,644 children (ages 10-15) across Canada were included in the analyses. The results showed that when EDA ratings and educational handicaps were controlled for, children identified with chronic illnesses still have weaker performance on the MCE test. However, illness did not appear to have an impact on children’s EDA ratings. The regression analysis indicated that community type and illness were the strongest predictors of MCE scores. Limitations of the study are discussed, and implications of the findings and directions for future research are highlighted.
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In loving memory of

my maternal grandmother and paternal grandfather

who both passed away during my magisterial studies at UBC.
CHAPTER 1

Introduction

Overview

Recent advances in the medical field have resulted in an increase of illness survivors over the past few decades (Copeland, 2002). Children, in particular, are surviving illnesses they were never expected to survive, and the recent shift in focus from the medical and physical effects of chronic illnesses has been in response to the emerging educational and psychological concerns found among illness survivors (Bartel & Thurman, 1992; Bauld, Anderson, & Arnold, 1998; Canadian Paediatric Society [CPS], 1994; Geist, Grdisa, & Otley, 2003; Peterson, Reach, & Grabe, 2003; Sexson & Madan-Swain, 1993; Shaw & Páez, 2002).

Chronic illnesses are defined as medical conditions of long duration that require some level of ongoing medical management and accommodations in life functioning that is above and beyond the normal requirements of a child (Geist, Grdisa, & Otley, 2003; Sexson & Madan-Swain, 1993). The definitions of these illnesses include persistence over 3 months in a given year and/or requiring over a 1-month period of continuous hospitalization (Mash & Wolfe, 1999).

Some of the most common chronic conditions found in children include asthma, epilepsy, leukemia and diabetes (Clay, 2004). High-incidence conditions (i.e., asthma, diabetes, juvenile rheumatoid arthritis) are more prevalent, but have a better prognosis and treatment regime, and are not as debilitating. Low-incidence conditions (i.e., cystic fibrosis, gastrointestinal disorders, infectious diseases [e.g., hepatitis, HIV/AIDS]), are less prevalent,
yet may require more frequent hospitalizations, intense medical supervision/treatment programmes, and are generally more debilitating for the child (Clay, 2004).

Although it is difficult to determine the specific prognosis of each condition, it is acceptable to say that many of these children have a decreased life expectancy, and experience some interruptions of daily life functioning, such as attending school, socializing with peers, and participating in recreational activities (Bartel & Thurman, 1992; CPS, 1994; Henning & Fritz, 1983; Katz, Rubinstein, Hubert, & Blew, 1989; Perrin, Lewkowicz, & Young, 2000; Power, DuPaul, Shapiro, & Parrish, 1998; Sexson & Madan-Swain, 1993). Thus, the term “chronic illnesses” will be used to cover the broad range of chronic health conditions children around the world face today, unless otherwise specified.

Current estimates indicate that as many as 20% of school-aged children are affected by a chronic illness. In North America, it is estimated that up to 12 million children are affected (Kubiszyn, 1999; Mash & Wolfe, 1999; Shaw & Páez, 2002). Yet it remains a challenge to determine the exact incidence and prevalence rates of these childhood illnesses as the term is broad and sometimes these children experience more than one health-related concern (Bartel & Thurman, 1992).

The various technological and scientific advances in the medical field have significantly contributed to improvement of health-related quality-of-life in children living with a chronic illness (Speith & Harris, 1996). Survival rates are at an all-time high, whereby 80-90% of children suffering from chronic illnesses, which may have been considered fatal at one point, now reach early adulthood (Paone, Whitehouse, & Stanford, 1998; Sexson & Madan-Swain, 1993).
An example of such illnesses is Acute Lymphoblastic Leukemia (ALL); four decades ago, ALL was the most common childhood cancer, one considered fatal where the average life expectancy was three months (Bartel & Thurman, 1992). However, it is now estimated that 71 to 80% of children with ALL achieve long-term remission (Bartel & Thurman, 1992; Paone et al., 1998; Rynard, Chambers, Klinck, & Gray, 1998). This translates to 70% of children surviving an illness they were not expected to outlive who now may have to face the educational and psychological remnants of ALL.

Preliminary studies have found that medical issues can result in various changes in the life of children, which often carry with them some degree of stress, emotional or psychosocial distress (La Greca, Swales, Klemp, Madigan, & Skyler, 1995; Serrano-Ikkos, Whitehead, Rees, & Graham, 1999; Shaw & Páez, 2002; Schneiderman, Antoni, Saab, & Ironson, 2001). Children living with chronic illnesses are often faced with the fear of death, anticipation of painful medical procedures, inability to keep up with academic/curricular requirements, physical limitations/deformities (i.e., amputation fatigue, nausea, blurred vision), which are referred to as primary effects of an illness. Changes in lifestyle and social activities, and isolation/separation from peers and family due to an illness are referred to as a secondary effect of an illness (Bauld et al., 1998; Shaw & Páez, 2002).

More specifically, primary effects are directly due to the illness or treatment regime, the most common being a change in a child's physical appearance. Other effects include physical abnormalities, delay in physical/maturational development, delayed puberty, nausea, pain and fatigue, all of which can have implications on a child's psychological, cognitive, physical and mental development (CPS, 1994). For example, a primary effect of more serious types of asthma would be a deformity in the chest, otherwise known as pigeon chest.
(pectus carinatum) where the child has a protrusion of the anterior chest wall (Cataletto, 2006). As a result of the physical deformity, the child may be teased and victimized by peers or become embarrassed of changing in front of other children at gym and have lowered self-esteem (secondary effect). These indirect effects, or secondary effects, are thus a result of the primary effect. Ultimately, secondary effects of an illness can be as devastating as the primary effects (CPS, 1994; Paone et al., 1998; Sexson & Madan-Swain, 1993).

**Problem Statement**

An emerging area of research with children with chronic illnesses concerns the educational and psychological effects of childhood chronic illnesses. However, these studies typically involve small numbers of participants, are limited to select geographic regions in the United States and other countries around the world, and thus may not be generalizable to Canadian populations. Essentially, studies linking educational, psychological, and physical health remain very limited. Research in this area is still in its infancy. Studies involving children with chronic illnesses are limited to relationships between chronic illness and educational effects, chronic illness and psychological effects; very few studies link the three areas. Specifically, there is a dearth of research exploring the complex relationship between chronic medical conditions in children, psychological effects and how this may affect a child's academic achievement (Bauld et al., 1998; Shaw & Páez, 2002).

One approach to study these inter-relationships in the Canadian context would be to explore large-scale assessment data collected in Canada. The *National Longitudinal Survey of Children and Youth* (NLSCY) is a large-scale survey jointly conducted by Statistics Canada (STC) and Human Resources Development Canada (HRDC) in efforts to provide information for policy analysis and program development on factors affecting the
development of children in Canada and to monitor the impact of these factors on the child’s development over time (STC, 2002). The NLSCY is the only nationally representative, longitudinal study of children and youth focusing on health, development and well-being to date, and provides us with a detailed look at the development of children as they make their way through to adulthood (STC, 2002).

The nature of the survey and breadth and depth of sampling (e.g., age range of children and youth surveyed, multiple informants/raters, etc.), promises to be an effective research tool in studying the relationships between physical health, psychological health and educational achievement in Canada. The key characteristics of the NLSCY are that surveying includes questions related to a child's physical health (e.g., indication of asthma, epilepsy, cerebral palsy, kidney condition/disease, etc.), academic achievement (e.g., performance on the Mathematics Computation Exercises [MCE]), and psychological health (e.g., ratings on the emotional disorders – anxiety factor), collected from the Person-Most Knowledgeable (PMK) about the child (usually the mother), the child's teacher and the child.

This is a retrospective study that uses the NLSCY dataset to investigate meaningful relationships between physical health, educational and psychological factors. Particularly, the goal of the study is to determine whether psychological and/or educational outcomes are associated with a child's health status. A major advantage in using retrospective designs is that these types of studies allow for the analysis of relationships among many different variables that are not necessarily tied to a specific research question. In addition, such designs facilitate large-scale analyses of data, which is an important component of exploratory research studies.
Studies systematically point to the conclusion that educational and psychological effects of childhood chronic illnesses do exist. There is emerging evidence showing that children with chronic medical conditions experience more problems related to school adjustment and social interaction/development, as well, children with illnesses are at a higher risk for developing anxiety (Adewuya & Ola, 2005; Baki et al., 2004; Chavira, Stein, Bailey, & Stein, 2004; Hommel et al., 2003). Although there have been some mixed findings, differences are often attributed to individual child differences (i.e., personality, coping skills, family support, etc.), and differences between illnesses (i.e., treatment rigor, severity of symptoms) (Brown & DuPaul, 1999; Frank et al., 1998). Yet despite the research investigating the educational and psychological effects of childhood chronic illnesses, there is a large gap in the literature; the combined educational and psychological effects of childhood chronic illnesses remain unexplored.

Objective of this Research

The purpose of this research is to investigate the educational and psychological effects of childhood chronic illness among Canadian children. This project is a retrospective analysis using data from the NLSCY. Although the NLSCY is a longitudinal study, the current study examines the cross-sectional relationships between childhood chronic illnesses, academic achievement and anxiety. For consistency and ease of reference, this project will refer to school-aged children ages 5 to 18 as a “child”, unless otherwise specified even though they are referred to as “children and youth” in the NLSCY.
The current research project aims to answer the following five research questions.

**Research Questions One and Two**

Are there differences between children with chronic illnesses and healthy children in their Mathematics Computation Exercise (MCE) scores? (Q1). Are there differences between children with chronic illnesses and healthy children in their Emotional Disorder – Anxiety (EDA) scores? (Q2).

**Rationale and Hypotheses for Questions One and Two**

Research concerning children with chronic illnesses has found higher rates of school-related problems (e.g., lower achievement, higher learning difficulties/disabilities) and higher reported psychological problems (e.g., anxiety and depression) (Frank et al., 1998; Shaw & Páez, 2002). As well, there has been substantial research demonstrating the effect of anxiety on a child's school achievement (Albano, Chorpita, & Barlow, 2003; Huberty, 1997; Leibert & Morris, 1967; Van Ameringen, Mancini, & Farvolden, 2003; Wigfield & Eccles, 1990; Wine, 1971; Wine, 1980). However, there are few studies investigating both educational and psychological effects of chronic illnesses.

**Research Questions Three and Four**

Is the relationship between illness and Mathematics Computation Exercise (MCE) scores different when MCE scores are adjusted for the effects of Emotional Disorder – Anxiety (EDA) scores? (Q3) In addition, how are chronic illnesses associated with performance on the MCE after removing the effects of various educational handicaps? (Q4)
Rationale and Hypotheses for Question Three and Four

Based on findings showing a strong association between academic achievement and anxiety (Albano et al., 2003; Van Ameringen et al., 2003), the relationship between illness and MCE scores will be tested with the variation in MCE scores due to EDA scores (covariate) removed. It is hypothesized that when EDA scores are controlled for, illness will show a stronger effect on MCE scores. The rationale for this hypothesis is that given the literature showing that children who have high anxiety have lower performance on achievement tests (Albano et al., 2003; Huberty, 1997; Leibert & Morris, 1967; Van Ameringen et al., 2003; Wigfield & Eccles, 1990; Wine, 1971; Wine, 1980), controlling for the possible moderating effect of anxiety (on MCE scores) will help better explain the effect of a physical (chronic) illness on achievement.

As for research question 3, the rationale is that by controlling for and removing the effects of “educational handicaps” (children who are identified by the PMK with mental retardation, a learning disability, attention deficit and/or an emotional disorder in the NLSCY data) on achievement, differences in performance across different illness groups on the MCE test can be better explained by a child having a physical (chronic) illness versus having a mental handicap, learning disability, attention deficit, and emotional disorder.

Research Question Five

What is the degree of the association between Mathematics Computation Exercise (MCE) scores, and each of health/illness and Emotional Disorder – Anxiety (EDA) scores? How do these associations compare to those between MCE and gender, community type, and household income?
Rationale and Hypotheses for Question Five

Given evidence showing the associations between chronic illness and academic achievement (Sexson et al., 1993; Taras & Potts-Datema, 2005), illness and anxiety (Adewuya & Ola, 2005; Hommel et al., 2003; Ortega, Huertas, Canino, & Rubio-Stipec, 2002; Rynard et al., 1998; Shaw & Páez, 2002) anxiety and achievement (Albano et al., 2003; Huberty, 1997; Van Ameringen et al., 2003), the fifth question addresses the degree to which illness and emotional disorders/anxiety predict mathematics achievement, above and beyond typical child background variables such as gender, community type and household income.

In addition to looking at the degree to which EDA scores predict MCE scores, other factors that have been found to be associated with performance on achievement tests, such as age, gender, household income, community type (urban vs. rural) were also investigated.

Summary

For children with a chronic illness, the prevalence of both educational problems and psychological problems (i.e., anxiety disorders) is nearly twice the proportion found in the general population (Frank et al., 1998). Anxiety disorders are the most common, under-treated, yet preventable psychological problem in all children (Albano et al., 2003). Given the increasing numbers of children affected by a chronic illness and the dearth of research in exploring the complex relationship between chronic illnesses, anxiety, and academic achievement, it is crucial to initiate a line of research to investigate these associations.
By understanding these associations, researchers and practitioners may be able to evaluate the outcomes of increased health management and medical/technological advances for Canadian children. Perhaps more importantly, our findings may suggest ways to plan strategic allocation of resources (e.g., prevention programs) that will foster the successful and healthy development of children as productive members of society (Paone et al., 1998; Sexson & Madan-Swain, 1993; Shaw & Páez, 2002; Speith & Harris, 1996).
CHAPTER 2

Literature Review

Overview

This chapter includes a review of current literature relevant to the relationships between childhood chronic illnesses, academic achievement and anxiety.

The first section will describe anxiety disorders in the general population, and then follow with research on anxiety disorders in children with chronic illnesses. Next, various models that attempt to explain the development of anxiety will be reviewed (e.g., psychoanalytic, behavioural-learning, and attachment theories), with a particular focus on Chorpita and Barlow’s (1998) Theory of Uncontrollability and Unpredictability. This particular theory will then be applied to current understanding concerning the development of anxiety in children with chronic illnesses, where current research in the area of anxiety in the pediatric population will be discussed.

Following the review of the psychological effects of chronic illnesses, the discussion will then move to a review concerning the educational effects of childhood chronic illnesses. Studies examining educational problems among children with chronic illnesses (e.g., learning disabilities and difficulties, problems with cognitive functioning and academic achievement) will be reviewed, and limitations of these findings will be discussed. The role of gender, socioeconomic status (SES), and culture will be considered throughout these reviews; these issues must be carefully considered, as these variables contribute to the manifestation and development of a host of problems (Mash & Wolfe, 1999).
It is important to note that there is very limited research integrating childhood physical health, mental health, and education. Previous research addressed one of three relationships: (1) the relationship between illness and psychological effects; (2) the effects of illnesses on education; or (3) the relationship between psychological and educational effects. The main gap in the literature concerns the association among these three areas; it is unknown how these factors interact together. Historically, the focus of treatment in individuals with chronic health conditions centers on addressing medical and physical ailments to ensure survival and treat illness symptomatology (Peterson et al., 2003).

There is evidence to support the contention that chronic illnesses not only bear physical consequences, but that these illnesses bear secondary psychological and educational consequences, and have significant impact on individual quality-of-life (Chavira et al., 2004; Peterson et al., 2003; Shaw & Páez, 2002). These concerns include: high levels of negative affect (e.g., anxiety and depression), problems with cognitive ability, academic skills, school performance, learning, adaptive behaviour, peer relationships, social withdrawal and peer conflict (Shaw & Páez, 2002; Taras & Potts-Datema, 2005). Although recent findings suggest that the prevalence of psychological and educational problems have nearly doubled in recent years for children with a chronic medical condition (Henry & DuPaul, 2004; Perrin et al., 2000), there is an absence of research in linking these three areas of study. This shift in addressing other facets of quality-of-life has a central goal of preparing children with illnesses for a successful and healthy adulthood (Paone et al., 1998).
Anxiety Disorders in the General Population

A common definition of anxiety has been captured by Huberty (1997, p. 305) as “apprehension, distress, or tension about real or anticipated internal or external threats that may be shown in cognitive, behavioural, or physiological patterns.” Healthy levels of anxiety have survival purposes (i.e., fight or flight response) and are part of normal development, however, at extreme levels; anxiety can have deleterious impact affecting a child's personal, social and daily functioning (Albano et al., 2003; and Huberty, 1997). For example, a child who has obsessive worries of being separated from his/her parents can cause extreme distress to parents and teachers, which are effects beyond those experienced by the child.

Symptoms of anxiety are thought to be expressed through three systems: a) the physical/physiological response system; b) the cognitive response system; and c) the behavioural response system. It is crucial to understand how these three systems interplay, as each level of symptomatology is expressed differently in children as a function of age, gender, previous experience, situational variables and coping styles (Huberty, 1997; Mash & Wolfe, 1999).

Some common physical/physiological responses include increased heart rate, flushes/chill, nausea, increased respiration, muscle tension, sweating, stomach upset and loss of breath. Examples of cognitive response systems include thoughts of being scared, forgetfulness, self-deprecatory/self-critical thoughts, blanking out, and difficulty concentrating. Finally, examples of behavioural response systems include avoidance, screaming, nail biting, clenched jaw, stuttering, fidgeting, and rigid posture (Mash & Wolfe, 1999).
Where it was once thought that anxiety in children was a mild and transitory period that will dissipate over time, current research findings suggest that anxiety has a chronic course where children who experience anxiety symptoms will continue to display problems in adjustment through to adulthood (Mash & Wolfe, 1999). Groups of anxiety symptoms can co-occur, and children with specific symptoms are likely to experience other symptoms. Hence, these clusters of symptoms are referred to as dimensions of anxiety, and are grouped using factor analysis.

The diagnosis and classification of anxiety disorders continues to be a debated issue because there is a lack of a common understanding of what is considered a normal and developmentally appropriate anxiety response (Albano et al., 2003; Mash & Wolfe, 1999). Although this research project does not concern the formal, clinical diagnosis of anxiety, anxiety disorders will be discussed in the next section in order to provide a more comprehensive definition and understanding of anxiety.

The diagnostic criteria for the nine anxiety disorders are described in the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV-TR) (American Psychiatric Association [APA], 1994): separation anxiety disorder (SAD), panic disorder, agoraphobia, generalized anxiety disorder (GAD), social phobia, specific phobia, obsessive-compulsive disorder (OCD), posttraumatic stress disorder (PTSD) and acute stress disorder. Anxiety is the predominant feature in each of these nine disorders, and what distinguishes one disorder from the other is the focus of the anxiety and how anxiety is expressed differently through the physical/physiological, cognitive or behavioural systems (Albano et al., 2003).
Anxiety disorders are the most common psychological disorder in children and adults. In children, prevalence rates across the nine disorders are reported to range from 0.6% (Panic Disorders) to 12% (Separation Anxiety Disorder [SAD]) in samples of children from the United States (Albano et al., 2003; Mash & Wolfe, 1999); lifetime prevalence is estimated to be around 28.8% (Kessler, Berglund, Demler, Jin, & Walters, 2005). Anxiety disorders are equally distributed across socioeconomic status (SES) and ethnic groups and remain quite stable throughout the lifespan (Dadds, James, Barrett, & Verhust, 2004; Huberty, 1997).

Research focusing on the effects of anxiety on academic performance has shown that higher levels of anxiety affected academic performance and cognitive functioning, where an increase of irrelevant thoughts of self-evaluation/deprecation, debilitating off-task thoughts, difficulties with task completion, and problems associated with attention, memory, speech and language have been found in children with higher levels of anxiety (Huberty, 1997; Mash & Wolfe, 1999). To add, researchers have found that anxiety in first grade predicted anxiety in the fifth grade, and anxiety levels in first grade significantly affected achievement at fifth grade (Ialongo, Edelsohn, Werthamer-Larsson, Crockett, & Kellam, 1994). Though there is sufficient research to demonstrate the relationship between anxiety and academic performance, there has been little research investigating the cause of lower performance on measures of achievement (e.g., absenteeism, direct interference on cognitive tasks, etc.) (Mash & Wolfe, 1999).

In terms of gender differences, girls have been found to be more likely to report anxiety-related symptoms on self-report measures than boys, however, any gender differences detected were generally quite small (Costello, Egger, & Angold, 2004; Huberty, 1997).
Anxiety in Children with Chronic Illnesses

For children affected with a medical condition, results reported in the literature suggest that they are twice as likely to develop psychological disorders as are their healthy peers, and children with certain health conditions (i.e., asthma, epilepsy and cancer) are at a higher risk of developing anxiety (Adewuya & Ola, 2005; Hommel et al., 2003; Ortega, Huertas, Canino, Ramirez, Rubio-Stipec, 2002; Rynard et al., 1998; Shaw & Páez, 2002). A review by Adewuya and Ola (2005) indicated that the prevalence of anxiety disorders among children with epilepsy ranged from 16% to 48.3%. Over 30% of children with asthma meet diagnostic criteria for an anxiety disorder, and have overall higher levels of anxiety compared to individuals who are not asthmatic (Hommel et al., 2003). These numbers suggest that the prevalence rate for anxiety disorders among chronically ill children is quite high, although the overall prevalence rate for children with chronic illnesses is still not well-established (Shaw & Páez, 2002).

New research is suggesting that un-addressed anxiety in childhood/adolescence can lead to secondary disorders in adulthood, disorders such as emotional disturbance/mood disorders and antisocial/criminal behavior (including violence and substance use/abuse) and can affect later life functioning (e.g., unproductive academic and occupational performances, premature death, chronic disability, marital discord and divorce and risk-taking behaviours) (Albano et al., 2003; Huberty, 1997; Perrin et al., 2000; Power et al., 1998; and Shaw & Páez, 2002). There is further evidence demonstrating that anxiety precedes many disorders (i.e., depressive disorders, substance abuse), and may lead to externalizing disorders, followed in turn by dysthymia, major depression and substance abuse. The developmental progression of anxiety is very disconcerting given the increased survival rates of children
with chronic illnesses. Thus, there is a need to curtail problems by identifying and treating anxiety early on in life (Ferdinand, Barrett, & Dadds, 2004).

The problem with the identification (and treatment) of anxiety in children with chronic illnesses is that symptoms may be over-looked and undetected. For example, because of the internalizing nature of the disorder (anxiety symptoms are within the child), children exhibiting anxiety-related symptoms are less aversive to people or property as compared to disorders of the externalizing type (e.g., oppositional defiant disorder [ODD], attention deficit hyperactivity disorder [ADHD]) where children can be aggressive, destructive and non-compliant (Albano et al., 2003; Chavira et al., 2004). Thus, children with anxiety disorders are often overlooked in a classroom among children with externalizing types of disorders.

Another problem with the identification of anxiety is that some individuals may not have a good understanding about the primary and secondary effects of a chronic illness to recognize anxiety symptomatology, or may minimize problems experienced by children (Chavira et al., 2004; Masia-Warner, Nangle & Hansen, 2006). The manifestation of anxiety symptoms in a child who is ill may be mistaken for fatigue from treatment, side effects from drugs, and general inability to keep up academically or socially (Albano et al., 2003). For example, a child with severe asthma may experience anxiety, thus have difficulty concentrating, and be flooded with fear and thoughts of an asthma attack and perhaps imminent death (cognitive response system). S/he may then respond by fidgeting, crying and immobility (behavioral response system), followed by fatigue and headaches (physical response system). Without a clear understanding of how these anxiety response systems
interplay and work, response systems can be mistaken as a side effect of the illness, behavioural problems and/or inattention.

Methods of assessment pose another problem in the identification of anxiety disorders. For example, the "Tripartite Model" (Clark & Watson, 1988) suggests that although anxiety and depression have unique symptoms, the two disorders also have overlapping symptomatology. In fact, Clark, Watson and Beck (1994) argued that symptomatology in self-report measures of anxiety tended to display high correlations with measures of depression. The reason for this is that both anxiety and depression measures are found to assess a broader nonspecific distress coined "negative affect" (NA) (Clark et al., 1994). Particularly, NA has been found to be highly correlated with almost all anxiety symptoms and depressive symptoms (Clark & Watson, 1988). For this reason, it may be difficult to decipher whether an individual has anxiety or depression by only using self-reports.

One way to address the problem of self-reporting is to use multiple methods of assessment such as structured clinical interviews with multiple raters (parents, teacher and child) and standardized measures of anxiety (e.g., Multidimensional Anxiety Scale for Children [MASC; Marsh, 1997], Revised Children's Manifest Anxiety Scale [RCMAS; Reynolds & Richmond, 2000], State-Trait Anxiety Scale for Children [STAIC; Spielberger, Edwards, Lushene, Montuori, & Platzek, 1973]). By using multiple methods of assessment, the error and bias involved in measuring anxiety can be reduced (Tarullo, Richardson, Radke-Yarrow, & Martinez, 1995).
Some studies have found that parents are the most thorough and reliable in reporting complex details about a child compared to reports from teachers or the self-reports from the child (Schniering, Hudson, & Rapee, 2000). However, other studies have yielded contradictory results, where other researchers have found parent-reports of anxiety to be highly flawed (i.e., under or over-reporting). For example, parents may inflate reports of anxiety, sometimes as a consequence of their own anxiety, and projecting this anxiety on their children (Dadds et al., 2004).

Self-reports of anxiety have also been criticized where a child's ability to read and understand a question has been challenged, especially when methods of questioning may be developmentally inappropriate for young children (Dadds et al., 2004). For example, younger children may not have the cognitive capacity to comprehend questions of complex problems within themselves. Another problem with self-reporting has to do with “faking good” or “faking bad” where some children may provide socially desirable responses (e.g., answering “Yes” when asked “I am always good”) to please the examiner (March, 1997). The incorrect/false reporting of one's feelings, attitudes or behaviours significantly affects the reliability and validity of the report. Unfortunately, it can be very time consuming and economically costly to administer a variety of parent-, teacher- and child-reports of anxiety and conduct structured interviews, and the feasibility of collecting data on anxiety using multiple measures is sometimes not possible.

The risk of emotional difficulty in children with chronic illnesses has been found to be positively associated with age with emotional risk increasing with age. Gershon, Zimand, Pickering, Rothbaum, and Hodges (2004) found that the experience of distress is quantitatively and qualitatively different for younger and older children. Younger children
seem to be less affected (emotionally) by illness, whereas adolescents experience more distress due to their increased understanding of their illness and other secondary effects (i.e., self-esteem, socialization). Younger children may not have as good an understanding of the impact of their treatment regimens as compared to older children. Older children may also experience greater distress because of a better understanding of the pathology of the disease (Frank et al., 1998).

**Theoretical Explanation of the Development of Anxiety**

There are various theories on the etiology of anxiety including: psychodynamic theories, behavioural/learning theories, attachment theories and cognitive theories, dating back to the early 1900s (Mash & Wolfe, 1999; Sweeny & Pine, 2004). Early psychoanalytic theory was documented by Sigmund Freud’s case of Little Hans where anxiety and phobias were viewed as a defense against unconscious conflicts in a child’s early upbringing (Mash & Wolfe, 1999). Following psychoanalytic theories were the behavioral and learning theories (John B. Watson [Watson, 1916]) where anxiety was believed to be learned through classical and/or operant conditioning; otherwise known as the “Two-Factor Theory” (Mash & Wolfe, 1999). Following the Two-Factor Theory, John Bowlby attempted to use an emotional explanation of anxiety, or “Theory of Attachment”, where it was believed that fear in children was biologically rooted in emotional attachments needed for survival in children (Mash & Wolfe, 1999).

More recently, Chorpita and Barlow’s (1998) “Theory of Uncontrollability and Unpredictability” has been used to explain the development of anxiety. This is a conceptual model and gives credit to the negative emotions associated with the development of anxiety, yet also acknowledges the role of early experiences and innate vulnerabilities or
predispositions in the experience of anxiety. The notion of the theory is that early experiences of children where control is lacking (or reduced) can predispose the child in developing anxiety in the future.

Chorpita and Barlow (1998) have used research with animal models, familial influences, locus of control in children and biological explanations to link control to the development of anxiety. Essentially it is believed that the experience with lack of control may play an important role in the development of anxiety, an area supported by diverse areas of research. Additionally, the biological correlates of chronic anxiety seem to be influenced by one's interpretation of a stressful event being controllable or not. They suggest that early experiences with lack of control (e.g., childhood chronic health conditions) contribute to a schema or template being developed, wherein it becomes fixed and diathetic. Early experiences with uncontrollable or unpredictable stimuli (e.g., unpredictability of epileptic seizures) can influence one's perception of control. Thus, as the individual progresses to a later developmental period, these control-related cognitions may intensify anxiety, inhibition, thus resulting in negative affect (Figure 2.1).
Figure 2.1

Model of the Development of Vulnerability for Anxiety

Although there is not one single theory to explain the development of anxiety, Chorpita and Barlow's (1998) theory is of interest as it integrates some of the classic theories (i.e., behavioural/learning, attachment and cognitive theories) and emphasizes the interaction between biological and environmental influences in the development of anxiety.

**Development of Anxiety in Children with Chronic Illnesses**

Preliminary research findings have suggested that the psychological well-being of children suffering from a chronic illness is compromised when a child is sick. It is estimated that these children are twice as likely to develop psychiatric disorders compared to their peers (Shaw & Páez, 2002), where rates of any psychiatric disorder range from 9 to 22% (Chavira et al., 2004).

Children with chronic medical conditions are at an increased risk for developing affective co-morbidity specifically with anxiety, as medical issues can result in various changes in the life of children and result in some stress or emotional distress (La Greca et al., 1995; Shaw & Páez, 2002). Chorpita and Barlow's (1998) Theory of Uncontrollability and Unpredictability, can be applied to better understand why anxiety develops in children with chronic illnesses; particularly, that illness diagnosis can result in a lack of control and compromise the predictability of one's health and life course.

Culture is an important area to address in childhood anxiety, given that culture plays a large role in the development, identification and treatment of many childhood disorders. Given that many illnesses are prevalent across cultures (i.e., epilepsy, cancer, etc.), a better understanding of the influence of culture must be understood in order to identify and treat the anxiety symptoms that accompany these health conditions. For example, Adewuya and Ola (2005) found that there is a higher prevalence of anxiety disorders among Nigerian
adolescents with epilepsy compared to their Western counterparts. Partially, the authors feel that this can be due to biological factors, stigma and dearth of information known about epilepsy, as well as family support. However there is limited cross-cultural research in this area.

Children who are ill face complicated medical procedures, treatment regimens, fear of death, anticipation of painful medical procedures, coping with pain, isolation and fear of being teased, change in lifestyle/disruption of normal development, being different from peers, and the inability to participate fully and keep up with academic and social activities and physical deformities resulting from the illness (Bartel & Thurman, 1992; Shaw & Páez, 2002; and Tyrrell, 2005). Four common types of stressors common among children with chronic illnesses include medical, physical, academic, psychological and social stressors (Clay, 2004).

Medical stressors an ill child may face include: integrating medical tasks into daily routine, managing a complex medication regimen and lifestyle modifications (e.g., eating restrictions, exercise restrictions, sleep difficulties). Physical stressors include: growth suppression, changes in physical appearance and intermittent or chronic pain. Academic stressors include: absence from school and social activities, decline in academic performance and development or exacerbation of learning difficulties. Psychological stressors include: somatic responses, losses associated with illness (e.g., eyesight, limbs, hair, uncertain future, and end-of-life concern). Finally, social stressors may include: environmental precautions, restrictions in freedom and activities, changes in the parent-child relationship, and changes in peer relationships (Clay, 2004). Regardless of stressors being real or perceived, the
additional stressors faced by children with chronic illnesses are likely to exacerbate developmentally appropriate fears and anxieties in children (Frank et al., 1998).

For example a study by Henning and Fritz (1983) demonstrated that the most common problem faced in children with cancer were worries and concerns. Concerns were based on the physical effects of cancer, such as fatigue, nausea and blurred vision, and about safety and management of treatment. Fear of being teased, feelings of embarrassment because of changes in appearance, keeping up with schoolwork, difficulties in talking about the illness, and returning to school were very common fears in all participants, but particularly in early adolescence. These findings have been replicated in cases of children with asthma, cystic fibrosis, diabetes, and epilepsy (Adewuya & Ola, 2005; Hommel et al., 2004; Peterson et al., 2003; Pumariega, Pearson, & Seilheimer, 1993).

In further support to Chorpita and Barlow’s (1998) theory, Hommel et al. (2003) found that the uncertainty associated with having an illness plays a significant role in individuals who have dealt with asthma for several years. In particular, anxiety-levels are associated with higher levels of uncertainty of the illness (e.g., when an asthma attack would occur) (Hommel et al., 2003). The authors further hypothesize that children with asthma may develop anxiety as a function of increased perceptions of uncertainty and unpredictability about the frequency, duration and intensity of attacks, possible hospitalization, use of medication, steroids and puffers, and other related health-management stressors. However, it is important to note that participants in the study by Hommel et al. (2003) were selected from an undergraduate college population. Therefore, results are not generalizable to children under the age of 18-years. Additionally, most participants were Caucasian, thus not adequately representing children of other ethnic groups. Given the
higher incidence and prevalence rates in asthmatic children among the African American population (Henry & DuPaul, 2004), it is important to include sampling from a diverse culture/ethnic sample in studies with asthma.

Despite the findings highlighting the role of control and predictability in living with chronic illnesses, Frank et al. (1998) report that overall adjustment to chronic illness is influenced more by environmental (e.g., family support) and psychological factors (e.g., coping skills) rather than to the severity of the illness. Unfortunately, this complex relationship between chronic medical conditions and the development of anxiety has been highly neglected despite anxiety disorders being remarkably common in pediatric settings (Chavira et al., 2004; and Shaw & Páez, 2002). Studies of anxiety are generally limited to adult populations, and studies with children involve physically healthy children (Ferdinand et al., 2004), resulting in limited knowledge in the relationship between chronic health conditions and anxiety in children.

**Educational Effects of Childhood Chronic Illness**

In addition to the psychological problems children with illnesses must deal with, they are also faced with problems with learning and academic achievement. Healthy school adjustment is a keystone developmental accomplishment, one found to be highly significant in achieving a sense of autonomy, independence and future self-sufficiency, essentially, a child’s overall adjustment (Henning & Fritz, 1983; Paone et al., 1998). A large part of a child’s development (physical, psychological, educational) is fostered within the school setting (Sexson & Madan-Swain, 1993), yet children with chronic illnesses may need to miss school frequently; it is estimated that chronic illnesses result in as many as 40 million school absence days a year (Sherman, 1995).
School absences can be a result of the illness itself (e.g., hospitalization, being too ill to attend school) or secondary effects (e.g., treatment effects, school refusal, etc.). In effect, children become more vulnerable to experience a host of other problems related to school absenteeism, such as problems with academic achievement and social interaction. Unaddressed educational issues have been found to be related to the development of school failure, dropout, depression, and unhealthy lifestyles (Henning & Fritz, 1983; Paone et al., 1998; Perrin et al., 2000; Rynard et al., 1998). Thus, it is critical to better understand how illnesses are impacting a child's learning and achievements in school, essentially, one's overall adjustment.

A detailed review of past research in the area of anxiety and school performance was conducted by Huberty (1997). Most of the reviewed research concentrated on the effects of anxiety on academic performance, task performance, and cognitions during performance and task-relevant behavior. For example, Leibert and Morris (1967; as cited by Huberty 1997) researched test performance and learning. Their findings revealed that worry is related to cognitive and attention cues, whereas emotionality is an involuntary conditioned response. Wine (1971, 1980; as cited by Huberty, 1997) and Wigfield and Eccles (1990; as cited by Huberty, 1997) then looked at off-task thoughts in children who scored high in anxiety, and found that thoughts consuming a child were often irrelevant thoughts, ones that are self-evaluative (negatively) and self-deprecatory. In sum, the review by Huberty (1997) revealed that the higher levels of anxiety affected cognitive functioning, specifically, increases of irrelevant thoughts of self-evaluation and self-deprecation, debilitating off-task thoughts, difficulties with task completion, and increased attentional problems. Essentially, healthy individuals who were experiencing anxiety had more difficulty with school-related tasks.
Learning Difficulties and Disabilities in Children with Chronic Illnesses

In support of the above findings among the general population, Sexson and Madan-Swain (1993) report that up to 40% of children with a chronic condition experience school-related problems. Learning disabilities and difficulties become a more serious problem during junior and senior high school year for children with chronic illnesses. There are greater demands on homework and studying time and previous existing learning problems may be compounded by illness process, medical interventions and treatments (CPS, 1994; Clay, 2004).

For example, in studies of children with asthma, Henry and DuPaul (2004) found a higher number of repeated grades than healthy controls, and are more likely to be found in special education settings and are almost two times more likely to have a learning disability. These findings are further supported by research with diabetic children; where 40% of males with diabetes were found to have learning problems warranting special instruction or grade retention, and both males and females had more learning difficulties than healthy peers (24% versus 13%) (Holmes, Dunlap, Chen, & Cornwell, 1992).

In studies that compare academic performance between children who are ill and their siblings, Bartel and Thurman (1992) report that one-third to one-half of children with ALL require specialized academic help (e.g., attend special education classes) and/or repeat grades, compared to only 15% of their siblings and general population requiring specialized assistance. Moreover, Schatz, Brown, Pascual, Hsu, & DeBaun (2001) found statistically significant differences among children with sickle-cell anemia in the number of grade retention and special education when compared to peers or siblings.
Most academic problems have been found in areas such as mathematics and reading; these areas require the student to achieve a level of mastery in the skill, prior to learning subsequent skills and knowledge (CPS, 1994; Fowler et al., 1988; Kaemingk et al., 2004; Paone et al., 1998; Seidenberg et al., 1986). Sexson & Madan-Swain (1993) report the incidence of reading problems (even when cognitive functioning is controlled for) is higher among children with chronic illnesses (14%) compared to healthy controls (4.5%). McCarthy et al. (2002; 2003) found that reading scores and GPA were significantly lower in children with diabetes, especially when metabolic control in these children was poor. To add, Kaemingk et al. (2004) have found differences in math performance between children who are healthy and children with ALL.

However, it is unknown as to whether these difficulties are a direct result of the illness (e.g., hospitalization, pain, fatigue), or secondary effects (e.g., anxiety, school phobia, effects of treatment regiments) or a combination of these factors. These results are similar to problems with achievement and cognitive functioning that is found in children with anxiety as previously outlined.

**Cognitive Functioning and Achievement in Children with Chronic Illnesses**

Declines in general cognitive ability (Intelligence Quotient, or I.Q.) have been found to range up to 20 points in children with chronic illnesses (Bartel & Thurman, 1992). Declines in cognitive functioning and academic ability are quite common among cancer survivors, specially leukemia or brain tumors, and other illnesses where the illness (and treatment) affect the structure and function of the brain (Bartel & Thurman, 1992; Henning & Fritz, 1983; Rausch & Stover, 2001). Moreover, researchers have found that illnesses that impact a child's central nervous system (CNS) have a greater negative effect on learning,
disorders of this nature include: cerebral palsy, epilepsy, infectious diseases (*Human Immunodeficiency Virus/Autoimmune Deficiency Syndrome* [HIV/AIDS]), and cancer (Clay, 2004).

Other areas related to cognitive functioning, such as attention, memory, processing speed, language, visuo-spatial knowledge, concept formation and motor functioning, have been found to be affected in children diagnosed with HIV/AIDS, diabetes, sickle-cell anemia, and epilepsy (Farwell, Dodrill, & Batzel, 1985; Hershey, Lillie, Sadler & White, 1999; Northam et al., 2001; 1999; Rausch & Stover, 2001; Rovet & Alvarez, 1997; Rovet & Ehrlich, 1999). For example, researchers found that diabetic children with hypoglycemia had more neurological problems, poorer performance on memory tasks, slower processing speed, decreased memory, learning, attention and inhibition (Hannonen, Tupola, Riikonen, & Ahonen, 2003; Hershey et al., 1999; Northam, et al., 1999; Rovet & Ehrlich, 1999). However, results are mixed as other researchers (Fox, Chen, & Holmes, 2003; Schoenle, Schoenle, Molinari, & Largo, 2002) did not find hypoglycemia to be related to learning.

In longitudinal studies with symptomatic *Human Immunodeficiency Virus* (HIV) infection, expressive language has been found to be more impaired than receptive language (Rausch & Stover, 2001). Behavioural effects of HIV infection of the CNS include: loss of interest in others or activities, less goal-directed behaviour, vacant staring and altered affect (Rausch & Stover, 2001), symptoms similar to those of anxiety.

In terms of gender effects, Holmes et al. (1992) found that diabetic males perform poorer than diabetic females in attention tasks (Holmes et al., 1992), and there were more reports of boys having learning problems than girls (40% vs. 16% girls). In addition, Fox, Chen, and Holmes (2003) found more difficulties in verbal learning tests for males compared
to females; although females still performed poorer than healthy controls. However, Eaton, Haye, Armstrong, Pegelow, & Thomas (1995) did not find differences in performance across standardized academic achievement tests in children with sickle-cell anemia.

Age-of-onset of an illness has been found to affect a child's academic and cognitive functioning. Findings reveal that children who are treated earlier in life (<4 years) are more vulnerable to academic and cognitive problems compared to children treated later in life. The rationale is that treatment may affect the developing brain of a younger child (Bartel & Thurman, 1992). More specifically, Schoenle et al. (2002) found an age effect on learning where declines in learning were negatively associated with age. In follow-up studies, Northam et al. (1999) found that age-of-onset of diabetes was a strong predictor of performance.

Unfortunately, it is not always easy to determine whether cognitive decline is directly affected by the illness (primary effect) or indirectly related to the treatment (secondary effect) (Bartel & Thurman, 1992). For example, although there is evidence showing a decrease in cognitive functioning in children surviving brain tumors, it is unclear whether the decline is due to the tumor itself, or a result of treatment. As well, in cases of children with cancer, toxicity of the central nervous system (CNS) may result in confusion, forgetfulness, and impaired school performance, which could be misinterpreted for inattention, problems with memory and school failure, respectively (Henning & Fritz, 1983).

It is hypothesized that factors that appear to have an effect on a child's cognitive and academic functioning include: amount/rigor of treatment, structural and functional changes to the brain (i.e., infection to the central nervous system) (Bartel & Thurman, 1992; Clay, 2004). For example, Armstrong et al. (1996), Brown et al. (2000) and Nabors and Freymuth
(2002) found that after experiencing strokes, the addition of abnormal MRIs in children with sickle-cell anemia revealed problems in arithmetic, vocabulary, executive functioning, reading, arithmetic, spelling and visual motor speed and coordination. Ultimately the success of the treatment comes in hand with children experiencing academic and cognitive problems.

Some researchers have found that at follow up (up to 7-years later) children with diabetes still demonstrated significant declines in verbal IQ compared to their peers. As well, these children experienced problems with perceptual motor, memory and attention tasks (Rover & Ehrlich, 1999). Although some medications have not shown to affect a child's cognitive functioning, the medication itself may result in the alteration in a child's mood (i.e., anxiety and depression). Another study found that even after 6 years, verbal IQ was significantly lower among children with diabetes especially with earlier onset of diabetes, and had problems with attention, processing speed and executive control (Northam et al., 2001).

**Summary**

Given the review of current literature demonstrating the relationships between childhood chronic illnesses, anxiety and academic achievement, and this research will aim to link findings in these three areas. Specifically, the research questions will build on past findings and look at the extent to which chronic illnesses affect children’s academic achievement and anxiety.
CHAPTER 3

Research Methodology

Research Questions

The following five research questions were addressed in the current study: 1) Are there statistically significant differences between children with chronic illnesses and healthy children in their Mathematics Computation Exercise (MCE) scores?; 2) Are there differences between children with chronic illnesses and healthy children in their ratings on the Emotional Disorder – Anxiety (EDA) scale?; 3) How are chronic illnesses associated with performance on the Mathematics Computation Exercise (MCE) after removing the effect of a child’s Emotional Disorder – Anxiety score?; 4) How are chronic illnesses associated with performance on the Mathematics Computation Exercise (MCE) after removing the effect of educational handicaps (mental handicap, learning disability, attention deficit or emotional disorder)?; and 5) What is the degree of association between a child’s performance on the Mathematics Computation Exercise (MCE), with health/illness, and on the Emotional Disorder – Anxiety (EDA) when other background factors such as gender, size-area of residence (community-type) and household income are considered?

Data

The data used to address the research questions posed in this study is the National Longitudinal Survey for Children and Youth (NLSCY). The NLSCY is the only nationally representative, longitudinal study of children and youth focusing on health, development and well-being in Canada, and it provides a detailed look at the development of children as they make their way to adulthood (Statistics Canada [STC], 2002).
The National Longitudinal Survey for Children and Youth (NLSCY)

The NLSCY data is based on probability sampling, and involves random sampling of representative Canadian "households". Households were selected from Statistics Canada's Labour Force Survey (LFS) sample frame of about 60,000 dwellings, and data is collected on a monthly basis. This sample has been deemed representative of the Canadian Population in previous studies (STC, 2002).

The NLSCY provides comprehensive information on children and youth from all ten provinces and three territories, excluding children living on Indian reserves or Crown lands, residents of institutions, full-time members of the Canadian Armed Forces, and residents of some remote regions. The age range of children and youth initially surveyed ranged from newborn to 10/11 year olds.

Data collection for the NLSCY has occurred every two years. Data was first collected in December, 1994 to April, 1995 (Cycle 1), followed by December, 1996 to April, 1997 (Cycle 2), October, 1998 to June, 1999 (Cycle 3), September, 2000 to May, 2001 (Cycle 4), September, 2002 to June, 2003 (Cycle 5), and September, 2004 to June, 2005 (Cycle 6). Although both longitudinal and cross-sectional data were available, only cross-sectional data from 5th Cycle was used. Cycle 5 was the most recently released data at the start of the current project.

The NLSCY provides opportunities for examining a child's daily functioning from multiple perspectives. The NLSCY collects data from multiple sources: a) the child/adolescent; b) the Person Most Knowledgeable (PMK, who typically is the child's mother); c) the child/adolescent's teacher; and d) the child/adolescent's school principal. The majority of data were collected via computer-assisted personal interviews, self-completed
instruments, and tests. Surveys that rely on multiple respondents increase the quality of data collected compared to surveys that only rely on one source of information (e.g., self-reports) (Schniering et al., 2000).

Separate databases are created for data that is collected from each respondent category. In other words, there are four datasets that make up Cycle 5: 1) the child/adolescent ("10 to 19 year" dataset); 2) the PMK ("master" dataset); 3) the child/adolescent's teacher; and 4) the child/adolescent's principal. Each of the databases can be matched on a PMK unique identifier variable.

For this project, only the master and 10 to 19 year old datasets from Cycle 5 were of interest. The master dataset includes information reported by the PMK about the age, gender, province of residence, size of residence (or community type), household income, child's health, educational handicap, and includes the child's score on the MCE test. The 10 to 19 year old dataset includes child's score on the EDA scale.

Measures

Only children with a valid report on the illness questions were included in the study. In addition to illness, data from two measures were of particular interest in this study: Mathematics Computation Exercise (MCE) and Emotional Disorders – Anxiety (EDA). These measures are described below.
Physical (Chronic) Illness

Inclusion in the “Illness Group” required a response of “Yes” by the PMK to one of the questions inquiring whether the child has an illness. The questions related to illness are:

1. “Does your child have asthma?”;
2. “Does your child have bronchitis?”;
3. “Does your child have heart condition?”;
4. “Does your child have epilepsy?”;
5. “Does your child have cerebral palsy?”;
6. “Does your child have a kidney condition?”; and
7. “Does your child have other long-term condition[s]?”.

Each report of “Yes” to an illness variable was recoded as “1”, and each report of “No” was recoded as “0. The rationale for this was so that frequency counts and analyses could be conducted for each illness category.

However, following a count of the frequencies for each of the eight illnesses, it was determined that the number of illnesses categories would have to be aggregated as there were low case counts for certain illness types (e.g., Cerebral Palsy and Kidney Condition) and the data would not allow statistical analyses by illness. As a result, a new composite illness variable was created, to adhere to STC’s data confidentiality and guidelines for disclosure of data.
This composite illness variable grouped children into one of two categories: children who have no illnesses and children who have one or more illnesses. Thus, children with PMK reports of "Yes" to any of the illness variables stated above were placed into the "Identified Illness" group. Children with PMK reports of "No" to all of the illness variables above were be placed into the "No Identified Illness" group.

**Measures of the Mathematics Computation Exercise (MCE)**

In the NLSCY, reviews of research literature and consultations with Canadian and international experts were used to identify a battery of measures of learning and achievement. Some of the criteria used in selecting measures were sound psychometric properties, whether they targeted measuring the domains identified in the research framework, and ease of administration (STC, 2002).

One of the direct measures of achievement used for children ages 10 to 19-years was the *Mathematics Computation Exercises* (MCE). The MCE is a shortened version of the *Mathematics Computation Test* from the *Canadian Achievement Test, 2nd Edition* (CAT/2) (Canadian Test Centre [CTC], 1992), and the score from this assessment appears in the Master dataset. The CAT/2 is a standardized test designed to measure achievement in basic academic skills (STC, 2002).

The shortened version MCE was created specifically for the NLSCY and includes 20 questions for Levels 1 to 8, and 15 questions for Levels 9 and 10. The MCE was administered to children in Grade 2 and above (ages 8 to 15) by the NLSCY interviewer in the child's home. This MCE includes a mathematical operations test and problem-solving test. The mathematical operations test measures the ability to add, subtract, multiply and
divide operations using whole numbers, decimals, fractions, negatives and exponents. The
problem-solving test involves percentage and order of operations (STC, 2002).

Substantial changes were made to some of the Cycle 5 testing components from
previous cycles. The MCE is one of the components that were modified. The first change to
the MCE was the number of items in the measure; items were added as anchors in order to
link assessment data across future cycles. The second change to the MCE was the collection
period of the Cycle 5 data; data collection occurred earlier in the year than in previous cycles.

Through analyses and evaluations, STC determined that these changes to the MCE
had resulted in a substantial effect on the MCE raw scores. Therefore, these scores were
considered no longer comparable with scores from other cycles and inappropriate to use in
analyses (STC, 2002). In particular, the concern was the comparability of raw scores across
data cycles.

Each child who took the MCE was given a raw score, a Classical scale score (CSS)
and an Item Response Theory scale score (IRT SS). Raw scores were obtained by adding the
number of correct answers in the MCE. The CSS and IRT SS are adjusted scores correcting
for changes made to the MCE test over time (e.g., different time periods of data collection
periods) (STC, 2002) and are considered more appropriate to be used in the analyses of the
NLSCY data.

The IRT approach is widely used in psychometric and educational testing. The
probability of a correct response (S-shaped curve over the range of abilities) is assumed to be
a logistic function of one's ability (STC, 2002). The three-parameter logistic model was used
to compute the MCE scores. The three-parameter logistic model depends on the difficulty of
the question, discrimination power of the question and chance of a hypothetical guessing
Overall, the IRT SS provides measurements that are comparable across cycles, and provides a greater precision in the estimates of test performance within the NLSCY population. In addition, IRT SSs allow comparisons to be made across different MCE levels, and age groups. Thus, the MCE IRT score was used in the current study.

**Measure of Emotional Disorder – Anxiety (EDA)**

The Emotional Disorder – Anxiety is one component of the Behaviour Scale in NLSCY Child Component data. The Behaviour Scale has nine theoretical constructs:

1) Separation Anxiety (ages 2 and 3 years);
2) Opposition (ages 2 and 3 years);
3) Conduct Disorder (ages 2 to 11 years);
4) Hyperactivity (ages 2 to 11 years);
5) Emotional Disorder (ages 2 to 11 years);
6) Indirect Aggression (ages 2 to 11 years);
7) Physical Aggression (ages 2 and 3 years and ages 8 to 11 years);
8) Inattention (ages 2 to 11 years); and
9) Prosocial behaviour (ages 8 to 11 years) (STC, 2002).

Each of these nine constructs were derived from either one, or a combination of questionnaire items from the *Achenbach’s Child Behavior Checklist* (Achenbach’s CBCL) (Achenbach, Rescorla, McConaughey, Pecora, Wetherbee, & Ruffle, 1991) the *Montreal Longitudinal Survey (Dr. R. Tremblay of the University of Montreal)*, the *Ontario Child Health Study* (OCHS) (STC, 2000) and scales by K. Weir and G. Duveen and by Lagerspetz, Björngvist and Peltonen of Finland (STC, 2002).
Factor and reliability analyses were conducted to assess the psychometric properties of the Behaviour Scale by STC. Only four scales were determined to be distinct and reliable: 1) Hyperactivity – Inattention; 2) Emotional disorder – anxiety; 3) Physical aggression – conduct disorder; and 4) Indirect aggression (STC, 2002). The Emotional Disorder – Anxiety (EDA) was one of these factors.

In NLSCY, EDA was used to measure emotional well-being of the children/adolescents. The EDA is comprised of seven questions:

1) “I am unhappy or sad”;
2) I am not as happy as other people my age”;
3) “I am too fearful or nervous”;
4) “I worry a lot”;
5) “I am nervous, high strung or tense”;
6) “I have trouble enjoying myself”; and
7) “I cry a lot” (STC, 2002).

Each question had three response format options: “Never or not true”, “Sometimes or somewhat true”, “Often or very true”, and assigned values of 0, 1 and 2, respectively. A raw score was then computed by adding up the response options; a score of 0 would infer that the symptom is not present (or very rare). Scale score were computed by STC for each of the factors. The EDA scale scores range between 0 and 14.

Clark and Watson’s (1991) Tripartite Model and Barlow and Chorpita’s (1998) Theory of Unpredictability and Uncontrollability provide support for EDA’s validity as a measure of anxiety in children. Questions 2, 3, 4 and 5, in EDA correspond to traditional factors of anxiety (e.g., “physiological anxiety” [questions 3, 4, 5] and “social
concerns/concentration” [question 2]), and questions 1, 6, and 7 correspond to traditional factors of depression (“dysphoria” and “negative mood”). In EDA, more unique features of anxiety are measured by questions 2, 3, 4 and 5, and overlapping features between depression and anxiety (NA) are measured in questions 1, 6, and 7.

Another line of support for EDA as a measure of anxiety in children is that research has found that children who are anxious often show signs of depression, in particular, these children appear unhappy and report feeling of sadness and loneliness (Beidel & Turner, 1998). Hence, the Theory of Unpredictability and Uncontrollability, Tripartite Model, and empirical research, provide support for EDA being a measure of symptoms related to anxiety in children.

Factor and reliability analyses were conducted by STC using a total of 13,765 children ages 4 to 11 years using the Cycle 4 dataset. The Chronbach's alpha (Cronbach, 1951) was .736 indicating moderate reliability (STC, 2002).

However, one of the limitations of the factor and reliability analyses conducted by STC is the age range used to conduct these analyses. Developmental level is an important characteristic to consider when making a diagnosis of anxiety, as the focus of the anxiety and how anxiety is expressed can differ across ages (Albano et al., 2003; Warren & Sroufe, 2000). Thus, further analyses were conducted to examine the degree to which results obtained using the Cycle 4 data with children ages 4 to 11, would generalize to Cycle 5 data with older children and adolescents.

An exploratory factor analysis was carried out using the Cycle 5 population data of children ages 10 to 15. In this factor analysis, the seven variables identified by STC were loaded onto one factor. The correlation between the EDA scale scores in Cycle 4 to the EDA
scale scores from Cycle 5 was \( r = .881 \) \((p < .001)\). Item-to-total test score correlations ranged from .893 to .948, and inter-item correlations ranged from .810 to .927, demonstrating strong internal consistency (Hair, Anderson, Tatham, & Black, 1998).

Additionally, a reliability analysis was conducted by the researcher to test how well this set of seven items measures the unidimensional construct of “EDA”. Chronbach’s alpha for the set of seven items in Cycle 5 was .981, further demonstrating very strong internal consistency.

**Data Preparation**

Some data cleanup (e.g., imputation for missing data) was already conducted by STC. Additional data preparation that involved creating normalized weights, and merging of the *master* and *10-19 year-old* data sets. The two data sets were merged by matching on the PMK unique identifier variable.

**Weighting**

Prior to analyses being conducted, a normalized weighting variable was created from the “Standard Longitudinal Weight” in the Cycle 5 data. The mean of the standard longitudinal weighting variable was computed, and then the standard longitudinal weighting variable was divided by its own mean. Thus, the new mean for this normalized weight is equal to 1.

The purpose of weighting the NLSCY data was to make the NLSCY sample comparable to the Canadian population. By weighting variables, the data was corrected for sample non-representativeness that resulted from survey design issues (e.g., over sampling population sub-groups), and data collection issues (i.e., non-response for particular sub-groups). However, by weighting the dataset using the standardized longitudinal weighting
variable, there would be an over inflation of power due to the immense increase in the sample size. Thus, using the normalized weighting variable corrected for this over inflation.

**Sampling/Participants for Current Study**

All of the NLSCY data were weighted using a normalized weighting variable to fulfill STC's confidentiality guidelines, as well as for appropriate use of national data. One exception to this is the overall sample size with valid responses for the key variable, chronic illness. In effect, there were 1,644 children between the ages of 10 to 15 (effective age at Cycle 5 testing), who had valid responses to the question about whether they had a chronic illness or not, as identified by the PMK (person most knowledgeable about the child).

The data was then weighted (using normalized weights), which showed a total of 1512 (N) children who would be included in the statistical analyses. Of these 1512 children, 978 children were identified with no illness(es), and 534 were identified with 1 or more illness(es). The sample included a higher proportion of males (n = 896) than females (n = 616). There were 275 children who were 10-11 years, 391 children who were 12-13 years, and 442 children who were 14-15 years.

A total of 1206 children (79.76%) had valid MCE scores and 868 children (57.41%) had valid EDA scores. These results are presented in Table 3.1.
Table 3.1

Frequency and Percentages (Unweighted and Weighted) for Children with a Valid Report of Illness

<table>
<thead>
<tr>
<th>Variable</th>
<th>Distribution</th>
<th>n (unweighted)</th>
<th>n (weighted)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Illness</td>
<td>No</td>
<td>1018</td>
<td>978</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>626</td>
<td>534</td>
</tr>
<tr>
<td></td>
<td>TOTAL</td>
<td>1644</td>
<td>1512</td>
</tr>
<tr>
<td>Educational Handicap</td>
<td>No</td>
<td>-</td>
<td>1320</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>-</td>
<td>193</td>
</tr>
<tr>
<td></td>
<td>TOTAL</td>
<td>-</td>
<td>1512</td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>-</td>
<td>896</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>-</td>
<td>616</td>
</tr>
<tr>
<td></td>
<td>TOTAL</td>
<td>-</td>
<td>1512</td>
</tr>
<tr>
<td>Age</td>
<td>10-11 years</td>
<td>-</td>
<td>275</td>
</tr>
<tr>
<td></td>
<td>12-13 years</td>
<td>-</td>
<td>391</td>
</tr>
<tr>
<td></td>
<td>14-15 years</td>
<td>-</td>
<td>442</td>
</tr>
<tr>
<td></td>
<td>TOTAL</td>
<td>-</td>
<td>1108</td>
</tr>
<tr>
<td>MCE</td>
<td>-</td>
<td>1206</td>
<td></td>
</tr>
<tr>
<td>EDA</td>
<td>-</td>
<td>868</td>
<td></td>
</tr>
</tbody>
</table>

Descriptive Statistical Analyses

MCE Scores

A child’s MCE score was based on his/her IRT scale score on the Mathematics Computation Exercise (MCE) test, a standardized mathematical operations and problem-solving test given to all NLSCY participants aged 8 to 15 years. The MCE score is a continuous variable, and MCE scores for children with a valid illness ranged from 248 to 739 points on a scale that had a population mean of 473.46 and standard deviation of 107.25 (Table 3.2).
Table 3.2

Statistics for MCE and EDA scores

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>MCE</td>
<td>473.46</td>
<td>107.25</td>
<td>248.00</td>
<td>739.00</td>
</tr>
<tr>
<td>EDA</td>
<td>3.13</td>
<td>2.55</td>
<td>.00</td>
<td>13.00</td>
</tr>
</tbody>
</table>

EDA scores

The Emotional Disorder – Anxiety (EDA) scale is purported to capture a child’s propensity to develop an emotional disorder, specifically, anxiety-related disorder. The EDA scale score is based on participants’ rating on seven questions related to emotional (anxiety) disorders on the NLSCY questionnaire. Based on a principal component analysis, a simple EDA score was created.

Although the scale scores on the EDA scale can range from 0 to 16, scores only ranged from 0 to 11 for children with a valid report of illness, with most children scoring 0, 1 and 4 and the mean EDA score was 3.13 and the standard deviation was 2.55. Higher scale scores on the EDA scale would be indicative of an increased likelihood of the child experiencing emotional disorder that is related to anxiety, and lower scores would be indicative of a decreased likelihood of an emotional disorder (anxiety) being present.

The sample EDA scores indicate that the children in the sample were not experiencing high levels of emotional, anxiety-related disorders. The frequency of EDA scores was plotted on a histogram. The distribution of scores showed a negatively skewed distribution with the highest frequency for scale score of 1, and a sharp decline at a scale score of 5. However, due to STC’s Confidentiality Guidelines, this histogram cannot be presented.
Educational Handicap

Given that children who were identified with a physical illness may also be identified with a mental handicap (mental retardation), or diagnosed with a learning disability, attention deficit disorder, or emotional disorder, it was important to take into consideration the extent to which these difficulties may hinder learning and one's performance on the MCE test.

A frequency count was run for each of these four variables (mental handicap, learning disability, attention deficit and emotional disorder) and it was determined that these variables would have to be aggregated into one category due to low case counts, as well as to adhere to STC's data confidentiality and guidelines for disclosure of data. Thus, the term "educational handicap" was used to describe children who were identified with one or more of the above illnesses.

Children with a response of "Yes" by the PMK on any one of the following questions were placed into the "Educational Handicap – Identified" group:

1. "Does child have mental handicap? (diagnosed)";
2. "Does your child have a learning disability? (diagnosed)";
3. "Does your child have attention deficit? (diagnosed)"; and
4. "Does your child have an emotional disorder? (diagnosed)".

Descriptive analyses were conducted for children with an identification of a chronic (physical) illness and with an identification of an educational handicap (Table 3.3). The rationale for this was to take into consideration the proportion of children with both a chronic illness as well as an educational handicap that would impact their performance on the MCE test.
For children who were not identified with an illness, there were 59 children (5.18%) who had an educational handicap, and 691 children (60.61%) who had an educational handicap. For children who were identified with an illness, there were 64 children (5.61%) who were also identified with an educational handicap, and 326 children (28.60%) who were not identified with an educational handicap. These numbers are presented in Table 3.3.

Table 3.3

<table>
<thead>
<tr>
<th>Illness</th>
<th>Educational Handicap</th>
<th>n (weighted)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>No</td>
<td>691</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>59</td>
</tr>
<tr>
<td>Yes</td>
<td>No</td>
<td>326</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>64</td>
</tr>
<tr>
<td>TOTAL</td>
<td>TOTAL</td>
<td>1140</td>
</tr>
</tbody>
</table>

Note. An "educational handicap" refers to an identification of a mental handicap, learning disability, attention deficit or emotional disorder by the PMK.

Age

The NLSCY uses "effective age" instead of the child's actual age to ensure that the child stays in the specified age group assigned regardless of whether data collection occurs before or after a child's birthday. For Cycle 5, the effective age was calculated as 2002 minus year of birth. Responses that were coded as "Valid Skip", "Don't Know", "Refused" and "Not stated" in the original NLSCY dataset were treated as missing data.

Although the effective age in Cycle 5 ranged from 0 to 19 years-old, only children ages 10 to 15 were of interest in this study. Children with valid illness reports who were 10 to 15 years were extracted from the sample, and then divided into three age composites: 10 to 11 years, 12 to 13 years, and 14 to 15 years. There were two reasons for creating age
composites; the first reason was due to the low number of case counts for children of a certain age who are identified with a chronic illness. The use of low case counts in specific age composites would affect the significance level and power of the statistical tests.

Secondly, categorizing children into separate age composites would be appropriate in running statistical analyses as MCE scores are based on a vertical scale with large errors and a wide range of performance across different age groups. The further apart children are in age along the continuum of MCE scores (e.g., comparing children who are 10-years-old to children who are 15-years-old), the less comparable the MCE test scores become. Thus, the creation of the three age composites increased the level of comparability of the MCE.

The sample of children with valid illness reports ranged between the ages of 10 and 15 years: 24.82% children were 10 to 11 years-old; 35.29% were 12 to 13 years-old; and 38.89% were 14 to 15 years-old (Table 3.4).

Table 3.4

<table>
<thead>
<tr>
<th>Age Categories</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 to 11 years</td>
<td>275</td>
</tr>
<tr>
<td>12 to 13 years</td>
<td>391</td>
</tr>
<tr>
<td>14 to 15 years</td>
<td>442</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1108</td>
</tr>
</tbody>
</table>
Province of Residence

There were 15 Province of Residence response options which included territories and options other than provinces: “Newfoundland and Labrador”, “Prince Edward Island”, “Nova Scotia”, “New Brunswick”, “Quebec”, “Ontario”, “Manitoba”, “Saskatchewan”, “Alberta”, “British Columbia”, “Yukon”, “Northwest Territories”, “Nunavut”, “United States”, “Outside Canada and USA”. Respondents living outside of Canada were collapsed into a variable named “Other”.

However, the sample of children with valid illness reports lived in only eleven provinces across Canada at the time of the Cycle 5 data collection: Ontario (38.49%), Quebec (25.13%), British Columbia (10.98%), Alberta (10.25%), Manitoba (3.24%), Saskatchewan (3.37%), Nova Scotia (3.37%), New Brunswick (2.58%), Newfoundland (2.18%) and Prince Edward Island (.53%) (Table 3.5).

Table 3.5

<table>
<thead>
<tr>
<th>Province</th>
<th>n (weighted)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alberta</td>
<td>155</td>
</tr>
<tr>
<td>British Columbia</td>
<td>166</td>
</tr>
<tr>
<td>Manitoba</td>
<td>49</td>
</tr>
<tr>
<td>New Brunswick</td>
<td>39</td>
</tr>
<tr>
<td>Newfoundland and Labrador</td>
<td>33</td>
</tr>
<tr>
<td>Northwest Territories</td>
<td>0</td>
</tr>
<tr>
<td>Nova Scotia</td>
<td>51</td>
</tr>
<tr>
<td>Nunavut</td>
<td>0</td>
</tr>
<tr>
<td>Ontario</td>
<td>582</td>
</tr>
<tr>
<td>Prince Edward Island</td>
<td>8</td>
</tr>
<tr>
<td>Quebec</td>
<td>380</td>
</tr>
<tr>
<td>Saskatchewan</td>
<td>51</td>
</tr>
<tr>
<td>Yukon</td>
<td>0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1512</td>
</tr>
</tbody>
</table>

Note. No valid reports of illness for children living in the Northwest Territories, Nunavut or Yukon Territories.
Size Area (Community Type) of Residence

There were 5 Size-area (Community Type) of Residence response categories: “Rural area”, “Urban Population, less than 30,000”, “Urban Population, 30,000 to 99,999”, “Urban Population, 100,000 to 499,999”, and “Urban Population, 500,000 or more” (Table 3.6). Most children lived in communities that had a population of 500,000 or more, and in populations of less than 30,000.

Table 3.6

Size-Area (Community Type) in which Children with a Valid Report of Illness Live

<table>
<thead>
<tr>
<th>Size-Area (Community Type)</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rural Area</td>
<td>164</td>
</tr>
<tr>
<td>Urban Population (less than 30,000)</td>
<td>379</td>
</tr>
<tr>
<td>Urban Population (30,000-99,999)</td>
<td>124</td>
</tr>
<tr>
<td>Urban Population (100,000-499,999)</td>
<td>244</td>
</tr>
<tr>
<td>Urban Population (500,000 or more)</td>
<td>602</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1512</td>
</tr>
</tbody>
</table>

Household Income.

There were 6 Household Income response categories: “Less than $10,000”, “$10,000 to 14,999”, “$15,000 to 19,999”, “$20,000 to 29,999”, “$30,000 to 39,999”, and “$40,000 or more” (Table 3.7). Most household incomes were between $30,000 to 39,999 per year.
Table 3.7

Family Annual Household Income of Children with a Valid Report of Illness

<table>
<thead>
<tr>
<th>Annual Household Income</th>
<th>n (weighted)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $10,000</td>
<td>7</td>
</tr>
<tr>
<td>$10,000 to 14,999</td>
<td>53</td>
</tr>
<tr>
<td>$15,000 to 19,999</td>
<td>42</td>
</tr>
<tr>
<td>$20,000 to 29,999</td>
<td>101</td>
</tr>
<tr>
<td>$30,000 to 39,999</td>
<td>130</td>
</tr>
<tr>
<td>$40,000 or more</td>
<td>1178</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1512</td>
</tr>
</tbody>
</table>

School Absent Days

There were 6 Number of Days Absent response categories: “0 days”, “1 to 3 days”, “4 to 6 days”, “7 to 10 days”, “11 to 20 days”, and “more than 20 days” (Table 3.8). Most children missed between 1 to 6 days of school per school year.

Table 3.8

School Absent Days of Children with a Valid Report of Illness

<table>
<thead>
<tr>
<th>Number of Absent Days</th>
<th>n (weighted)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 days</td>
<td>70</td>
</tr>
<tr>
<td>1 to 3 days</td>
<td>423</td>
</tr>
<tr>
<td>4 to 6 days</td>
<td>472</td>
</tr>
<tr>
<td>7 to 10 days</td>
<td>262</td>
</tr>
<tr>
<td>11 to 20 days</td>
<td>173</td>
</tr>
<tr>
<td>More than 20 days</td>
<td>87</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1487</td>
</tr>
</tbody>
</table>
Reason Absent from School

Children miss school for a myriad of reasons, however, approximately 80.00% of the sample from the NLSCY missed school due to a health reason (Table 3.9). Other responses, such as “Problems with weather”, “Family vacation”, etc. made up the other ~20% of the sample. Although “School Phobia” was listed as one of the reasons for school absence, the case counts were so small that releasing this data would have violated the STC guidelines for disclosure of data.

Table 3.9

Reason that Children with a Valid Report of Illness are Absent from School

<table>
<thead>
<tr>
<th>Reason for School Absence</th>
<th>n (weighted)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Reasons</td>
<td>418</td>
</tr>
<tr>
<td>Other (weather, vacation, etc.)</td>
<td>105</td>
</tr>
<tr>
<td>TOTAL</td>
<td>522</td>
</tr>
</tbody>
</table>

Missing Data.

All responses that were coded as “Valid Skip”, “Don't Know”, “Refused” and “Not stated” in the original NLSCY dataset were treated as missing data. Due to the systematic pattern of missing data, and the exploratory nature of this study, imputation methods were not used. Thus, only children with valid reports of the variables of interest were included in the study.

Statistical Analyses

Due to data confidentiality and adherence to STC's guidelines for disclosure of data, all case counts and statistical analyses were conducted using normalized weighted data (see Appendix A for more details on these guidelines).
Statistical Analyses for Question One and Two

The first and second research questions were: “Are there statistically significant differences between children with chronic illnesses and healthy children in their Mathematics Computation Exercise (MCE) scores?; and “Are there statistically significant differences between children with chronic illnesses and healthy children in their Emotional Disorder – Anxiety (EDA) scores?”, respectively.

Two Analysis of Variance (ANOVA) analyses were conducted to address these research questions. For the first ANOVA test, MCE was treated as the dependent variable, and illness and gender were treated as the independent variables. For the second ANOVA model, EDA was treated as the dependent variable, and illness, gender and age were treated as the independent variables. The ANOVAs helped us test whether there were statistically significant differences in MCE and EDA scores for groups of children who were identified with and without a chronic illness, while also looking at the effect of gender (on MCE and EDA scores) and age (on EDA scores only).

Statistical Analyses for Question Three and Four

The third and fourth research questions were: “How are chronic illnesses associated with performance on the Mathematics Computation Exercise (MCE) after removing the effect of a child’s Emotional Disorder – Anxiety score?; and “How are chronic illnesses associated with performance on the MCE after removing the effects of various Educational Handicaps (mental handicap, learning disability, attention deficit and emotional disorder)?”

Two Analysis of Covariance (ANCOVA) analyses were conducted to examine the effect of illness on MCE after controlling for EDA and educational handicaps. The dependent variable was MCE scores in both of these analyses, and the covariate for the first
ANCOVA was EDA, and the covariate for the second ANCOVA was educational handicap. Illness and gender were used to test for interaction effects.

**Statistical Analyses for Question Five**

The final research question was: “What is the degree of association between a child’s performance on the Mathematics Computation Exercise (MCE), with health/illness, score on the Emotional Disorder – Anxiety (EDA) scale, and when other factors such age, gender, household income, community type (urban vs. rural) are also considered?”

A blockwise regression analysis was used with MCE scores as the dependent variable. First, gender and household income were entered as Block 1. The size area (community type) of residence was included in Block 2. Illness was then added in Block 3. Finally, EDA scores were added in Block 4.
Testing Assumptions of Statistical Models

The statistical analyses that were proposed for use in this study are the Analysis of Variance (ANOVA), Analysis of Covariance (ANCOVA) and Regression. Prior to running these analyses, the assumptions of the statistical models were tested.

Assumptions for Analysis of Variance (ANOVA), Analysis of Covariance (ANCOVA) and Regression Analyses

The two assumptions common to an ANOVA, ANCOVA and Regression are the assumptions of normality and homogeneity of variance. The assumption of normality posits that the data is normally distributed for the dependent variables. In order for the assumption of normality to be met, the deviation from normality must be small. This can be assessed by looking at the slope of the data distribution for the variable of interest (i.e., MCE scores and EDA scale scores) using a normal probability plot (Hair et al., 1998). A diagonal line is indicative of normality in a probability plot. Figures 3.2 and 3.3 are the probability plots for MCE scores and EDA scale scores, respectively. Given that the expected and observed cumulative probability plots are both linear, both the MCE scores and EDA scale scores met the assumption of normality.
Figure 3.2

Normal P-P Plot of MCE Scores

Normal P-P Plot of Regression Standardized Residual

Dependent Variable: Recoded MCE IRT Scores

Cases weighted by longwtn
The second assumption, homogeneity of variance, posits that each population of scores has equal variance. Typically, the *Levene's Test of Equality of Error Variances* for each of the ANOVA, ANCOVA and Regression analyses tests the null hypothesis that the error variance of the dependent variable (MCE scores and EDA scale scores) is equal across the different groups being tested (illness, age and gender). Thus, a Levene's test that is statistically significant is indicative that the groups do not have equal variances (Table 3.10).

The significance levels of the Levene's tests were all significant at the $p < .001$ level. The effect sizes from the Lack of Fit Tests are presented in Table 10.
Table 3.10

Significance Levels and Effect Sizes for Levene's and Lack of Fit Tests

<table>
<thead>
<tr>
<th>Test</th>
<th>Variables</th>
<th>p-value Levene's Test</th>
<th>Effect size η-value Lack of Fit Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>ANOVA 1</td>
<td>Dependent Variable = MCE</td>
<td>.000</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Independent Variable = gender, illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ANOVA 2</td>
<td>Dependent Variable = EDA</td>
<td>.000</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Independent Variable = gender, age, illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ANCOVA 1</td>
<td>Dependent Variable = MCE</td>
<td>.000</td>
<td>.127</td>
</tr>
<tr>
<td></td>
<td>Independent Variable = gender, illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Covariate = EDA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ANCOVA 2</td>
<td>Dependent Variable = MCE</td>
<td>.000</td>
<td>.002</td>
</tr>
<tr>
<td></td>
<td>Independent Variable = gender, illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Covariate = educational handicap</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

However, given that the effect sizes were very small, despite the significance of the Levene's tests, both ANOVA and ANCOVA are robust to violations of this assumption. Any transformation of the dependent variables is expected to complicate the interpretation of findings and a decision was made not to transform these variables.

The third and final assumption of the ANCOVA and Regression tests is the assumption of linearity of the relationship between the dependent variable and each of the independent variables. This assumption requires that the within-group relationship between the covariate and dependent variable (ANCOVA analysis), and between the predictor and dependent variables (Regression analysis) is linear (Grimm & Yarnold, 1995).

Scatterplot was used for the visual identification of nonlinear patterns of the MCE data. MCE data points were plotted against EDA data points, which demonstrated a linear relationship. However, due to the STC confidentiality and data disclosure guidelines, this particular plot was not permitted to be released. Thus, the standardized predicted values
were plotted against the standardized residuals (Figure 3.4), and linearity was again detected. Hence, transformations to the MCE data were not necessary.

**Figure 3.4**

**Scatterplot of MCE Scores**

**Scatterplot of MCE IRT Scores**

**Summary of Data Preparation and Testing for Statistical Assumptions**

Following these data preparation and preliminary analyses (e.g., frequency counts, probability plots) the data appeared to meet the assumptions for the data analyses procedures selected as well as STC’s data confidentiality and disclosure risk guidelines. Thus, the statistical analyses were conducted to answer the five research questions posed.
CHAPTER 4

Results

This study investigated the educational and psychological impact of childhood chronic illnesses on learning and achievement and emotional well being using data from the National Longitudinal Survey of Children and Youth (NLSCY). The objective was to understand whether there are differences in performance on a mathematics achievement measure (Mathematics Computation Exercise [MCE]) and differences in scores on an emotional disorder-anxiety measure (EDA) in children who are identified as being healthy versus children identified as having chronic illnesses. Further, this research investigated whether there was an effect of gender and socio-economic status, such as community type and household income on the relationship between illness and academic achievement for these two groups of children.

This chapter contains a summary of statistical findings to help answer the five research questions posed at the outset of the study. All tests of statistical analyses, assumptions and results were conducted based on normalized weighted data to fulfill STC’s confidentiality guidelines, as well as for appropriate use of national data (see Appendix A). One exception to this is the overall sample size with valid responses for the key variable, chronic illness.

Analysis of Variance for MCE Scores by Illness and Gender

A univariate Analysis of Variance (ANOVA), with illness and gender as independent variables and MCE scores as the dependent variable, was conducted to examine whether there were statistically significant differences between children with chronic illnesses and healthy children in their MCE scores.
MCE Scores by Illness

The mean MCE score for children with no identified illness is 485.56, with a SD of 110.07 points, and the mean MCE score for children with an identified illness is 461.90, with a SD of 100.33; this is a 23.66 point difference in SS between children with no identified illness and an identified illness.

MCE Scores by Illness and Gender

For the analyses on gender, females had a mean MCE score of 491.45, and males had a mean MCE score of 466.34. Even though mean MCE scores were very similar for males and females with an identified illness (466.73 and 458.75, respectively), there was a larger difference in MCE scores between females and males (502.29 and 470.84, respectively) with no identified illness.

The descriptive statistics for the MCE scores for children by illness and gender are presented in Table 4.11.

Table 4.11

Means and Standard Deviations for MCE Scores by Illness and Gender

<table>
<thead>
<tr>
<th>Illnesses</th>
<th>Gender</th>
<th>Mean MCE</th>
<th>SD</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(weighted)</td>
</tr>
<tr>
<td>No Illness</td>
<td>Male</td>
<td>470.84</td>
<td>114.83</td>
<td>399</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>502.29</td>
<td>102.00</td>
<td>351</td>
</tr>
<tr>
<td></td>
<td>TOTAL</td>
<td>485.56</td>
<td>110.07</td>
<td>750</td>
</tr>
<tr>
<td>1 Illness</td>
<td>Male</td>
<td>458.75</td>
<td>98.38</td>
<td>236</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>466.73</td>
<td>103.39</td>
<td>154</td>
</tr>
<tr>
<td></td>
<td>TOTAL</td>
<td>461.90</td>
<td>100.33</td>
<td>390</td>
</tr>
<tr>
<td>TOTAL</td>
<td>Male</td>
<td>466.34</td>
<td>109.09</td>
<td>635</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>491.45</td>
<td>103.63</td>
<td>505</td>
</tr>
<tr>
<td></td>
<td>TOTAL</td>
<td>477.47</td>
<td>107.38</td>
<td>1140</td>
</tr>
</tbody>
</table>
Illness, \((F(1, 1136)=12.53, p < .001)\), and gender, \((F(1, 1136)=8.58, p < .05)\), were identified as significant factors, however, the interaction effect illness by gender was not significant, \((F(1, 1135)=3.04, p > .05)\).

Overall, females performed higher on the MCE test. Mean MCE scores for children with one or more identified illnesses were lower than the mean for children with no identified illness. However, the effect sizes for illness \((\eta^2 = .011)\) and gender \((\eta^2 = .007)\) were small. The results are presented in Table 4.12.

Table 4.12

Analysis of Variances for Mathematics Computation Exercises (MCE) Scores

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>(F)</th>
<th>(\eta)</th>
<th>(p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness (I)</td>
<td>1</td>
<td>12.53(**)</td>
<td>.011</td>
<td>.000</td>
</tr>
<tr>
<td>Gender (G)</td>
<td>1</td>
<td>8.58(*)</td>
<td>.007</td>
<td>.003</td>
</tr>
<tr>
<td>I * G</td>
<td>1</td>
<td>3.04</td>
<td>.003</td>
<td>.082</td>
</tr>
</tbody>
</table>

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

Analysis of Variance for EDA Scores by Illness, Gender, and Age

EDA Scores By Illness

The mean score on the EDA scale for children with no identified illnesses is 3.14 \((SD = 2.65)\), and the mean score on the EDA scale for children with an identified illness is 3.50 \((SD = 2.25)\). In other words, there is a mean difference of .36 EDA score points between children with no illnesses and with an identified illness. This suggests that the two groups of children (ones with no identified illnesses and ones with identified illnesses) score very similarly on the EDA scale.
EDA Scores By Illness And Gender

Males with no identified illness scored lower on the EDA scale ($M = 2.85, SD = 2.66$) compared to males with an identified illness ($M = 2.86, SD = 2.02$). As well, females with no identified illness scored lower on the EDA scale ($M = 3.39, SD = 2.62$) compared to females with an identified illness ($M = 3.53, SD = 2.71$). This may suggest that there are some differences between males with no identified illnesses compared to females with no identified illnesses, and between males with an identified illness compared to females with an identified illness.

EDA Scores By Illness By Age And Gender

The highest mean EDA scores by age, and mean EDA score by gender was found in females. Females who were 14-15 years with an identified illness, reported a mean EDA score of $4.40 (SD = 2.99)$, and females who were 10-11 years without an identified illness, reported a mean score of $4.31 (SD = 2.96)$. Interestingly, the lowest scores are also found in females. The lowest scores were found in females who were 12-13 years with an identified illness ($M = 2.43, SD = 2.12$), and females 12-13 years without an identified illness ($M = 2.52, SD = 2.22$). Mean EDA scores for children by illness, gender and age are presented in Table 4.13.
Table 4.13

Mean EDA Scores by Illness, Age and Gender Groups

<table>
<thead>
<tr>
<th>Health</th>
<th>Gender</th>
<th>Age Groups</th>
<th>Mean EDA</th>
<th>SD</th>
<th>n (weighted)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Illnesses</td>
<td>Male</td>
<td>10-11</td>
<td>3.00</td>
<td>2.79</td>
<td>62</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12-13</td>
<td>2.98</td>
<td>3.06</td>
<td>82</td>
</tr>
<tr>
<td></td>
<td></td>
<td>14-16</td>
<td>2.69</td>
<td>2.29</td>
<td>120</td>
</tr>
<tr>
<td></td>
<td></td>
<td>TOTAL</td>
<td>2.85</td>
<td>2.66</td>
<td>264</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>10-11</td>
<td>4.31</td>
<td>2.96</td>
<td>54</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12-13</td>
<td>2.52</td>
<td>2.22</td>
<td>123</td>
</tr>
<tr>
<td></td>
<td></td>
<td>14-16</td>
<td>3.89</td>
<td>2.58</td>
<td>117</td>
</tr>
<tr>
<td></td>
<td></td>
<td>TOTAL</td>
<td>3.39</td>
<td>2.62</td>
<td>294</td>
</tr>
<tr>
<td></td>
<td>TOTAL</td>
<td>10-11</td>
<td>3.61</td>
<td>2.94</td>
<td>116</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12-13</td>
<td>2.70</td>
<td>2.59</td>
<td>205</td>
</tr>
<tr>
<td></td>
<td></td>
<td>14-16</td>
<td>3.28</td>
<td>2.50</td>
<td>237</td>
</tr>
<tr>
<td></td>
<td></td>
<td>TOTAL</td>
<td>3.14</td>
<td>2.65</td>
<td>558</td>
</tr>
<tr>
<td>1 Illness</td>
<td>Male</td>
<td>10-11</td>
<td>3.26</td>
<td>2.03</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12-13</td>
<td>2.77</td>
<td>1.86</td>
<td>47</td>
</tr>
<tr>
<td></td>
<td></td>
<td>14-16</td>
<td>2.71</td>
<td>2.13</td>
<td>63</td>
</tr>
<tr>
<td></td>
<td></td>
<td>TOTAL</td>
<td>2.86</td>
<td>2.02</td>
<td>144</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>10-11</td>
<td>3.81</td>
<td>2.51</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12-13</td>
<td>2.43</td>
<td>2.12</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td></td>
<td>14-16</td>
<td>4.40</td>
<td>2.99</td>
<td>43</td>
</tr>
<tr>
<td></td>
<td></td>
<td>TOTAL</td>
<td>3.53</td>
<td>2.71</td>
<td>109</td>
</tr>
<tr>
<td></td>
<td>TOTAL</td>
<td>10-11</td>
<td>3.50</td>
<td>2.25</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12-13</td>
<td>2.61</td>
<td>1.98</td>
<td>87</td>
</tr>
<tr>
<td></td>
<td></td>
<td>14-16</td>
<td>3.40</td>
<td>2.64</td>
<td>106</td>
</tr>
<tr>
<td></td>
<td></td>
<td>TOTAL</td>
<td>3.15</td>
<td>2.36</td>
<td>253</td>
</tr>
<tr>
<td>TOTAL</td>
<td>Male</td>
<td>9-11</td>
<td>3.09</td>
<td>2.54</td>
<td>96</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12-13</td>
<td>2.90</td>
<td>2.68</td>
<td>129</td>
</tr>
<tr>
<td></td>
<td></td>
<td>14-16</td>
<td>2.70</td>
<td>2.23</td>
<td>183</td>
</tr>
<tr>
<td></td>
<td></td>
<td>TOTAL</td>
<td>2.86</td>
<td>2.45</td>
<td>408</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>9-11</td>
<td>4.15</td>
<td>2.82</td>
<td>80</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12-13</td>
<td>2.50</td>
<td>2.19</td>
<td>163</td>
</tr>
<tr>
<td></td>
<td></td>
<td>14-16</td>
<td>4.03</td>
<td>2.70</td>
<td>160</td>
</tr>
<tr>
<td></td>
<td></td>
<td>TOTAL</td>
<td>3.43</td>
<td>2.64</td>
<td>403</td>
</tr>
<tr>
<td></td>
<td>TOTAL</td>
<td>9-11</td>
<td>3.57</td>
<td>2.72</td>
<td>176</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12-13</td>
<td>2.67</td>
<td>2.42</td>
<td>292</td>
</tr>
<tr>
<td></td>
<td></td>
<td>14-16</td>
<td>3.32</td>
<td>2.54</td>
<td>343</td>
</tr>
<tr>
<td></td>
<td></td>
<td>TOTAL</td>
<td>3.14</td>
<td>2.56</td>
<td>811</td>
</tr>
</tbody>
</table>
Analysis of Variance for EDA scores by Illness, Gender and Age

The main effect for illness, 2-way interaction effect (illness by gender, and illness by age), and the 3-way interaction (illness, gender and age) were not significant. Significant effects were found for gender and age ($F(1, 799)=11.05, p \leq .001$), and $F(2, 799)=8.48, p < .001$). However, the effect sizes for these main effects were small. The effect size for gender was $\eta^2 = .014$, and the effect size for age was $\eta^2 = .021$. Thus, these findings do not seem to have practical implications.

Table 4.14

Analysis of Variances for Emotional Disorder-Anxiety (EDA) Scores

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>$F$</th>
<th>$\eta$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness (I)</td>
<td>1</td>
<td>.00</td>
<td>.000</td>
<td>.988</td>
</tr>
<tr>
<td>Gender (G)</td>
<td>1</td>
<td>11.05(*)</td>
<td>.014</td>
<td>.001</td>
</tr>
<tr>
<td>Age (A)</td>
<td>2</td>
<td>8.48(**)</td>
<td>.021</td>
<td>.000</td>
</tr>
<tr>
<td>I * G</td>
<td>1</td>
<td>.02</td>
<td>.000</td>
<td>.884</td>
</tr>
<tr>
<td>I * A</td>
<td>2</td>
<td>.55</td>
<td>.001</td>
<td>.579</td>
</tr>
<tr>
<td>I * G * A</td>
<td>2</td>
<td>.80</td>
<td>.002</td>
<td>.449</td>
</tr>
</tbody>
</table>

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

Post Hoc Tests for EDA Scores

The Tukey HSD test showed that there were significant differences between children who were 10-11 years from children who were 12-13 years, in addition, there were significant differences detected between children 12-13 years from children who were 14-15 years. Differences were not found between the youngest children of this sample (10-11) from the eldest children (14-15) (Table 4.15).
Table 4.15

Tukey's Post Hoc Test for EDA scores by Age

<table>
<thead>
<tr>
<th>Age Groups (Comparison)</th>
<th>Mean Difference</th>
<th>SE</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>10-11</td>
<td>12-13</td>
<td>.90(*)</td>
<td>.24</td>
</tr>
<tr>
<td></td>
<td>14-15</td>
<td>.26</td>
<td>.23</td>
</tr>
<tr>
<td>12-13</td>
<td>10-11</td>
<td>-.90(*)</td>
<td>.24</td>
</tr>
<tr>
<td></td>
<td>14-15</td>
<td>-.64(*)</td>
<td>.20</td>
</tr>
<tr>
<td>14-15</td>
<td>10-11</td>
<td>-.26</td>
<td>.23</td>
</tr>
<tr>
<td></td>
<td>12-13</td>
<td>.64(*)</td>
<td>.20</td>
</tr>
</tbody>
</table>

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

The Tamhane’s T2, Games-Howell, Dunnett’s T3, and Dunnett’s C Post Hoc comparisons were also computed, given that the homogeneity of variance assumption was violated. The pairwise comparisons for illness by age were very similar to what was found in the Tukey’s HSD test. Table 4.16 summarizes the results from the Tamhane’s T2, Games-Howell, Dunnett’s T3, and Dunnett’s C Post Hoc tests.
Table 4.16
Tamhane, Dunnett T3, Games-Howell and Dunnett C Post Hoc Tests for EDA scores by Age

<table>
<thead>
<tr>
<th>Post Hoc Test</th>
<th>Age Groups</th>
<th>Age Group (Comparison)</th>
<th>Mean Difference</th>
<th>SE</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tamhane</td>
<td>10-11</td>
<td>12-13</td>
<td>.90(*)</td>
<td>.25</td>
<td>.001</td>
</tr>
<tr>
<td></td>
<td>12-13</td>
<td>14-15</td>
<td>-.64(*)</td>
<td>.20</td>
<td>.004</td>
</tr>
<tr>
<td></td>
<td>14-15</td>
<td>12-13</td>
<td>-.26</td>
<td>.25</td>
<td>.656</td>
</tr>
<tr>
<td>Dunnett T3</td>
<td>10-11</td>
<td>12-13</td>
<td>.90(*)</td>
<td>.25</td>
<td>.001</td>
</tr>
<tr>
<td></td>
<td>12-13</td>
<td>14-15</td>
<td>-.64(*)</td>
<td>.20</td>
<td>.004</td>
</tr>
<tr>
<td></td>
<td>14-15</td>
<td>12-13</td>
<td>-.26</td>
<td>.25</td>
<td>.656</td>
</tr>
<tr>
<td>Games-Howell</td>
<td>10-11</td>
<td>12-13</td>
<td>.90(*)</td>
<td>.25</td>
<td>.001</td>
</tr>
<tr>
<td></td>
<td>12-13</td>
<td>14-15</td>
<td>-.64(*)</td>
<td>.20</td>
<td>.003</td>
</tr>
<tr>
<td></td>
<td>14-15</td>
<td>12-13</td>
<td>-.26</td>
<td>.25</td>
<td>.553</td>
</tr>
<tr>
<td>Dunnett C</td>
<td>10-11</td>
<td>12-13</td>
<td>.90(*)</td>
<td>.25</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>14-15</td>
<td>12-13</td>
<td>.26</td>
<td>.25</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>12-13</td>
<td>14-15</td>
<td>-.64(*)</td>
<td>.20</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>14-15</td>
<td>12-13</td>
<td>-.26</td>
<td>.25</td>
<td>-</td>
</tr>
</tbody>
</table>

*p < .05.
Comparison of Children With or Without Illnesses in Their Mathematics Computation Exercise (MCE) Scores with EDA as a Covariate

This analysis addressed the degree to which differences in MCE scores for children with and without illnesses may be moderated by their emotional health. In other words, do the differences in EDA scores account for differences in MCE scores for children with and without illnesses? To examine differences of MCE scores after removing the effect of EDA scores for children who are healthy and children who are ill, an Analysis of Covariance (ANCOVA) was conducted where EDA scores were used as a covariate.

Table 4.17 summarizes the results from the ANCOVA analyses for illness and gender as the independent variables, MCE scores as the dependent variable and EDA scores as the covariate. The main effect of illness was found to be significant, $F(1, 720) = 4.07, p < .05$, but the strength of the relationship was very weak with effect size $\eta^2 = .006$. However, the main effect for the covariate (EDA) was not significant, $F(1, 720) = .12, p > .001$, nor were the effect of gender, or any of the 2-way and 3-way interactions significant.

Table 4.17

Analysis of Covariance for MCE Scores, After Removing the Effects of EDA Scores

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>$F$</th>
<th>$\eta$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness</td>
<td>1</td>
<td>4.07(*)</td>
<td>.006</td>
<td>.044</td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>.35</td>
<td>.000</td>
<td>.554</td>
</tr>
<tr>
<td>EDA</td>
<td>1</td>
<td>.12</td>
<td>.000</td>
<td>.725</td>
</tr>
<tr>
<td>I * E</td>
<td>1</td>
<td>.13</td>
<td>.000</td>
<td>.719</td>
</tr>
<tr>
<td>G * E</td>
<td>1</td>
<td>.25</td>
<td>.000</td>
<td>.617</td>
</tr>
<tr>
<td>I * G * E</td>
<td>1</td>
<td>1.34</td>
<td>.002</td>
<td>.247</td>
</tr>
</tbody>
</table>

* $p < .05$.

Thus, EDA scores do not seem to moderate the effect of illness. In fact, when the variation in MCE scores by EDA scores is accounted for, the effect size for illness is higher.
Comparison of Children With or Without Illnesses in Their Mathematics Computation Exercise (MCE) Scores with Educational Handicaps as a Covariate

This analysis addressed the degree to which differences in MCE scores for children with and without illnesses may be moderated by the presence of an educational handicap. An educational handicap is defined as the identification of at least one of the following: mental handicap, learning disability, attention deficit and/or emotional disorder. In other words, does a child’s educational handicap account for differences in MCE scores?

Table 4.18 illustrates the mean MCE scores by children identified with a chronic illness and an educational handicap. Children who were not identified with either a chronic illness or an educational handicap had the highest mean MCE score ($M = 487.39, SD = 110.34$).

Children with a “dual identification” (identified with both a chronic illness and an educational handicap) had higher mean MCE scores ($M = 482.56, SD = 100.96$) compared to children with only a single identification. To add, children identified with a chronic illness but without identification of an educational handicap had the lowest mean MCE scores overall ($M = 457.85, SD = 99.86$).

Table 4.18

Mean MCE Scores by Illness and Educational Handicap

<table>
<thead>
<tr>
<th>Chronic Illness</th>
<th>Educational Handicaps</th>
<th>Mean MCE</th>
<th>SD</th>
<th>n (weighted)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>No</td>
<td>487.39</td>
<td>110.34</td>
<td>691</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>464.14</td>
<td>105.38</td>
<td>59</td>
</tr>
<tr>
<td>Yes</td>
<td>No</td>
<td>457.85</td>
<td>99.86</td>
<td>326</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>482.56</td>
<td>100.96</td>
<td>64</td>
</tr>
</tbody>
</table>
To examine differences of MCE scores after removing the effect of being identified with an educational handicap for children who are healthy and children who are ill, an Analysis of Covariance (ANCOVA) was conducted where educational handicap status (0 for unidentified, and 1 for identified) was used as a covariate. Table 4.19 summarizes the results from the ANCOVA analyses for illness and gender as the independent variables, MCE scores as the dependent variable and educational handicap status as the covariate.

The main effect of illness, gender and educational handicaps were not significant ($F(1, 1132) = .37, p > .05, F(1, 1132) = 2.94, p > .05, F(1, 1132) = .06, p > .05$, respectively). However, the effect sizes of these relationships were very small ($\eta^2 = .000$ for illness, $\eta^2 = .003$ for gender, and $\eta^2 = .000$ for educational handicaps). This effect size decreased (from $\eta^2 = .011$ to .000 for illness, and from $\eta^2 = .007$ to .003 for gender) compared to the first analyses where educational handicaps were not used as a covariate.

Table 4.19

Analysis of Covariance for MCE Scores, After Removing the Effects of Identification of an Educational Handicap

<table>
<thead>
<tr>
<th>Source</th>
<th>df</th>
<th>$F$</th>
<th>$\eta$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness (I)</td>
<td>1</td>
<td>.37(**)</td>
<td>.000</td>
<td>.545</td>
</tr>
<tr>
<td>Gender (G)</td>
<td>1</td>
<td>2.94(**)</td>
<td>.003</td>
<td>.087</td>
</tr>
<tr>
<td>Educational Handicap (EH)</td>
<td>1</td>
<td>.06</td>
<td>.000</td>
<td>.809</td>
</tr>
<tr>
<td>I $\times$ EH</td>
<td>1</td>
<td>4.25(*)</td>
<td>.004</td>
<td>.040</td>
</tr>
<tr>
<td>G $\times$ EH</td>
<td>1</td>
<td>.04</td>
<td>.000</td>
<td>.849</td>
</tr>
</tbody>
</table>

*p < .05. **p < .001.
The interaction effect between illness and the covariate (educational handicap) was significant \( F(1, 1132) = 4.25, p < .05 \). This unexpected interaction effect is very interesting. Among the children who did not have a physical (chronic) illness, children with educational handicaps tended to score lower, whereas among the children with a physical (chronic) illness, children with educational handicaps tended to score higher.

To What Extent Do Illness And EDA Variables Predict Children's MCE Scores, When Gender And Socio-Economic Factors And Community Type Accounted For?

To test the degree of association between a child's performance on the MCE test, illness and EDA, after gender, community type and household income were accounted for, a hierarchical (stepwise) regression analyses was conducted. Tables 4.20 and 4.21 summarize findings from the regression analyses.

In the first step, gender and household income were entered into the regression model. These variables were not significant predictors of MCE scores.

In the second step, community type (e.g., urban versus rural communities) was added to the model and resulted in a statistically significant R-square change, increasing the adjusted R-square to \( R_{\text{adjusted}}^2 = .03, F(3, 749) = 8.84, p < .001 \).

In the third step, illness was added to the model and there was again a significant R-square change, thus increasing the adjusted R-square to \( R_{\text{adjusted}}^2 = .04, F(4, 748) = 8.11, p < .001 \). In other words, approximately 4% of the variance is accounted for by gender, household income, community type and illness.

Finally, in the fourth step, EDA scores were added to the model, however the F-change was not statistically significant.
Model 3 appeared to be the best fitting model for this regression analysis. The standardized beta weights ($\beta_{\text{standardized}}$) in this step were the strongest for size-area of residence (community type) ($\beta_{\text{standardized}} = -.086$, $t(748) = -2.40$, $p < .05$) and illness ($\beta_{\text{standardized}} = .16$, $t(748) = 4.49$, $p < .001$). The negative relationship between MCE scores and community type suggests that children in rural communities have higher MCE scores compared to children from larger communities (communities with a population of 30,000 >), whereas the positive relationship between MCE scores and illness suggests that children with an identified illness have lower MCE scores compared to children with no identified illness(es). Illness and community type appeared to be the only statistically significant predictors of MCE, after accounting for gender, income and EDA scores. However, they are very weak predictors of MCE scores.

Table 4.20

Analysis of Variance for Hierarchical Regression Analysis for SES Variables Predicting MCE Scores Above and beyond the effects of Illness, Gender and EDA scores

<table>
<thead>
<tr>
<th>Model</th>
<th>df</th>
<th>$F$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>2.17</td>
<td>.115</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
<td>8.84</td>
<td>.000</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>8.11</td>
<td>.000</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>6.49</td>
<td>.000</td>
</tr>
</tbody>
</table>

*p < .05. **p < .001.
Table 4.21

Summary of Hierarchical Regression Analysis for SES Variables Predicting MCE Scores Above and beyond the effects of Illness, Gender and EDA scores

<table>
<thead>
<tr>
<th>Model</th>
<th>Variable</th>
<th>$R^2_{\text{Adjusted}}$</th>
<th>$\beta$</th>
<th>Standardized $\beta$</th>
<th>$t$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>(Constant)</td>
<td>.003</td>
<td>496.28</td>
<td></td>
<td>31.211</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td></td>
<td>10.85</td>
<td>.063</td>
<td>1.732</td>
<td>.084</td>
</tr>
<tr>
<td></td>
<td>Household Income</td>
<td></td>
<td>3.53</td>
<td>.047</td>
<td>1.280</td>
<td>.201</td>
</tr>
<tr>
<td>2</td>
<td>(Constant)</td>
<td>.030(**)</td>
<td>460.83</td>
<td></td>
<td>26.477</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td></td>
<td>8.35</td>
<td>.049</td>
<td>1.346</td>
<td>.179</td>
</tr>
<tr>
<td></td>
<td>Household Income</td>
<td></td>
<td>4.13</td>
<td>.055</td>
<td>1.517</td>
<td>.130</td>
</tr>
<tr>
<td></td>
<td>Community Type</td>
<td></td>
<td>9.84</td>
<td>.169(**)</td>
<td>4.696</td>
<td>.000</td>
</tr>
<tr>
<td>3</td>
<td>(Constant)</td>
<td>.036(**)</td>
<td>467.09</td>
<td></td>
<td>26.621</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td></td>
<td>7.37</td>
<td>.043</td>
<td>1.190</td>
<td>.234</td>
</tr>
<tr>
<td></td>
<td>Household Income</td>
<td></td>
<td>4.25</td>
<td>.056</td>
<td>1.567</td>
<td>.118</td>
</tr>
<tr>
<td></td>
<td>Community Type</td>
<td></td>
<td>9.41</td>
<td>.162(**)</td>
<td>4.486</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Illnesses</td>
<td></td>
<td>-16.02</td>
<td>-.086(*)</td>
<td>-2.395</td>
<td>.017</td>
</tr>
<tr>
<td>4</td>
<td>(Constant)</td>
<td>.035(**)</td>
<td>467.49</td>
<td></td>
<td>26.537</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td></td>
<td>7.61</td>
<td>.044</td>
<td>1.216</td>
<td>.224</td>
</tr>
<tr>
<td></td>
<td>Household Income</td>
<td></td>
<td>4.37</td>
<td>.058</td>
<td>1.590</td>
<td>.112</td>
</tr>
<tr>
<td></td>
<td>Community Type</td>
<td></td>
<td>9.34</td>
<td>.161(**)</td>
<td>4.459</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Illnesses</td>
<td></td>
<td>-16.04</td>
<td>-.086(*)</td>
<td>-2.397</td>
<td>.017</td>
</tr>
<tr>
<td></td>
<td>EDA</td>
<td></td>
<td>-.34</td>
<td>-.010</td>
<td>-2.76</td>
<td>.783</td>
</tr>
</tbody>
</table>

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

It is interesting to note that although there was a significant effect of gender across the ANOVA tests, gender did not come out as being a statistically significant in the regression models when combined with other predictors.
CHAPTER 5

Discussion

The numbers of children affected by a chronic illness has been steadily increasing over the last few decades, to the degree that the effect on children and families is regarded as the most serious issue in pediatric medicine (Hobbs, Perrin, & Ireys, 1985; Shaw & Paez, 2002). Despite the medical advancements prolonging the lives of chronically ill children, the educational and psychological effects of childhood chronic illnesses continue to be pervasive.

Most of previous research on effects of childhood chronic illnesses used small sample sizes and has mostly been conducted outside of Canada. The National Longitudinal Survey of Children and Youth (NLSCY) provides opportunities for examining such effects in Canada, using a large nationally representative sample. Previous research has systematically found that children with chronic illnesses do experience higher levels of educational and psychological problems. In particular, there has been substantial evidence that children with chronic medical conditions are at a higher risk for developing anxiety and experience more problems related to school adjustment and social interaction/development. The NLSCY contains a variety of data from measures of educational, psychological, and physical health that are all relevant to research on childhood chronic illnesses.

The primary purpose of this study was to utilize data from the NLSCY, collected by Statistics Canada, to investigate the extent to which children with an identified chronic illness had different mathematics achievement levels and whether they differed in their emotional/anxiety disorder compared to children who are healthy. A second goal of this study was to better understand whether higher levels of emotional/anxiety were associated with lower mathematics achievement. The third goal of this study was to better understand
what other types of factors, such as household income, community type, might predict mathematics achievement, over and above the effect of illness, gender and emotional health/anxiety.

The findings from this study are informative to build on the current state of research in this field. In some cases, the results were consistent with findings from previous research literature. For example, the findings from the current study demonstrated that children who had even one identified chronic illness (asthma, bronchitis, heart condition, epilepsy, cerebral palsy, kidney condition, or other long-term condition), had poorer performance on the MCE test compared to children who were unidentified with an illness. However, other findings were divergent from past literature. For example, children who are ill were not found to have higher rates of emotional disorders and anxiety, and factors such as household income and emotional disorders and anxiety did not seem to have a strong effect in predicting math achievement.

A summary of each of the four findings and how these findings build on past literature will be discussed. Following this, limitations and future directions specific to each of the findings will be highlighted, and general implications of the findings, including theoretical, research and practical implications will be discussed to better understand how the findings have extended our knowledge in this current field. Finally, the chapter will conclude with general limitations of the study and future directions to consider, specifically, issues related to research design/internal validity, external validity/generalizability, statistical analyses/power and measurement.
Summary and Discussion of Findings

Explanation of Findings for the Educational Effects of Childhood Chronic Illnesses

In the first research question, it was hypothesized that children with an identified illness would have poorer performance on the MCE test compared to their healthy peers. The analysis demonstrated that there were indeed statistically significant differences between groups of children who are identified with an illness, and children who are not identified with an illness on their MCE scores. Therefore, this finding rejects the null hypothesis that the two illness groups are the same.

In order to rule out the possibility that performance on the math test may be further affected by children having mental handicaps, learning disabilities, attention deficit or emotional disorders, these difficulties were controlled for, however differences in performance on the math test across the two groups of children (illness and no illness) continued to hold true.

This main finding is consistent with previous reports in the literature that have found that most academic problems are in areas that require students to achieve a level of mastery in the particular skill, prior to learning subsequent skills and knowledge, as it is the case in learning mathematics (CPS, 1994; Fowler et al., 1988; Kaemingk et al., 2004; Paone et al., 1998; Seidenberg et al., 1986). Past researchers have suggested that this difference in academic performance can be attributed to children missing more school days due to their illness compared to their healthy counterparts (Sherman, 1995). Essentially, by attending fewer school days compared to their healthy peers, children with illnesses are missing out on critical learning opportunities, as well as the opportunity to master core skills (e.g., basic...
addition and subtraction) that are required to progress onto more advanced skills (e.g., multiplication and division).

Unfortunately, the data concerning absent days (and reason for these absent days) that were made available in the NLSCY dataset were not informative, as it was unclear how many of the specified absent days were a result of health factors versus other reasons such as family vacation, bad weather, transportation problems, etc. This is an area worth exploring in the future with more refined methods of measuring days absent and reasons for days absent.

The findings regarding this first research question has implications for children living with a chronic illness, as well as for individuals working with such children in educational settings. In particular, the findings inform us that children with identified chronic illnesses tend to perform poorer in math measures compared to their healthy peers. Thus, it is necessary in future research to explore intervention programs to target these discrepancies in math achievement for children with illnesses.

The effect of gender was also found to be related to mathematics performance. Given that there were equivalent numbers of males and females in the sample, this difference cannot be attributed to a difference in the sample size.

**Explanation of Findings for the Psychological Effects of Childhood Chronic Illnesses**

As part of the second research question, it was hypothesized that children with an identified illness would report higher scores on the EDA scale compared to their healthy peers. The findings revealed that illness did not have a statistically significant main effect on EDA scores. Thus, the findings did not provide evidence to support a relationship between illness and symptoms of anxiety and emotional disorder.
In terms of the effect of age on EDA scores, the findings from this study showed that there were significant differences between the three different age groups, children 10-11, 12-13 and 14-15. The findings are difficult to interpret given that children who are 12-13 years appear to score lower on the EDA scale compared to children who are 10-11 and 14-15. The effect of age on how children rate themselves on symptoms related to anxiety was interesting to consider, however, there has already been robust evidence showing the relative consistency in prevalence rates for anxiety disorders across childhood (Albano et al., 2003; Curry, March, & Hervey, 2004; Kessler et al., 2005; Mash & Wolfe, 1999).

Though these findings help build on the current understanding of how age, gender and illness contribute to a child’s report on a measure of emotional/anxiety, these relationships must be further researched in the future to better understand the interactions among these variables. It is also important to note that all of the identified statistically significant effects had very small effect sizes. Therefore, even though the findings point to systematic effects, these effects were not identified to be at a level that was of practical meaning and consequence. This is not to say that these effects should be ignored, since these small effect sizes could be due to a number of limitations of the study that will be discussed later on in this chapter.

**Emotional Disorder-Anxiety As a Moderating Variable for Mathematics Achievement**

When EDA scores were used as a covariate to examine whether controlling for the effects of emotional disorder and anxiety would have an effect on the relationship between illness and mathematics achievement, the results did not provide evidence to support for such a moderating effect. This meant that the emotional disorder and anxiety did not have a
confounding effect on chronic illness and differences in achievement could be attributed to the illness.

**Educational Handicaps as a Moderating Variable for Mathematics Achievement**

The results did not provide supporting evidence for educational handicaps (mental handicap, learning disability, attention deficit or emotional disorder) having a moderating effect on achievement. Thus, we were able to rule out educational handicaps being a confounding factor with chronic illness and the lower achievement scores for the chronic illness group could be attributed to the illness itself.

It is noteworthy that there was an interaction detected between illness and educational handicaps. This suggests that the patterns of differences in MCE scores among illness groups varied for different educational handicap groups. While children with illnesses scores were higher for children with handicaps, the reverse was true for children without illnesses.

**Predictors of Mathematics Achievement**

The final question for this study was to investigate the degree of association between mathematics achievement and gender, family household income, community type the child lives in, and chronic illness. The findings indicate that although the 4 independent variables (gender, income, community type and illness) are statistically significant predictors of MCE, they are very weak predictors of MCE scores.

The regression analysis showed that the “best fitting” model was the one where household income, gender, community type, and illness were used as predictors; 4% of the variance could be explained by these four predictor variables. In this model, community type contributed the most to the overall model in predicting MCE scores. The second variable of considerable strength to the model was illness. However, the results indicated that there are
other factors that are affecting a child's performance on the MCE test at a much greater degree (would account for 96% of the variation in achievement) above and beyond the effects of income, gender, community and illness.

These findings provide information to the current literature, in particular, adds to research conducted with Canadian children. To date, there have been no published articles with Canadian children, looking at the effects of physical and mental health on educational outcomes. Thus, even the findings that these child background variables are not strong predictors of achievement is important information in understanding and interpreting the effect chronic illnesses may have on children, in particular their education.

**General Implications of Findings**

The findings from the current study provide theoretical, research and clinical implications for individuals who work with children with chronic illnesses, as well as the families where there are children with a chronic illness. Given that this line of research is still in its infancy, the use of large-scale data, like the NLSCY, can provide exploratory information to gain better insights in an area with dearth of research.

**Theoretical Implications**

One of the most important contributions of this study was to knowledge about the effects of illness on children's academic achievement. Several theories underlie this research project: a) Children with illnesses perform weaker in school; b) Children with illnesses experience a higher level of anxiety; and c) Children with illnesses experience a higher level of anxiety, which then in turn, impacts their performance on achievement tests; and d) Additional factors, like income, and community type also contribute to a child's overall performance in school.
It is not practical to say that our findings confirmed these theories; rather, the findings provided valuable insight to better understand the role of chronic illness and anxiety on learning as demonstrated by performance on a math test. In addition, the study provided insights about the strengths and limitations of the NLSCY in measuring such variables.

**Research Implications**

The core research implications of this study have to do with measurement issues of the NLSCY variables. To reiterate, this type of large-scale longitudinal assessment is necessary to provide information about how children make their way through to adulthood, by looking at physical and psychological health and educational achievement in Canadian children. To add, the breadth and depth of sampling in the NLSCY lends itself to be an effective research tool, especially for research in need of pilot data.

What is important for researchers to do in the future is to ensure that effect sizes for all analyses are included in their results, given the large sample sizes. As well, it is important to be cautious about the measures that are used in the NLSCY. Although there was considerable time and effort put into developing the questions in the NLSCY by panels of experts, the magnitude of a Canada-wide longitudinal study is subject to time and economical constraints. As a result, it would not be feasible to measure every concept extensively. Thus, the scales that were developed capture a general concept of interest, and are not fine grained enough for diagnostic purposes in clinical and applied settings.
Clinical and Applied Implications

The primary purpose of this type of research is to increase the health-related quality-of-life in children with chronic illnesses, as they are living longer and healthier lives than ever before. Given the increasing numbers of children with chronic illnesses attending schools, researchers and practitioners need to understand how such illnesses affect children.

Issues concerning a child’s psychological well-being and school success are becoming pervasive issues due to the increased medical and technological advances that are increasing the life-span of children with illnesses, and allowing many of them to attend schools. So far, research has been able to demonstrate that children with illnesses are having more difficulty functioning in schools and in daily life, and this may be related to the level of anxiety a child experiences due to their illness. However, the results of the current study did not support these past findings. Given the pathogenesis of anxiety disorders in the general population, it is important that this mental health concern is addressed in its early stages so that subsequent mental and physical health problems can be curtailed. This is especially important in vulnerable populations, such as children with chronic health conditions, as their risk for developing other mental health or educational problems are magnified from living and coping with a chronic illness.

Another implication of this research is on understanding the effect of anxiety and stress on illness. This is especially important, because research with adult populations have found that individuals with higher levels of psychological stress have been found to be more susceptible to illness (compromised immune system) (Cohen, Tyrrell, & Smith, 1991). Thus, it is vital to continue this line of research in the future in hopes of improving health outcomes for children with illnesses who experience high levels of anxiety.
There are also implications for educators of children with illnesses. In particular, educators need to be more sensitive to working with children with illnesses as the numbers of children who attend schools continue to grow. As well, educators need to learn to be more sensitive to anxiety symptomatology, and not confuse these symptoms with other effects of the illness (e.g., side effects of medication), so that children can be referred on to a mental health professional as soon as possible.

Also, when measuring children on achievement measures, educators need to understand the impact of a chronic illness on a child’s performance on such tests. As previously mentioned, there can be both primary and secondary effects that may impact a child’s performance on these measures.

Finally, these findings have implications for treatment and intervention for children with chronic illnesses. Aside from addressing physical health concerns in children with chronic illnesses, educational concerns also need to be addressed. Given that children with illnesses are living longer and healthier lives, it is important to provide these children with tools to facilitate their development into productive members of society. Research concerning educational intervention programs must be researched so that secondary effects of these chronic illnesses can be curtailed early on.

**General Limitations of Study and Future Directions**

There are several limitations of the current study that need to be highlighted, specifically related to survey methodology and design.
Measurement

Measures of illness.

The main limitation of the NLSCY dataset in addressing the research questions in this study is the way in which the illness variable was measured and operationalized. Specifically, the NLSCY lists a subset of illnesses that are commonly found in children (e.g., asthma, diabetes, cerebral palsy, etc.), however, this list is not exhaustive. In other words, children with cancer, blood disorders (e.g., HIV/AIDS, sickle-cell), gastrointestinal disorders, would be aggregated into the “other long term condition” variable. Thus, resulting in a “cloudy” measure of illness.

Another problem with the measure of illness is the response format of these illness variables. The Person-Most-Knowledgeable (PMK) about the child were asked to identify the presence or absence of an illness by checking off “Yes” or “No” to the question: “Does the child have (illness)?” Given that there were no questions to follow-up on the severity and frequency of these illness(es), children with varying degrees of illness are categorized into one group. Thus, children with mild forms of asthma are treated the same as children with very severe forms of asthma.

Aggregating children with varying grades of an illness into one variable can present problems in interpreting and understanding the results. Past research literature has found that children with more serious types of chronic conditions show more frequent interruptions to daily functioning and perform poorer on academic achievement measures compared to children with milder variants of the same illness. Hence, it would have been useful to know the severity and frequency of each of the chronic illnesses so that the relationship between the severity and frequency of illness on academic achievement can also be examined.
Another problem with aggregating children with any of the seven illnesses into one category is that children with varying illnesses were treated equally. Given the different educational and psychological outcomes found for children with different types of illnesses, aggregating all children with any illness into one category increases the variance in the group. In other words, there may have been a stronger effect of illness on MCE scores, and illness on EDA scores detected if individual groups of illnesses were measured separately. As well, analyses of between-group differences could have been assessed.

**Mathematics computation exercise test.**

One of the original goals of the study was to research the effect of illness on academic achievement as well as on cognitive functioning. However, the MCE test was the only measure of achievement that was available for the age group of interest (10 to 15 years old) as these children are the only ones who completed both the MCE test and the EDA scale.

Other measures that were used in the NLSCY, such as the *Peabody Picture Vocabulary Test (PPVT)* (measure of receptive vocabulary) (Dunn, Dunn, Robertson, & Eisenberg, 1981), and the cognitive functioning test, could not be used in the current study. For example, the PPVT was only administered to children 2 to 3 years old (where EDA scores were not collected) and the cognitive functioning test was only administered to adolescents/adults 17 to 19 years old. Thus, the MCE test score was the only measure of achievement that could be used to capture a child’s academic achievement, where EDA scores were also collected, and a report of illness by the PMK.

As a result, the dependent variable in this study, MCE scores, is based on performance of mathematic computation. However, it is important to note that this measure is not a global measure of achievement, which usually consists of reading, writing, oral
language and mathematics (Kaufman & Kaufman, 2004; Flanagan, Ortiz, Alfonso, & Mascolo, 2006). To add global math achievement measures usually comprise of math computation (calculation) and problem solving. Both of these subcomponents assess achievement and math knowledge, however, math calculation additionally measures number facility, and problem solving additionally measures quantitative reasoning. This means that the MCE test is essentially a measure of math achievement, knowledge and number facility, whereas it does not measure quantitative reasoning.

Also, the MCE test is comprised of a subset of the math questions asked in the Canadian Achievement Test (CAT) in which it was derived. The CAT was originally designed to be administered and interpreted as a global achievement measure. In the case of the NLSCY, the math component of the CAT was extracted from the battery and used as a “stand-alone” measure of math achievement. Thus, the psychometric properties for this individual subtest are unknown (both reliability and validity), and the use of and interpretation of the MCE scores must be cautioned as it is not a global measure of academic achievement.

**Emotional disorder-anxiety scale.**

The EDA scale is used to measure Emotional Disorders — Anxiety (EDA) in the NLSCY, and in the current study, the EDA scale is used to represent “psychological problems”. Although the items were derived out of a sound theoretical and conceptual model (items were drawn from the Ontario Child Health Study [OCHS]) the scale is based on empirical findings (factor analysis), which may not necessarily be supported by theory. This is very different to standardized measures such as the *Multidimensional Anxiety Scale for Children* (MASC) (March, 1997), the *Revised-Children’s Manifest Anxiety Scale* (RCMAS)
(Reynolds & Richmond, 2000), or the State-Trait Anxiety Scale for Children (STAIC) (Spielberger et al., 1973), which were developed after careful examination of other anxiety measures in children, adolescents and adults. As well, these standardized tests measure various domains of anxiety, and demonstrate sound psychometric properties and.

To add, such scales generally undergo an extensive test of reliability and validity, and selection of items for the measure is based on evidence for reliability (e.g., internal consistency, test-retest reliability) and validity (criterion, construct, and concurrent) (Spielberger et al., 1973). As well, item development may also be based on the DSM-IV criteria for anxiety disorders and have a clear operationalized definition of the construct of interest (anxiety) (Spielberger et al., 1973).

Another problem with the EDA scale is the number of items used to measure “emotional disorder – anxiety” in children. The EDA scale is comprised of 7 questions that are believed to measure anxiety disorders in children and adolescents. On more popular standardized measures of anxiety, the number of items generally ranges from 20 items (STAIC) to 39 items (MASC). Thus, the use of only 7 questions to measure anxiety may not be sufficient enough to measure anxiety reliably and validly. However, due to the scope of the NSLCY, it is understandable that it would not have been feasible to administer scales that are over 20 items each.

Another problem with the EDA scale has to do with the dimensions of anxiety disorders. The dimensions measured in the RCMAS are: physiological manifestations of anxiety, worry and over-sensitivity, and fear/concentration. For the MASC, the dimensions measured are: physical symptoms, harm avoidance, social anxiety and separation/panic. Finally, for the STAIC, the scale differentiates between how children feel at a particular point
in time, and how children generally feel. Thus, given that the EDA scale is made up of 7 questions that purport to measure the wide array of dimensions found to measure and correlate highly to anxiety, it is unclear which of these dimension(s) the EDA scale measures.

Although the name of the EDA scale: “Emotional Disorder – Anxiety” implies that a high score on this scale would equate to a child having an emotional and/or anxiety disorder, it is important to note that the purpose of the scale is not to diagnose or identify children with an emotional and/or anxiety disorder. Despite the reliability (internal consistency) of the EDA scale for Cycles 4 and 5 were quite high ($r = .736$, and $r = .981$, respectively), this scale may not be a very sensitive measure of emotional or anxiety disorders, thus, may not have the diagnostic capacity to identify such disorders. To add, some questions may actually be more appropriate as a measure of negative affect or depression, such as the question: “I cry a lot”. However, because this question is part of the EDA scale, it infers that children who cry a lot are also high on emotional disorders – anxiety.

For the purposes of the current study, the scores on the EDA scale provided insight as to a child’s sadness/mood, fear, nervousness, worry, and anhedonia (loss of interest) at the time of testing, as opposed to a true indication of an emotional and/or anxiety disorder. Finally, given that the data collection for the NLSCY occurs every two years, the EDA report is ultimately a report of anxiety at that particular point in time. Without measures over different points in time, it is unclear whether the EDA reports are representative of children’s feelings at the time of measurement (state) or in general (trait) (Spielberger, 1973).

Another limitation of the EDA scale is that items are self-reported by children. Although parent reports of the EDA scale are collected for children up to 10/11 years, the current study looked at children from 10 to 15 years, thus the parent reports could not be used
in the analyses. For children 10 to 15 years, the NLSCY only inquired with the PMKs on the amount a child worries about death in the family, worries about divorce, etc., data which was not appropriate to use in the current study.

Two potential problems in relying on a single measure are the reliability and validity of the self-report. In terms of validity of test results, children could potentially "fake good" and report positive responses on the anxiety measure to please the researcher or out of fear that his/her parent may see the results. Alternatively, children may have been tired of the long battery of tests that were administered, thus started randomly responding to the items. Given that there was not an inconsistency index (or a "Lie" scale), it is hard to decipher the validity of the responses.

As well, it is unclear what the child's reading ability/level is, thus, the use of the EDA scale assumes that the child is able to read and comprehended the questions being asked. Only children over the age of 10 years old were used in the analyses given the potential problem of younger children not having the reading ability to understand the questions, cognitive capacity to understand the questions being asked, or having the level of introspection required for a self-report of anxiety symptoms. Given the weaker performance on the MCE test in children with a reported illness, there may have been problems in comprehending and validly responding to the questions being asked in the group of children with an illness, hence affecting the results.

Overall, if the EDA scale is subject to too many psychometric problems, the measure may not have been sensitive enough to detect true symptoms of anxiety in the sample of children included in our analyses. Perhaps symptoms of anxiety do have a large effect in children with chronic illnesses, however, without a multi-method assessment approach and a
sound measure of anxiety, these effects may not have been detected between groups of children identified with and without a chronic illness. The current analyses did not capture these differences systematically.

**School absence days.**

Although data concerning school-absence days were collected as part of the NLSCY dataset, this variable was not particularly useful in our analyses as it was presented as a range of the number of school days a child missed in the past school year (e.g., 1 to 3 days, 4 to 6 days, etc.). As well, there was a separate variable asking the PMK about the child, the reason why children missed these school days. However, there was no way to link the number of school-absence days to the reasons school was missed. Thus, it was unknown how many of the school-absence days were due to weather, transportation, a family vacation, a fear of school, or health reasons. Finally, the category of "health reasons" included both illnesses and injuries, thus there was no way to decipher the exact health reason as to why the child missed a school day.

Although these two variables (school absent days and reason for school absence) are informative on a qualitative level, neither variable was appropriate to include in the statistical analyses. The visual inspection of the analyses, however, was not able to confirm the notion that children with chronic illnesses miss more sickness-related absence days compared to children without an identified illness. In fact, it appears that children without identified illnesses have more illness-related school absences (81.5%) compared to children with an identified illness (45.8%). Due to the shortcomings of the data investigating school absent days and reasons for school absences, future research should investigate this relationship so
that we are better able to understand the extent to which missing school affects learning, which then impacts performance on academic achievement tests.

**Primary and secondary effects of illness.**

Another problem with the data was that it remains unclear whether group differences in MCE scores were associated with the primary or secondary effect of their illness. For example, there was no way to determine whether a child’s performance on the MCE test was due to the primary effect of the chronic illness (e.g., difficulty breathing), or to the secondary effect of the illness (e.g., a child not having enough sleep the night before because of difficulty breathing, thus affecting his/her concentration), or both. However, there was no way to gauge such effects using the NLSCY dataset.

**External validity and generalizability.**

An issue worth noting that concerns the generalizability of the results is that there were no valid reports of illness for children living in Nunavut, the Yukon Territories or the Northwest Territories in the unweighted sample. Even though, the NLSCY is a nationally representative sample of Canadian children, the way in which the variables were measured restricts the generalizability of the findings. Thus, despite weighting the cases, children from Nunavut, the Yukon and Northwest Territories are not represented in our analyses.

As well, there were no children with a report of “Yes” to the chronic conditions of Cerebral Palsy or Kidney Condition who had a valid MCE and EDA score. This is interesting given that we know that the prevalence rate of these two conditions is not zero. In effect, this would deflate our sample of children with chronic conditions.
The key limitation of findings is the very small effect size for all of the statistically significant effects of factors such as illness and gender. All of the measurement limitations discussed above are expected to contribute to low possible low effect size even when larger, true effects are present. For example, the degree to which illness groups can be compared is critically dependent on whether these categories in the data refer to distinct groups and that this distinction is tied to the degree of illness. In addition, in order to examine the effects of illness on school learning, the measurement of achievement needs to be tied to school learning. The brief (20 questions) mathematics achievement test that focuses on a narrow set of mathematics skills would be expected to be a limited measurement of school learning at best.

**Specific Research Needed to Clarify or Extend Findings**

**Measures of illness.**

When measuring health/illness, it is important to employ multiple measures of health. For example, a more comprehensive list of common childhood chronic illnesses needs to be included, such as Cancer, Diabetes, Juvenile Rheumatoid Arthritis, Cystic Fibrosis, Gastrointestinal Conditions, Blood Disorders (i.e., Hemophilia), and Infectious Diseases (i.e., HIV/AIDS). A multi-method assessment approach would be important to employ when measuring the presence, severity and frequency of an illness. Not only should the parent provide a report of the child’s illness, but also other subjective (child self-report, daily diaries) and objective reports (physician) need to be collected. Also, other objective measures of health (e.g., blood test results, etc.) would be important to measure based on the research question asked.
A set of such objective and subjective measures of health would be very informative to researchers and practitioners so that they are better able to understand the effects of an illness on a child's daily functioning as well as their mental health and educational achievement. Additionally, these types of information would provide some insight to the within group differences of children diagnosed with an illness.

Aside from the use of reports from the child/youth, parent, physician and other test results, it would be very informative to obtain reports from the child's teacher(s), so that there is another source of information regarding the effect of an illness on a child's functioning at school. In addition to asking teachers about a child's illness/physical functioning at school, teachers can also be asked about a child's academic achievement and psychological well-being.

Given that teachers interact with the child on a daily basis, she/he would be able to provide insight as to the child's behaviour and performance in school. These supplemental reports from physicians and teachers would provide a better insight to the variables of interest, although, would pose as an economic constraint to the project and extra burden to teachers working with children with illnesses.

It is also imperative that future research focuses on the extent to which anxiety affects the healing of an illness (e.g., removal of tumors) or how a child's immune system can be compromised (e.g., the frequency of a child getting bronchitis, or coping with HIV/AIDS), given findings demonstrating a strong relationship between stress and physical illness in adults (slowing of wound healing and weakening of the immune system) (Cohen et al., 1991; Kiecolt-Glaser, Marucha, Balarkey, Mercado, & Glaser, 1995).
Measures of academic achievement.

A larger battery of achievement measures (or a global achievement measure) should be used in future research instead of only one subtest of a global achievement measure. For example, standardized measures of global academic achievement (e.g., Kaufman Test of Educational Achievement, 2nd Edition, [KTEA-2] [Kaufman & Kaufman, 2004]), that have demonstrated sound psychometric properties should be employed, so that achievement scores are better representative of a child's overall academic achievement.

As well, measures of achievement should be supplemented with cognitive measures and other qualitative data such as clinical interviews and observations thus providing a more comprehensive look on a child's difficulty with the MCE test. Although the use of a global achievement battery (such as the KTEA-2) would not be practical in large-scale assessments like the NLSCY (due to the training and administration time of these measures), it is important for the results of this study to be replicated using more sound measures of achievement.

Additionally, it would be very important to include measure of cognitive functioning, given the emerging literature looking at the effects of illnesses on a child's cognitive ability (e.g., deficits with processing speed, memory). Such a robust measure of ability and achievement would provide us with more information about how chronic illnesses affect children.
Measure of anxiety.

Although the EDA scale was a useful tool for looking at anxiety in children sampled for the NLSCY, the scores on the EDA scale are probably not sensitive enough to detect true emotional disorders or anxiety disorders. Future research examining the effect of anxiety must utilize a multi-method assessment approach that incorporates both objective (e.g., clinical interviews, observations, parent- and teacher reports) and subjective (e.g., self-reports, daily diaries) measures of anxiety. In particular, anxiety measures that should be used are ones that are standardized and ones that demonstrate sound psychometric properties (reliability and validity), such as the MASC (March, 1997), the RCMAS (Reynolds & Richmond, 2000), or the STAIC (Spielberger et al., 1973) which are designed to measure anxiety in children and adolescents.

These self-reported checklists should also be supplemented with clinical interviews of the child, as well, include reports from teachers and parents on a child’s anxiety. Another approach to measure anxiety in children is the use of daily diaries where children report daily feelings of worries and fears. This would provide an idea about whether anxiety is a state or trait of the child, as well, would provide information about a child’s level of anxiety at multiple time-points. By using a multi-method assessment approach, a child’s anxiety score would be a more valid and reliable representation of a his/her actual level of anxiety.

Gender and age effects.

The findings related to gender differences also warrant further research, because if it is indeed true that chronic illnesses (or certain types of illnesses) impact females differently than males, intervention programs must be designed to address such gender differences in academic settings. Also, because this study did not differentiate between children with
different types of illnesses (e.g., asthma versus diabetes versus kidney conditions), it is uncertain whether there may be gender differences between groups of children with varying illness “profiles” (e.g., a child with asthma, a child with asthma and diabetes). There is a need to replicate the current findings with more sensitive measures of illness and anxiety so that we are better able to make better sense of the results.

In terms of the findings concerning the effect of age on EDA scores, other qualitative measures need to be incorporated in measuring anxiety so that there can be a more comprehensive understanding of why older children experience higher levels of anxiety compared to younger peers, as well, to understand differences between males and females in their reports of anxiety. Questionnaires concerning the particular illness, how much education a child has received about treatment, management and pathology of their illness, social support, and magnitude of the primary and secondary effects of their illnesses (i.e., self-esteem, socialization) must be explored. With a more comprehensive set of qualitative information, we will be better able to explain why older children may report more symptoms of anxiety compared to their healthy peers, and why females and males may report different levels of anxiety.

Although it was hypothesized that children with no reported illness, regardless of age and gender, score lower on the EDA scale compared to children with one reported illness, it was interesting to find that the highest and lowest EDA scores were found among males 12 to 13 years-old. The effect of illness on age and gender need to be more extensively explored in the future to better understand patterns of emotional problems related to anxiety for males compared to females, across different ages. The results from the current study revealed mixed results that are difficult to interpret. A potential reason for the mixed findings of age
and/or gender on EDA scores could be due to the sensitivity of the EDA measure. Given that past research has found that anxiety disorders are positively associated with age, and that females report higher levels of anxiety, the effect of age and gender warrants further research.

**Primary and secondary effects of illness.**

To address issues concerning the relationship between effects of an illness and performance in school, future research should utilize self-reports and daily diaries to monitor the primary and secondary effects of an illness so that we are better able to understand the effect(s) of illness on learning. Thus, children will be able to report on their subjective experiences in how an illness appears to affect their performance in school.

**Measures of community type, household income, etc.**

Given the mixed findings concerning SES and school achievement and mental health outcomes, there was reason to believe that household income would help predict achievement scores. However, this effect was not found in the current study. In the future, other variables that may affect school achievement and mental health outcomes, such as ethnicity, parental income, mental health history, should be considered.

**Conclusion**

The prevalence of children with chronic illnesses is increasing as a result of improved health care and services. For children with a chronic illness, the prevalence of psychological problems (i.e., anxiety disorders) and educational problems are nearly double in comparison to the general population. These trends require us to ensure that the educational and psychological effects of their illness are understood and addressed.
This line of research is important to provide information about the educational and psychological outcomes of children with illnesses. By understanding such associations, researchers and practitioners will be more capable of providing tools to help children with illnesses increase their quality-of-life.

Despite the array of limitations highlighted in the current study and the small effect sizes detected in the statistical analyses, the secondary use of the NLSCY dataset was very informative as a research tool. The data provided us with a wealth of information in researching an area that is still in its infancy. Future studies should be directed to replicating these findings with improved methods of collecting information about a child’s physical and psychological health status. As well, improved methods of measuring children’s academic achievement and cognitive functioning in such large-scales studies are warranted.
References


Appendix A: Guide for Researchers under Agreement with Statistics Canada

Statistics Canada Research Data Centres (RDCs)

Guide for Researchers under Agreement with Statistics Canada

October, 2005
PREFACE

This guide applies to researchers working under contract to the federal department Statistics Canada accessing data in the Research Data Centres (RDCs) located at universities throughout the country. The RDC Program intends for this guide to assist researchers working or who plan to work in an RDC as well as summarizing the role of the RDC staff, so that researchers understand all facets of the RDC.

The guide is organized as follows:

- **Chapter 1:** Introduction to the Research Data Centres and the general application process for accessing the centres.

- **Chapter 2:** Procedures to follow at each phase of the research process, starting from the project proposal to submission of the final product.

- **Chapter 3:** Describes the procedures for protecting the confidentiality of respondents in statistical output. And, explains how to remove statistical outputs from the RDC.

- **Chapter 4:** Provides website addresses if researcher requires additional information.

- **Appendices** providing more detailed information on some of the guidelines for disclosure analysis, proposal and research paper guidelines and contract information.

*Any comments or questions can be directed to the RDC staff or you may contact:*

Dr. Gustave Goldmann, RDC Program Manager Room 1710 Main Building Tunney’s Pasture Statistics Canada Ottawa, ON K1A 0T6 Phone: (613) 951-1472 Fax: (613) 951-4942 Email: rdc-cdr@statcan.ca
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CHAPTER 1 - INTRODUCTION TO THE RESEARCH DATA CENTRES AND APPLICATION PROCESS

1.1 Background

Decision-makers need an up-to-date and in-depth understanding of Canadian society to help them respond not only to today's needs, but to anticipate the needs of tomorrow as well. This need underlies the growing demand for analytical output from the rich sources of data collected by Statistics Canada.

The Research Data Centres (RDC) program is part of an initiative lead by Statistics Canada, the Social Sciences and Humanities Research Council (SSHRC) and a university consortia to help strengthen Canada's social research capacity and to support the policy research community.

RDCs provide researchers with approved access, in a secure university setting, to microdata from population and household surveys. The centres are staffed by Statistics Canada employees. They are operated under the provisions of the Statistics Act in accordance with all the confidentiality rules and are accessible only to researchers with approved projects who have been sworn in under the Statistics Act as 'deemed employees.'

RDCs are located throughout the country, so researchers do not need to travel to Ottawa to access Statistics Canada microdata.

Each Research Data Centre (RDC) employs an RDC Analyst who would be happy to advise you during the preparation of your proposal. The Analyst can assess your proposal to determine whether the required elements are present. The Analyst can also advise whether your project is appropriate for access to the detailed microdata. Also, the RDC Analyst can provide you with information about conducting research in the RDC environment and the data holdings of the RDC.

Please contact your local RDC Analyst for more information.

You may also find it helpful to access documentation for the surveys located on the Research Data Centre’s website:

- http://www.statcan.ca/english/rdc/whatdata.htm
- or read about tips on proposal writing located at http://www.statcan.ca/english/rdc/apply.htm or http://www.statcan.ca/english/rdc/apply.htm#guides)
1.2 Research Data Centres: Application Process

Any researcher (or team) from academic organizations with legitimate research interests related to public policy development is eligible to apply to the RDC program. The detailed microdata kept by Statistics Canada in an RDC are protected under the Statistics Act. Only employees or deemed employees of Statistics Canada may have access to these data. A process has been established to permit academic researchers with approved proposals to work with these data. Researchers must become deemed employees of Statistics Canada and produce a research paper that follows the Statistics Canada mandate (Statistics Act sections 3, 19, 20, 22).

To be granted access to the RDCs, a researcher must submit a research project proposal to SSHRC for peer and institutional review, undergo a security evaluation, and take an oath promising to protect confidentiality. The proposed project, once approved, will be the basis of a contract between the researcher and Statistics Canada.

1.2.1 Research Proposal

Research proposals are submitted to an adjudicating committee operating under the auspices of SSHRC and Statistics Canada. It is done electronically by accessing the submission form on the SSHRC website:

http://www.sshrc.ca/web/apply/application/rdc_application_e.asp

Researchers must submit a separate proposal for each new project that they wish to carry out in the RDC. In the case of significant changes in scope of the approved project, researchers may be asked to re-submit another proposal incorporating the changes.

To apply for RDC access, you also obtain personal security clearance from Statistics Canada (refer to the section Security Clearance Procedures).

SSHRC invites applications from individual researchers or research teams led by a principal applicant. The principal applicant is responsible for submitting application forms on behalf of the team.

Applicants must complete the Web-based CV (https://webapps.nserc.ca/sshrc/logon_ciss_e.htm) and application forms and include the attachments listed below. Before you begin your on-line application, please ensure that you have prepared all required attachments. These attachments include research contributions (maximum five pages) and the Project Proposal (maximum five pages).

To ensure a swift review of your proposal, applicants are encouraged to include all elements of the Project Proposal Template.
1.2.2 Approval of proposals based on four criteria

- scientific merit and viability of the proposed research;
- viability of the methods to be applied—the data to be analyzed;
- demonstrated need for access to detailed microdata; and,
- expertise and ability of the researchers to carry out the work..

1.2.3 Project Proposal Template

The Project Proposal is a maximum of five pages and must include the following:

- Title of the Project
  - The project title
- Rationale and objectives of the study
  - Clearly identify the specific questions or objectives of the project
  - State how the research will contribute to the knowledge in the field of study
- Proposed data analysis and software requirements
  - What is the proposed statistical methodology? How is it suitable for this project?
  - What software will you use?
- Data Requirements
  - An explanation of why access to the confidential data (as opposed to public use microdata files) is necessary.
  - Which survey file/files or cycles are to be used?
  - Provide a statement that the confidential data file(s) identified is (are) in fact suitable for the proposed research.
  - What is the specific population of interest in the required data set(s)?
  - What are the variables to be used?
- Expected project start and end dates
  - Expected project start and end dates
- References
  - Sources used to cite your quotes used in the proposal or for specific analytical methods employed

1.2.4 Granting Access to an RDC for students

Access will be granted based on the nature of the proposal. For example if a proposal requires analysis of cross-sectional data sets this would not on its own be considered in depth enough to warrant access to RDC data.

In general, students listed as either principal or co-investigators on proposals (for thesis or dissertation research) should include in their application a letter of recommendation from their supervisor stating that they are capable of utilizing statistical software such as SPSS, STATA, or SAS and that the supervisor will be an active member of the research team supporting the student throughout the process.
Students are to send a copy in electronic format to lle@sshrc.ca, and a signed hard copy to:

Luc Lebrun, C/O SSHRC
RDC Program Officer
350 Albert Street
P.O. Box 1610
Ottawa, Ontario K1P 6G4

1.2.5 Masters degree students

Master degree students can apply as Principal Investigator (PI) or co-investigator, but their supervisor must be part of the research team and be included on the contract.

1.2.6 PhD students

All PhD students who request access to the RDC must include their Academic Advisor as the co-investigator on their research team.

1.2.7 Undergraduate Students

Access will only be granted to Honour's year undergraduate students. The Academic Supervisor/Advisor must be the Principal Investigator of the research team in order to grant access. The student then becomes a co-investigator (the PI does not necessarily have to access the RDC and can leave this data research solely to the student).

1.3 Proposal Review Process

The formal review process is coordinated by SSHRC. A three-member peer-review committee selected by SSHRC and Statistics Canada is formed for each proposal submitted. Two of the peers are from academic institutions with expertise in the field of the proposal. The third member is chosen from Statistics Canada.

The committee evaluates each proposal based on its scientific merit and recommends to Statistics Canada whether or not the project meets the established criteria (refer to the criteria outlined above). As such, the task of the committee differs fundamentally from other selection committees run by SSHRC. The committee does not select winners from a range of applicants, and there is no financial grant involved in this process. The committee acts as a gateway.

Research proposals that have undergone peer review from one of the tri-council funding agencies (SSHRC, CIHR, NSERC or FQRSC) will bypass peer review and move directly to institutional review.
1.3.1 Committee Decision

Within eight weeks of the date of application (sooner if possible), SSHRC will communicate the adjudication committee's decision to the project's principal applicant. The review process will produce one of two outcomes – acceptance or rejection; and the decision must be unanimous among all peers. The applicant is advised of the results via written correspondence. The decision rationale is included in the report of the evaluation results for the projects that are rejected. Researchers are free to address these concerns and resubmit the proposal.

1.3.2 Clarification of Proposal is Requested by the Committee

On occasion, committee members request clarification from the principal applicant if the proposal does not demonstrate, clearly, for example that their project requires access to detailed micro-data (i.e., that their analyses cannot be accomplished with publicly available micro-data). If clarification is requested of the principal applicant, then the Strategic Programs and Joint Initiatives program officer, will act as a liaison between the committee members and the principal applicant, and request the necessary information.

1.3.3 The Steps for Researchers to Take if the Strategic Programs and Joint Initiatives program officer requests clarification of your proposal

Provide the necessary clarification to the Strategic Programs and Joint Initiatives program officer as soon as possible so that the committee members can review your comments and continue to evaluate your proposal.

1.3.4 What Happens if the Committee Members Request that You Revise and Resubmit your Proposal?

Some proposals require substantial modifications and it is simpler to request that the principal applicant revise and resubmit their proposal in order to avoid many rounds of committee member evaluations. If the Strategic Programs and Joint Initiatives program officer contacts you for a revise and resubmit, you are invited to consult with the local RDC analyst if you are unclear about the revisions requested of you. Once you have modified your proposal, resubmit it online (http://www.sshrc.ca/web/apply/application/rdc_application_e.asp) to the SSHRC application page.

1.3.5 Are there Circumstances where a Proposal has been Rejected?

If a proposal is rejected by all committee members then the researcher is invited to resubmit their revised proposal. The Strategic Programs and Joint Initiatives program officer, Luc Lebrun, will inform the researcher that they can modify their proposal and re-submit through the proper SSHRC-channels. All rejected applications
must be officially re-submitted through the RDC electronic system and be subject to review by the overall evaluation committee. Researchers can expect that this process will take the same estimated time as their original proposal submission to SSHRC.

The only exceptions to the overall evaluation process apply to the CIHR, SSHRC or FQRSC-funded projects which need only be sent back to the Strategic Programs and Joint Initiatives program officer, Luc Lebrun, who will then forward the revised proposal directly to the relevant Statistics Canada Institutional reviewer for evaluation (omitting the Academic peer review step).

1.4 Proposal Approved

If your proposal is approved and you are given access to a Research Data Centre, your contract with Statistics Canada allows you to access only the microdata specified in your approved research project and only for the purpose of completing that project. You must submit a proposal for any subsequent research project that you wish to carry out at an RDC. In addition, SSHRC and Statistics Canada may ask for a new proposal if the scope of your research changes significantly.

Once the proposal is approved, researchers are required to get personal security clearance from Statistics Canada.

1.4.1 Security Clearance Procedures

Once a project is approved a number of security procedures must be followed:

- Statistics Canada will perform an Enhanced Reliability Check on any researcher who needs to access its data.
- Researchers will have to complete the security clearance forms within the presence of the Statistics Canada analyst at the RDC where the research will be conducted.
- The RDC analyst will send this form to Statistics Canada in Ottawa to be processed and will contact researchers to inform them of the results of the security check.
- The RDC analyst will invite the researcher, or group of researchers, for an orientation session to explain procedures at the RDC. (All team members accessing the data:
  1. require security clearance;
  2. must sign the contract;
  3. must attend an orientation session; and,
  4. must sign The Oath or Affirmation of Office and Secrecy.

• During the orientation session, researchers will sign their contract with Statistics Canada and take the Oath or Affirmation of Office and Secrecy (refer to Appendix 4).

**Note:** Researchers with no active research contracts with Statistics Canada for more than a year are required to update their security clearance.

**1.4.2 RDC Microdata Research Contract**

The accepted proposal will become part of the contract between the researcher(s) and Statistics Canada. The contract specifies the following terms of access:

• Data sets to be provided by Statistics Canada (please note the contract grants researchers access only to the microdata specified in the approved research proposal).

• Project start and completion date.

• Agreement that the researchers abide by the RDC security and confidentiality requirements.

• In fulfillment of the contractual obligations, the researcher will provide a product to Statistics Canada once the contract end date has arrived.

**1.4.3 Orientation**

The orientation session is a presentation designed to familiarize researchers with the privilege and duty of becoming deemed employees of Statistics Canada and working in the RDC. It includes a discussion of the policies and procedures related to data confidentiality, disclosure analysis, and other information regarding the operation of the RDC. Procedures for obtaining the release of research output will also be discussed. Researchers will also sign the Oath of Office during the orientation.

The orientation session is not and should not be considered a substitute for a thorough reading of this document (Guide for Researchers).

**1.4.4 Oath (Oath of Office and Secrecy)**

Before accessing data, researchers are asked to take an Oath of Office (oath of secrecy) to become a deemed employee of Statistics Canada. This is the legal requirement to maintain data confidentiality. A copy of the oath can be found in Appendix 4.

As part of this process the researcher(s) agree(s) to:

"... not disclose or knowingly cause to be disclosed, by any means, any information obtained under the Statistics Act in such a manner that it is possible from the disclosure to relate the particulars obtained from any individual return to any identifiable individual person, business or organization" (Statistics Act).
This oath requires that researchers be personally accountable to uphold the confidentiality provisions of the Statistics Act, and not to reveal anything about individual respondents, either directly or indirectly. The oath is binding for life; hence even after researchers have completed their research contract, they may not reveal any confidential information. A violation of confidentiality, whether intentionally or accidentally, would put the RDC endeavour at risk, and reduce research opportunities. In this document, the majority of the discussion is intended to help prevent an accidental breach of confidentiality.

1.4.5 Deemed Employee Status

Once you have signed the Oath, you are a deemed employee of Statistics Canada for the duration of the microdata research contract. All deemed employees within the RDC Program are legally responsible for upholding the Statistics Act and all policies and procedures of Statistics Canada. Deemed employees are not permitted to take away with them any sensitive statistical information. They remain subject to the oath/affirmation of secrecy even after their project is terminated.

The contractual arrangements between Statistics Canada and deemed employees do not involve payment to the researcher but require:

- Statistics Canada is to provide access to confidential microdata (sensitive statistical information); and,
- The researcher is to deliver a product at the end of the contract.
CHAPTER 2 - THE LIFE CYCLE OF RESEARCH AT THE RDC

2.1 Beginning your Project at the RDC

All Statistics Canada's RDCs have particular elements in common that researchers should be aware of and adhere to. All RDCs are physically secure environments with an isolated computer network (i.e., no internet capabilities or other external capabilities). Statistics Canada staff, RDC analysts, are on site to assist researchers and to approve all output leaving the RDC. This chapter is designed to help researchers through each phase of the life cycle of a research project conducted in the RDC environment.

2.1.1 Physical Security of the Centre

The RDC is a physically secure facility to the extent that the researchers use it properly.

- Each researcher will be issued a security pass. One cannot gain access to the RDC without the pass.
- Do not share or lend your security pass to anyone else.
- Report lost or stolen security passes immediately to the RDC Analyst.
- No visitors. Researchers may not escort individuals who do not have security clearance into the centre. Only RDC Analysts can permit entry of any individual into the premise.
- Do not open the door for anyone (i.e. do not answer a knock/doorbell indicating that someone without a pass would like entry into the RDC).

2.1.2 The Computer Facilities

Researchers are not assigned specific workstations in the RDC. It is important to book a time in the RDC in advance to minimize conflicts over resources and workstations. As a courtesy to other users, please adhere to the booking as much as possible.

Contact the RDC Analyst to request the purchase and installation of new software or software upgrades. Researchers may not install their own copies of software onto any RDC workstation.

- Each computer in the RDC is a workstation to which researchers can log on and connect to the server.
- Data
- Do not operate laptop computers, PDAs, cell phones or any other storage devices in the lab area.
- Workstations do not have CD/floppy disk-write capabilities. Disk-writing can only be conducted by the RDC Analyst through secured terminals.
- It is strictly prohibited to connect any portable or mass storage device to a workstation.
2.2 Guidelines for Statistical Analysis of Statistics Canada Surveys

Statistics Canada household surveys, such as those whose data are available in the RDCs, are based on complex sample designs that include stratification, multiple stages of selection, and unequal probabilities of selection. Generally, commercially available statistical software packages ignore these complexities. (Some of these packages can make use of the weights, which do contain some design information, but do not compute correct variances.) However, software that accounts for the design complexities is available.

Ignoring the design complexities could have an impact on the results of the analysis of the data. As an example, because of special interest in certain subpopulations, a survey might sample some units at higher rates than other units; an analysis of the population as a whole that ignores these differential rates will generally produce biased results. As another example, clusters of units are often included in a sample, such as several people from the same household; this clustering may lead to correlation between the observations, which, if ignored, could lead to underestimation of the standard errors of parameter estimates.

Many standard analytical procedures have been adapted to incorporate the sample design information. However, there are some analytical procedures for which there is currently no recommended design-based approach. Research is ongoing into appropriate analytical methods for such cases. In the meantime, approaches developed for non-survey data would have to be used; however, for these cases, there still may be some facility for making use of the survey weights.
2.3 Your Use of the RDC - Security

2.3.1 Getting Support

RDC Analyst

The first line of support while working at the RDC comes from the RDC Analyst. Researchers can direct questions about the dataset to the RDC analyst. The analyst will either have the answer or will direct the question to other Statistics Canada employees. When managed properly, this type of knowledge exchange benefits both the researchers and the Statistics Canada data programs.

Data Analysis Resource Centre (DARC)

The second line of support is available through the Data Analysis Resource Centre (DARC) at Statistics Canada. There has been considerable research carried out by this group on the appropriateness of various statistical analyses for complex sample designed datasets produced by Statistics Canada. DARC can provide suggestions on suitable methods and software tools. DARC also conducts seminars and research on various methods specific to longitudinal data. These services are offered on a cost-recovery basis. For more details, please contact your RDC analyst.

2.3.2 Accessing the RDC

As a Statistics Canada's deemed employee, it is your responsibility (as well as the RDC analyst's) to maintain the RDCs' security:

- Breaches in security or lost door keys should be reported to the RDC analyst immediately.
- RDC entrance information must not be shared.
- Consult with the RDC analyst for the sign-in procedures for the RDC.
- No visitors are permitted into the secure RDC facilities.
2.3.3 System and Electronic Devices

- Do not operate any personal electronic device such as laptop computers, palm pilots, cellular phones or other devices with optical beam capability inside the RDC secure premises. In case of emergency, cellular phones, or similar device may be used inside the RDC but away from the workstation.

- You are accountable for your working files and how you use the system. With this accountability comes the responsibility of protecting your log-on information.

- Make sure to log off after every work session. If you need to be away from your workstation during the session, all work should be saved and the computer locked to prevent others from accessing it.

- Save all work in your assigned electronic folder. This aides in the disclosure avoidance that the RDC analyst must do before your output can be released, project folder backup and system maintenance.

2.3.4 Data

- Do not discuss confidential information at any time outside the RDC, whether over the telephone, by e-mail (or other electronic media) or in person.

- Do not ask other researchers at the RDC for access to their data sets. Researchers are granted access only to the data for which access has been approved. Written requests or a new proposal is required for access to other data sets.

- Do not give other researchers, other than members of your team, access to any of your secondary datasets or output files. See the RDC Analyst for ways to share files with team members electronically without sharing passwords.

- Do not carry out analyses for colleagues or other researchers who do not have approved RDC research projects or who are not deemed employees.

- Do not use RDC data files to conduct data analysis outside the mandate of the approved project.

- Please place any output containing confidential data that you wish to discard into a designated receptacle, shredder, or return to the RDC Analyst.
2.4 Your Use of the RDC – Procedures

2.4.1 Confidentiality and Release of Research Output

Statistics Canada considers it important not only to avoid disclosure of confidential information, but also to avoid the perception of disclosure. It is the trust of the respondents that makes it possible for Statistics Canada to provide valuable data on the socio-economic condition of Canadian society.

The following is a brief summary of Statistics Canada policies regarding confidentiality and obtaining release of the research output.

- Absolutely no detailed microdata may leave the facilities.
- Absolutely no research results may leave the facilities without being examined and approved by the RDC analyst.
- All output leaving the RDC must undergo disclosure analysis, first by the researcher and then by the RDC Analyst. Disclosure analysis is the means by which researchers ensure that any material removed from the RDC does not pose a disclosure risk of data confidentiality. See Chapter 3, Appendix 1 and Appendix 6 for a complete discussion of the topic.

Researchers must complete a Disclosure Request Form each time they make a disclosure request. Researchers must provide description of variables used, new variables created, documentation of data sets and programs used in producing output to help the RDC Analyst better understand the materials requested for release. Working closely with the RDC Analyst during the disclosure analysis process will help to avoid misunderstandings and speed up the final approval for release.

Disclosure of individual cases in any manner – in research papers, via email, phone or fax, or in casual conversation – with persons outside designated facilities is prohibited. This includes researchers working on other projects who have deemed employee status.

Research output that emphasizes model output rather than tabular (descriptive) output are encouraged in order to reduce disclosure risk.

Removal of “intermediary output” from the RDC is discouraged. Intermediary output is typically produced during the exploratory and model development stages of the analysis. These outputs often consist of detailed tables of descriptive statistics. Such outputs often present more detailed information than final model outputs; their removal can greatly increase the risk of disclosure, especially residual disclosure.

Within the secure premises of the RDC, output of any type can be printed, but it must not be removed from the RDC before being examined and approved by the RDC analyst. Output without disclosure control will be printed on coloured paper (usually green) to avoid accidental confusion with outside material brought into the centre or output already approved to leave the centre. Coloured paper (usually green) DOES NOT LEAVE THE RDC. At the end of a
session, materials should be returned to the RDC analysts for secure storage until the next visit. This material will be shredded by the researcher or when the project is completed.

Researchers must comply with Statistics Canada rules and regulations on data confidentiality when removing output from the RDC.

2.4.2 Obtaining New Data
On rare occasions, it may be appropriate to access another data set to complete the project. An appropriate case may be that the sample size in the originally selected data set is not adequate but another data set contains similar questions and more respondents. The researcher may also want to verify their findings from one data set using another dataset. The nature of the project or objective of the research questions must not change significantly.

If the researcher wishes to add a data set to their project under these conditions, they must submit a written request to the RDC Analyst detailing the rationale for accessing a new data set and a commitment to maintain the objectives of the original proposal.

Provide a detailed discussion when requesting new data be added to your project. This request will be subject to the formal project review process. If the proposed use of the new data does not fit within the original proposal as judged by Statistics Canada, you will be asked to begin a new project by submitting a new proposal.

The contract does not have to be amended to add a new cycle of a longitudinal data set, only for a new data set or if there are changes to the research questions.

2.4.3 New Research Project with Same Data
While working on a project a researcher can begin to develop new ideas for other analyses. If these analyses do not fit under the original objective of the initial proposal a new proposal will be required. Do not start a new project without submitting a proposal to the review process. Violation of this rule will result in immediate withdrawal of data access privileges including data access to projects currently under contract.

2.4.4 Add or Remove a Team Member
After approval of the research proposal, researchers may make changes to the research team. To remove a research team member from the project, please provide a written memorandum to the RDC analyst. Both the principal investigator and the team member being removed from the contract need to sign the amendment. To add a new researcher, please provide a written memorandum along with a curriculum vitae of the researcher to the RDC Analyst. The new member will be required to complete the PERSONNEL SCREENING, CONSENT AND AUTHORIZATION FORM; part of the process for the researcher to undergo a Reliability Check.
And they will also need to take the oath/affirmation of secrecy and attend an RDC Program orientation session.

2.4.5 Amendment of the Contract Completion Date

There are two ways to grant RDC data access after contract expiry: by contract extension or by a revision contract.

2.4.6 Contract Extensions

This type of extension applies when the principal investigator realizes that they have significantly underestimated the time needed to complete the project or other factors may be preventing them from completing their project by the date specified in the contract.

Contract extensions occur when a project reaches its contract end date but the research team has not yet completed enough analysis to prepare their product. There are valid reasons for a project extension including:

- The data analysis is in the final stages and the extension will cover the completion of the data analysis;
- Funding or staffing shortages have prevented progress on the contract to date (including leaves of absence, long-term illnesses, etc.);
- There have been complications in obtaining data to complete the analysis.

The contract can be extended for up to one year past the contract due date at the request of the principal investigator.

Anticipate the need for an extension of your project and provide your RDC analyst with a written justification well in advance of the contract expiring.

2.4.7 Revision Contracts

A revision contract for data access may be obtained only in the following two cases:

(1) A researcher has submitted to a scholarly journal a manuscript based on results obtained from their RDC research;
   - The researcher has received a "revise and resubmit" from the editors of that journal that requires them to return to the data; and,
   - The researcher's original project contract has expired.

(2) A student has submitted a dissertation or thesis to their academic review committee;
o The student has received comments, usually through marked up copies of the text, and must now submit a written request to the RDC analyst for permission to re-enter the RDC in order to perform additional work with the data.

o The student's original project contract has expired.

Access under a Revision Contract is provided with the understanding that the research team is undertaking only the work suggested by the referees and not undertaking a new research project. They are generally used when a project has expired and their manuscript has already been submitted to Statistics Canada in fulfilment of their contractual obligations.

- Revision contracts usually last up to six months from start to finish. A product is required at the end of the contract even if the content is very similar to their original manuscript.

- In addition to providing the information required on the Contract Extension/Revision Contract Request Form, the Principal Investigator must provide a copy of the referee reports as evidence that the project continues to have scientific merit and requires re-access to the microdata. If you are uncomfortable sending these reports in their entirety, a summary of these comments will suffice.

2.4.8 Transferring of Results

Results may be transferred to another RDC without disclosure analysis when used by other team members in another RDC. Transfers require that the results be encrypted by the RDC analyst to encrypt the results before they are recorded on the transportation medium (CD or DVD). Please schedule time for transferring files with the RDC Analyst.

2.5 Completing the Contract

RDC Program at Statistics Canada has a mandate to provide a publicly available document from all research conducted on its data sets and this requirement extends to research conducted by deemed employees in exchange for data access. Researchers are responsible for producing a product from their research. See the contract, Appendix 3, section (5), “Limitations on uses of the microdata file and proposed output”.

Approximately one to two months prior to contract expiry date a reminder letter (signed by the Program Manager) will be sent by email to the Principal Investigator.

2.5.1 Producing a Product for the Project

Researchers with approved projects in the RDCs are granted access to the detailed micro data as deemed employees of Statistics Canada under the terms of the Statistics Act. The Act stipulates that only employees and deemed employees of Statistics Canada may have access to the detailed
(non-public use) micro data. To be a deemed employee of Statistics Canada implies that some product or service must be rendered to the agency. The product is defined in the research proposal that was submitted as part of the application process and it is stipulated in the contract that is entered into between the researcher(s) and Statistics Canada.

A project is complete\(^1\) when the Principal Investigator submits the product to Statistics Canada thus fulfilling their contractual obligations. The Research Data Centre Program has redefined its policy on the type(s) of products they would like researchers to submit in fulfilment of their contractual obligations for data access. For the most part, it means that instead of submitting an RDC working paper, researchers now have the option to submit a number of different products such as a journal article as their final product for the contract. Researchers are always encouraged to submit all final products to us so that we track these as measures of success for the RDC program.

There are five types of products that a researcher can produce as a product for their project.

1. RDC working paper
2. Peer-reviewed journal article
3. Book or book chapter
4. Graduate level thesis or dissertation\(^2\)
5. Commissioned report (e.g., a government commissioned report)

If a researcher identifies an alternate possibility, this should be discussed with an RDC Analyst supervisor before the contract is written. Changes to contract wording of the acceptable product will not be made retroactively, only proactively for new contracts.

If a researcher would like to submit a product other than a Statistics Canada working paper as the main product from their already existing contract, they should discuss this with their RDC Analyst who will be submitting the product to the RDC Manuscript Coordinator.

\(^1\) Note: the contract end date does not always coincide with the project completion date. The contract end date dictates when data access must stop. The researchers may continue to work on the project outside the RDC environment to complete the writing phase. A project ends when the main product is submitted.

\(^2\) If a member of a research team wishes to use the analysis for a thesis or dissertation, a separate contract should be written to cover their analysis, even if it was not indicated separately on the original proposal. The student should submit a one-page description of the analysis plan explaining how their work is consistent with the original group proposal and sign a contract along with their supervisor.
2.6 What happens to the product(s) when submitted?

This is an important new development: Not all products will be peer and institutionally reviewed. Instead, the product will be given to a Triage committee. The Triage committee will identify the 'gems' that we would like to showcase through a Statistics Canada flagship publication venue. What is a gem? It is a product that has wide appeal to a Canadian audience with a clear message about social trends or policy. There are three outcomes from the Triage process:

1. The product is not appropriate for a Statistics Canada flagship publication, for one reason or another. For example, the results of the analysis did not identify any conclusions or the analysis was not feasible given the data. The Principal Investigator will be notified by email from Statistics Canada head office that the product was received and that their contractual obligations are fulfilled. The local RDC Analyst will receive a carbon copy of this message.

2. The product is a good product but it is not of general interest to a Canadian audience. The Principal Investigator will be notified by email from Statistics Canada head office that the product was received and that their contractual obligations are fulfilled. This product will be included in a bibliography of research conducted in the RDC. The local RDC Analyst will receive a carbon copy of this message.

3. The product is a 'gem' and Statistics Canada is interested in publishing it in a flagship publication. The Principal Investigator will be notified by written letter from Statistics Canada head office that the product was received and that their contractual obligations are fulfilled. That letter will also invite to the Principal Investigator to consider a Statistics Canada publication under one of three possible scenarios dependent upon their other intentions for publication. The three publication scenarios are:

   (a) A joint release between a peer-reviewed journal and the Statistics Canada Daily. On the day the journal publishes the article, an advertisement for this will be listed in the Daily along with a brief description of the research.

   (b) A release in the Statistics Canada Daily after a journal publication has occurred.

   (c) A publication in a Statistics Canada flagship publication such as Canadian Social Trends, Health Reports, Perspectives on Labour and Income. The timing of this publication can be postponed to accommodate a peer-review journal publication first if requested by the Principal Investigator.

If the Principal Investigator is interested in pursuing one of these publication options and re-access to the data is required, either an extension or a revision contract will be prepared depending on the circumstances.

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3 Some researchers who are new to the data set utilized in their project may have concerns about how they have analyzed the data. The Principal Investigator has the right to request an institutional review of their paper at any time after the submission of the final product to Statistics Canada. If a researcher would like an institutional review, the RDC Analyst should notify the RDC Manuscript Coordinator who will make the necessary arrangements.
2.6.1 Seminars and Conference Presentations

Results may be presented at seminars or conferences. All work presented must reflect the proposal. And, all results must undergo disclosure analysis by the RDC Analyst.

Please give the RDC Analyst a copy of all presentations so an inventory can be maintained.

2.6.2 Related Papers and Research Reports

Beyond the RDC product produced, you are requested to provide a reference, a copy of the abstract, or the full document of any subsequent papers produced from the original RDC product and analysis. Statistics Canada hopes to maintain a bibliography of publications resulting from the RDC program. Papers, abstracts or references can be sent to the RDC analyst or to the Program Manager.

2.7 Exit Process

When submitting the final paper, researchers are asked to provide secondary data sets, model programs, relevant documentation, output, etc used in creating the product. This information will be archived and can be accessed during the revision contract.

At the time the project is complete, the Academic Director of your RDC will be interested in posting your product (or a reference to it) on the local RDC website. This is negotiable and is done on a case by case basis.

See your RDC Analyst about cleaning out your storage area, archiving files and returning your security card and/ or locker keys.

2.8 Re-entering the RDC under a New Agreement

To access the RDC to begin a second or subsequent research project, researchers will follow the application process outlined earlier in this document by submitting a research proposal through the Social Science and Humanities Research Council (SSHRC) web site.

After the proposal is approved, the research team members will sign a new contract and may be asked to review the orientation material with the RDC Analyst and reaffirm the oath before accessing the data.
CHAPTER 3 - DATA ACCESS, CONFIDENTIALITY, DISCLOSURE
ANALYSIS POLICIES AND PROCEDURES

The material in this chapter applies only to output that you intend to remove from the RDC. Any amount of output can be produced and stored (up to available capacity) for use on-site. This chapter presents policies and procedures to follow to clear research results for release.

Appendix 1 provides examples of disclosure problems and suggested approaches in correcting them. The goal of disclosure avoidance is to protect the information provided by respondents while presenting the least possible hindrance to research pursuits. Ultimately, users of confidential micro data files are responsible for avoiding disclosure of confidential data and minimizing the risk of disclosure. The RDC Analyst and researchers will work together to find solutions to data confidentiality problems.

3.1 What is Disclosure?

Disclosure occurs when data that can be attributed to individual respondents (e.g., persons, households, businesses, other organizations), are released.

3.1.1 Types of Disclosure

There are three types of disclosure; Identity, Attribute and Residual.

Identity disclosure occurs when an individual can be identified from the released output, leading to information being provided about that identified subject.

Attribute disclosure occurs when confidential information is revealed and can be attributed to an individual. It is not necessary for a specific individual to be identified or for a specific value to be given for attribute disclosure to occur. For example, publishing a narrow range for the salary of persons exercising a particular profession in one region may constitute a disclosure.

Residual disclosure can occur when released information can be combined to obtain confidential data.), Care must be taken to examine all output to be released. While a table on its own might not disclose confidential information, disclosure can occur by combining information from several sources, including external ones. (e.g., suppressed data in one table can be derived from other tables).

3.1.2 Some Examples of Disclosure in Survey Data

- A well-known personality, e.g., a professional athlete, is selected in a survey and;

- Information published about her community, such as the highest reported income in that community, almost certainly was reported by her. (Identity disclosure.)
• Results from a longitudinal survey highlight one household with a highly unusual migration pattern, leading to its identification. (Identity disclosure.)

• The parents of a 16-year-old selected in the sample see a table showing that all sampled 16-year-old respondents in their region have tried drugs. (Attribute disclosure.)

• A newspaper article relates a 37-year-old widower's complaints about being surveyed, and there are only two sampled 30 to 39-year-old widowers in survey cross-tabulations. (Eventually leading to identity and/or attribute disclosure.)

• By combining several results a person identifies information that was purposely excluded from the Public Use Microdata File (PUMF) because it presented too high a disclosure risk (e.g., the country of birth of recent immigrants).

Note that even the appearance of disclosure can tarnish a statistical organization’s reputation with respect to confidentiality. Damage could occur even if it turned out that the wrong person or household had been identified in the first two examples. Refuting a mistaken identification may increase the risk of exposing the real respondents.

3.2 How Can Researchers Protect Against Disclosure?

Disclosure analysis is the term applied to the examination of output researchers would like to remove from the RDC site. It involves a careful look not only at whether obvious identification of individual cases has occurred, but whether information about individual cases can be inferred or deduced from the output. This chapter outlines some broad approaches to disclosure analysis that researchers can use to prepare output for release from the RDC. Appendix 1 presents some examples of specific problems and approaches to solve them.

The most important policy is:

Absolutely no data and/or research results may leave the facilities without being examined and approved by the RDC Analyst.

3.3 General Risks for Confidentiality Problems

Researchers should keep in mind that data confidentiality is primarily a problem for descriptive data, tables of magnitude, individual statistics, etc. It tends not to be a problem for multivariate analysis results (as regression coefficients) except for a few special cases. Confidentiality is also a problem when you are using small geographical identifiers or narrowly defined population groups.
3.4 Disclosure Analysis

3.4.1 Disclosure Analysis for Tabular Output

Tabular output is what is often called ‘descriptive statistics.’ Researchers should limit the requests for disclosure clearance of tabular output to the minimum necessary to describe the sample used in models, and how it might compare to an underlying population.

Tables of summary statistics (means, variances, and related statistics) intended to describe the distributions of variables present certain special issues:

- Tables should not contain low frequency cells. Unless otherwise specified in the survey documentation, this means less than 5 observations in a cell.

- Take care with “full cells” (In two-way tables these occur when all the respondents in a particular row or column are concentrated in a single cell) or “zero cells”. Cells with no respondents can pose a particular problem with sensitive variables. These are variables such as income or health problems not generally known by the public.

- For many quantitative variables the maximum and minimum values must not be released. This applies particularly to sensitive variables related to income or consumption. Maximum values may also present a risk for apparently harmless variables, such as household size or age, as extreme values can lead to identity disclosure.

- Care must be taken in presenting other statistics intended to describe the shape of distributions. Where possible, present general statistics on distributional shape (e.g., skewness, kurtosis measures) rather than showing anything closely related to individual observations (e.g., the 99th percentile if small sample). Tables or graphs that report quintiles of distributions should be discussed with the RDC analyst.

If the researcher or the RDC Analyst finds a disclosure risk, modification of the output will be necessary (e.g., collapsing categories). This will avoid disclosure risk at the expense of output detail, and is the preferred course of action.

3.4.2 Disclosure Analysis for Parametric Model Output

Parameter estimates from some models, or the accompanying diagnostics generated by analysis packages, provide sufficient information to enable the re-creation of simpler statistics such as means and totals for cross-classes of variables. This is particularly true of so-called “saturated models” using binary coded variables, i.e., models that include all main effects and possible interaction terms. If the models or accompanying diagnostics provide much detail, it may be necessary to produce the underlying (un-weighted) summary results or tables for purposes of disclosure analysis.
If the researcher or the RDC analyst finds disclosure risk, modification of the output and possibly the model specification may be required. For example, researchers may be asked not to report the values of the affected coefficients (a good example would be the estimates of the fixed-effects in a fixed effects model). Or researchers may report that the coefficient is in a certain range (e.g., positive and significant). The RDC analyst and the researcher will work together to ensure, as much as possible, that the research results remain meaningful after any such modifications.

3.4.3 Disclosure for Non-parametric, Semi-parametric or Hierarchical Data

Non-parametric or semi-parametric estimates (for example, those used in survival analysis or kernel estimators used in discrete choice models) may pose special disclosure risks. An example is the now increasingly popular hierarchical linear model. This is likely to happen if the clusters contain small numbers of observations. Special care must be taken with output such as these. The RDC analyst and researcher will work together to avoid disclosure risk in these cases.

3.4.4 Disclosure Analysis for Variance-Covariance Matrices

While Statistics Canada prefers that all data analysis be completed in the RDC, some researchers will prefer to leave the RDC with variance-covariance matrices in order to conduct statistical inference and hypothesis testing. This is permitted, provided that the variance-covariance matrix adheres to the data confidentiality guidelines for tabular output and tables of magnitude. See Appendix 1 for guidelines.

3.5 Use of Weights

Statistics Canada household surveys like those found in the RDC, are based upon complex sample designs with stratification, multiple stages of selection, and unequal probabilities of selection of respondents. Using data from such complex surveys presents problems to analysts because the survey design and the selection probabilities affect the estimation and variance calculation procedures that should be used. In order for survey estimates to minimize bias, the survey weights must be used.

Weighting brings results from a sample to the level of the population. Even when population estimates are not the main interest weighting corrects for sample non-representativity arising from the survey design (as over-sampling population sub-groups) and from data collection and processing operations (e.g., higher non-response among young adults). Weighting also assists in the protection of confidentiality because one case may no longer represent one respondent. In very limited circumstances un-weighted results can be released, such as analytic procedures that can not assimilate the use of weights. Researchers have to provide a written justification for requesting un-weighted results to be released.

It is important to include a statement in research manuscripts and presentations informing your audience that estimates may be influenced by the survey design and that population inferences are not valid when based on un-weighted results.
Please consult the documentation accompanying the survey for more information on the use of weights.

3.6 Quality Guidelines for Releasing Data

While data confidentiality is closely related to data quality, it is the responsibility of the researcher as RDC analysts do not screen output for data quality.

Documentation for each survey contains guidelines on what the minimum cell size should be to obtain acceptable estimates and maintain data quality. Before releasing and/or publishing any estimate, users should first determine the quality levels of the data set they are using. The quality levels are acceptable, marginal and unacceptable. All estimates can be considered releasable. However, those of marginal or unacceptable quality level must be accompanied by warning to caution subsequent users.

Please consult the documentation accompanying the survey for more information on data quality.

3.7 Responsibilities

3.7.1 The Researcher’s Responsibility

Researchers are responsible for applying the rules and regulations for disclosure analysis as specified by Statistics Canada. Limiting the number of requests will reduce the risk of disclosure and facilitate the timeliness of processing. Disclosure analysis involves a certain amount of processing time, researchers should consider this when planning their activities and submitting output for release. A three day turn around time is typical; however, this time can vary depending on staffing resources and the number of other submitted disclosure requests.

3.7.2 The Analyst’s Responsibility

A major responsibility of the RDC Analyst is to control the output released and ensure that confidentiality is not breached. When a problem of potential disclosure of confidential information is discovered in the results presented for review, RDC Analysts will do their best to find a solution. All attempts will be made in collaboration with the researchers. But overall, the RDC Program must maintain confidentiality and sometimes no release may be the outcome.

3.8 How to Remove Research Output from the RDC

You will be asked to provide materials that allow Statistics Canada to document all approved releases of research output. The documentation must indicate that the output was produced as part of an approved project (and which project), and it must allow Statistics Canada to document that published output does not disclose confidential information.

3.8.1 Disclosure Requests

At the beginning of your project you will be assigned a project computer directory on the network where all data sets, programming syntax, logs, and output should be stored. The RDC
Analyst will provide you with two folders (‘to be vetted’ and ‘vetted’) in your project directory. The ‘to be vetted’ folder is where you will copy the output for disclosure by the RDC Analyst as well as the Disclosure Request Form. Once the output has been vetted a copy will be placed in the ‘vetted’ folder and e-mailed to the researcher.

When you have output to be removed from the RDC:

1. Make an appointment with the RDC analyst to discuss the clearance request.
2. Fill out a Disclosure Request Form (see Appendix 6 for a copy of the form). You are required to provide:
   • The survey name, weighting information, types of methods and sub-sample characteristics (or location of the files)
   • Supporting documentation files (or location of the files)
   • Information about possible residual disclosure

Please properly document the output. This can be done by ensuring variables are clearly labelled and cell sizes below the minimum requirement are collapsed or re-categorized. The researcher is to ensure that mistakes in the output have been corrected and specific disclosure issues for the survey are addressed.

Please be prepared to discuss the clearance request with the analyst performing disclosure analysis. This may require changes in the output to satisfy clearance requirements. Working interactively with the analyst performing disclosure analysis will maximize learning on both sides, avoid costly misunderstandings, and speed the review process. The clearer and more complete the request is, the sooner it can be released.

3.8.2 Some Quick Tips for How Researchers Can Check for Disclosure

Verifying these elements can speed up the vetting process:

- Provide un-weighted frequency counts (in an identical separate file).
- Do not submit tables with small cell sizes.
- Restrict cross-tabular analysis to two or three dimensions.
- Do not submit listings of cases or show graphs with outliers (i.e. no minimum or maximums).
- Provide supporting information for the correlation matrices.
- Be cautious when using small subgroups or small areas.
- Limit the release of tabular output before the end of your project.
- Schedule time with an RDC analyst well in advance.
- **Check documentation for survey specific rules.**

Refer to Appendix 1 for further instructions on approaching disclosure problems.

---

4 The names of these folders may vary between centres.
CHAPTER 4 - Acquiring More Information

If more information is required about the RDC Network please log on to:

If more information is required about the RDC Program please log on to:

If more information is required about the Statistic Canada’s data sets or research tools
please log on to:
http://www.statcan.gc.ca/english/rdc/whatdata.htm

For an up-to-date list of the projects currently being conducted at the various centres or
for abstracts and citation details of research papers published by researchers involved in
the program, please log on to:

We are pleased to welcome you to the RDC program and facilities. We hope that
your experience with the Program is going to be very profitable and rewarding for
you and your research team.
APPENDIX 1 - MORE ON DISCLOSURE AND DISCLOSURE RISK

All variables on a database can be categorized according to their importance to data confidentiality:

**Direct identifiers**: Variables such as name, address or telephone number, etc. that provide an explicit link to a respondent. These are all stripped from the master files to which you will have access.

**Indirect identifiers**: Variables such as age, sex, marital status, area of residence, occupation, type of business etc. that could be used to identify an individual.

**Sensitive variables**: Characteristics relating to respondents' private lives, or business, which are not usually known.

These variables seem harmless on their own but used together could reveal information about individuals. For example, consider the case of drug experimentation during adolescence. The parents of a 16 year-old respondent may see a table showing that all sampled 16 year olds (indirect identifier) in their socio-economic group (indirect identifier) have experimented with drugs (sensitive variable). They thus know that their 16-year-old has experimented with drugs.

Data confidentiality is primarily a problem for frequency data and tables. It tends not to be a problem for correlative or causal analysis results such as regression coefficients. But it can occur in any kind of data output.

General rules to apply at all times:

- Use weighted data: the disclosure risk is reduced when weights are used to generate output.
- Do not report statistics or cells with fewer than five respondents (or the number reported in the documentation of the survey you are using, whichever is less).
- No anecdotal information may be given about specific respondents.
APPENDIX 2 - SAMPLE MICRODATA RESEARCH CONTRACT

MICRODATA RESEARCH CONTRACT

BETWEEN:

HER MAJESTY THE QUEEN IN RIGHT OF CANADA,
represented by the Minister of Industry, designated as the Minister
for purposes of the Statistics Act, (hereinafter referred to as
"Statistics Canada"),

AND:

(Name and affiliation of Principal Investigator),
(hereinafter referred to as the "Principal Investigator"),

and,

(Name and affiliation of Co-investigators)
(hereinafter referred to as the “Co-investigators”),

WHEREAS Statistics Canada requires the services of the Principal Investigator to
undertake statistical research and analysis on (Name of the Microdata File) to fulfill its
mandate under the Statistics Act;

AND WHEREAS to perform these services and to have access to confidential
information, the Principal Investigator and the Co-investigators must become “Deemed
Employees” of Statistics Canada and are required to take the Oath of Secrecy;

AND WHEREAS Statistics Canada wishes to make clear the terms and conditions
under which access to the microdata will be granted;

NOW THEREFORE the Parties agree as follows:

SERVICE PROVIDED BY PRINCIPAL INVESTIGATOR

1. (1) The Principal Investigator will carry out the research project set out in
Appendix “A” and provide the report described under “Proposed Output”. 
(2) It is understood that this is a contract for the performance of a service and the Principal Investigator and Co-investigators are engaged for the sole purpose of providing that service.

CONDITIONS OF ACCESS TO THE MICRODATA

2. The Principal Investigator and the Co-investigators must undergo an enhanced reliability check satisfactory to Statistics Canada and take the oath of secrecy in order to obtain access to the non identifiable microdata file required to perform the analysis pursuant to this contract.

3. (1) Access to the non identifiable microdata file (no names, addresses or identifying numbers) and associated documentation shall be provided on Statistics Canada premises, which includes Headquarters and the Statistics Canada Regional Offices during normal hours of operation, Monday to Friday, and the Research Data Centres.

(2) The Principal Investigator and Co-Investigators will be provided with the necessary computing facilities, software and documentation as is reasonably necessary to complete the research and analysis pursuant to this contract.

DEPARTMENTAL REPRESENTATIVE

4. The Director of the (name of the division) or the Manager of the Research Data Centre Program is the designated Statistics Canada representative responsible for the administration of this contract.

LIMITATIONS ON USES OF THE MICRODATA FILE AND PROPOSED OUTPUT

5. (1) The Principal Investigator and the Co-investigators shall not use or disclose any of the information obtained or produced pursuant to this contract for any administrative or regulatory purposes.

(2) Access to the microdata file is being provided for the statistical and research purpose outlined in the proposal attached as Appendix A and the microdata file shall not be used for any other purposes without the prior written consent of Statistics Canada.

(3) The Principal Investigator and the Co-investigators shall not disclose any of the information from the individual records obtained or produced
pursuant to this contract to anyone other than current Statistics Canada employees.

(4) The Principal Investigator and the Co-investigators shall ensure that no attempts are made to link the microdata file to any other files in order to relate the particulars to any identifiable individual person, business or organization.

(5) The Proposed Output must meet the requirements of both peer and institutional review prior to being released by Statistics Canada, for example, in one of its publications or in a research paper.

(6) Thereafter, the Principal Investigator may, subject to subsection 6(5), carry out a secondary analysis, but such analysis shall be based solely on the approved “Proposed Output” produced pursuant to this contract and be related to the analytical work undertaken to produce the “Proposed Output”.

(7) The Principal Investigator agrees to work with Statistics Canada in trying to meet the requirements of peer and institutional review required for the publication or research paper. For the Research Data Centres, a timetable for conducting the peer and institutional review is available in the guidelines for producing the “Proposed Output”.

- In the event the “Proposed Output” fails a peer or institutional review and Statistics Canada decides not to publish it, Statistics Canada will give the Principal Investigator written notice to this effect within thirty days of having made the final decision.

- Subject to subsections 6(5) and 10(2), in the event Statistics Canada notifies the Principal Investigator in writing that the proposed output will not be published, the Principal Investigator will not be prevented from:

  (a) Publishing the “Proposed Output” elsewhere, and/or

  (b) Using the “Proposed Output” for purposes of the attainment of an educational degree.

OWNERSHIP

6. (1) The microdata file and related documentation shall at all times be and remain the sole and exclusive property of Statistics Canada, it being mutually agreed that this contract pertains to the use of the microdata file and related documentation to produce a “Proposed Output” for Statistics Canada.
Canada and that nothing contained herein shall be deemed to convey any
title or ownership interest in the microdata file or the related
documentation to the Principal Investigator or the Co-investigators. The
computer equipment provided for use by the Principal Investigator and the
Co-investigators must never be removed from the premises of Statistics
Canada and remains the sole and exclusive property of the access facility.

(2) Statistics Canada reserves the right to publish in whole or in part, to
publish an amended version or not to publish at all, as Statistics Canada
deems appropriate, the "Proposed Output" produced by the Principal
Investigator pursuant to this contract.

(3) Copyright in the "Proposed Output" produced by the Principal
Investigator pursuant to this contract shall vest in Her Majesty the Queen in Right of
Canada. The Principal Investigator shall provide to Statistics Canada at
the completion of the contract or at such other time as Statistics Canada
may require a written permanent waiver of Moral rights from every author
who contributed to the aforementioned material. Statistics Canada (Her
Majesty the Queen in Right of Canada) hereby grants to the Principal
Investigator a non-exclusive license to use, reproduce, publish and
distribute the "Proposed Output" for any purpose, including, without
limitation, research, teaching and publication in any medium.

(4) Secondary releases of the "Proposed Output" may be considered by
Statistics Canada subject to obtaining consent from the Principal
Investigator.

(5) In publishing the "Proposed Output" elsewhere, using the "Proposed
Output" in the attainment of an educational degree or carrying out any
secondary analysis, any reports, documents, or materials which are
subsequently prepared by the Principal Investigator which use, incorporate
or are in any way based on any material produced under this agreement,
shall prominently display the following notice:

"The research and analysis are based on data from Statistics Canada and
the opinions expressed do not represent the views of Statistics Canada."

CONFLICT OF INTEREST

7. (1) All persons engaged in the course of carrying out this contract shall
conduct themselves in accordance with the principles and spirit of the
Conflict of Interest and Post-Employment Code for the Public Service.
(2) Should a conflict exist prior to the commencement of this contract or be acquired or develop during the life of this contract, the person with the conflict engaged in carrying out this contract shall be responsible for discussing the conflict with the Director of the Division sponsoring the project or the Manager of the Research Data Centre Project and, should it be determined that a conflict exists, for completing the Confidential Report as required by the Conflict of Interest and Post-Employment Code for the Public Service.

(3) No person engaged in the course of carrying out this contract may use any of the information gained by accessing the confidential data for any other purpose except that which was agreed upon in this contract.

(4) Notwithstanding subsection 7(3), it is understood that the principles of the Conflict of Interest and Post-Employment Code for the Public Service were not meant to prohibit the persons engaged in this contract from accomplishing any secondary analysis as permitted by the contract.

SECURITY REQUIREMENTS

8. (1) Any material to be removed from the Statistics Canada premises by the Principal Investigator or Co-investigators must first be screened by Statistics Canada to ensure that there is no risk of disclosure of confidential information or information that may lead to the identification of an individual respondent. It is the responsibility of the Principal Investigator or Co-investigators to take all precautions to avoid disclosure of confidential information or information that may lead to the identification of an individual respondent. The Principal Investigator or Co-investigators may remove summary files, tabulations and analytical output under the terms of this subsection.

(2) The Principal Investigator and the Co-investigators shall not remove any of the original data set or copies of subsets of the microdata file or any confidential sensitive statistical information provided pursuant to this contract from the premises of Statistics Canada.

(3) The Principal Investigator and the Co-investigators shall be provided with copies of all relevant Statistics Canada policies related to confidentiality, privacy and security and the standard operating procedures of the appropriate access facility and shall acknowledge in writing their compliance with all of the policies and operating procedures.
TERM

9. This contract comes into force when signed by both parties and shall continue in force until ________________ unless revoked or terminated at an earlier date.

TERMINATION

10. (1) Where the Principal Investigator is in default in carrying out any of its obligations under this Contract, Statistics Canada may, upon giving written notice to the Principal Investigator, terminate the Contract immediately.

(2) The Contract may, by providing 30 days written notice, be terminated by mutual written consent between the Principal Investigator and Statistics Canada.

(3) Any notice to be given to Statistics Canada or the Principal Investigator shall be sent by registered mail to:

(Address of Statistics Canada) (Address of the Principal Investigator)

(4) Any notice shall be deemed to be effective on the day it is received at the address set out above.

PENALTIES

11. (1) As a Deemed Employee of Statistics Canada, the Principal Investigator and the Co-investigators are subject to all the applicable penalties provided for in the Statistics Act for contravention of any of the confidentiality provisions and is liable on summary conviction to any of the applicable fines or imprisonment terms.

(2) Subsection 11(1) survives indefinitely the completion of this contract or the termination of this Agreement pursuant to subsections 10(1) or 10(2).

AMENDMENT

12. No amendment to this contract shall be valid unless it is reduced to writing and signed by the Parties hereto.
CONSIDERATION

13. The Parties agree that consideration for this agreement shall be the mutual promises and covenants of the Parties included in this contract.

ENTIRE AGREEMENT

14. This contract constitutes the entire agreement between the Parties listed below and Statistics Canada with respect to the subject matter described herein and supersedes all previous negotiations, communications and other agreements on the same issue with Statistics Canada unless they are specifically incorporated by reference in this contract.

IN WITNESS WHEREOF, this Agreement has been executed in duplicate on behalf of Statistics Canada and the Principal Investigator by:

FOR STATISTICS CANADA:

Witness ___________________________ Date ___________________________

Director of (Name of Division) or
Manager of the Research Data Centre Program

FOR THE PRINCIPAL INVESTIGATOR:

Witness ___________________________ Date ___________________________

(Name of Principal Investigator)

Witness ___________________________ Date ___________________________

(Name of Co-investigator)
Appendix “A”

- Research Proposal Title

Submitted By: Name of Division and Director
Name of Principal Investigator and Co-investigator
Address of Principal Investigator
Telephone Numbers
Affiliation

Proposal

Detailed description of the proposed research.

Data Requirements

List of files, additional data fields or variables required for the analysis.

Proposed Output

Indicate the type of output to be generated from the list below (delete those which do not apply)

- RDC working paper: A paper for the RDC working paper series authored by the Principal Investigator for Statistics Canada.
- Peer-reviewed journal article: A journal article authored by the Principal Investigator for a peer-reviewed journal.
- Book or Book chapter: A book or book chapter authored by the Principal Investigator.
- Thesis or Dissertation: A graduate level thesis or dissertation.
- Commissioned Report: A commissioned report authored by the Principal Investigator for ____________ (insert name of commissioner and proposed title of the report).

Completion Date

Proposed Completion Date: (Enter Dates and expected product)

Research Location

Indicate where the Co-investigator is to be located for purposes of this project.

Source of Funding

List any agencies which may be providing funds related to this project.
APPENDIX 4 - THE OATH

Statistics Statistique
Canada Canada

Note: This to be taken by all team members listed on the contract.

OATH OR AFFIRMATION OF OFFICE AND SECRECY

I, ____________________________, do solemnly swear (or affirm) that I will faithfully and honestly fulfill my duties as an employee of Statistics Canada in conformity with the requirements of the Statistics Act, and of all the rules and instructions thereunder and that I will not without due authority in that behalf disclose or make known any matter or thing that comes to my knowledge by reason of my employment.

Sworn (affirmed) before me
at
this _____ day of _____ 20____.

(Authorised to administer oaths and affirmations pursuant to the Statistics Act)

Source: Statistics Act.
APPENDIX 5 – SAMPLE RESEARCH CONTRACT AMENDMENT

RESEARCH DATA CENTRES MICRODATA RESEARCH CONTRACT

AMENDMENT

(Could be used as an extension of contract, addition of team members or addition of dataset)

BETWEEN:

HER MAJESTY THE QUEEN IN RIGHT OF CANADA, represented by the Minister of Industry, designated as the Minister for purposes of the Statistics Act, (hereinafter referred to as "Statistics Canada"),

AND: (NAME OF INVESTIGATOR)
(hereinafter referred to as the "Principal Investigator")

(NAME OF CO-INVESTIGATOR OR RESEARCHER)
(hereinafter referred to as the "Co-investigator")

WHEREAS Statistics Canada and the Principal Investigator named above have signed an On-Premises Microdata Research Contract (copy attached) to undertake a study of

AND WHEREAS the Co-Investigator named above will be working on this project as a 'deemed employee' of Statistics Canada and by signing this amendment will be subject to the same terms, obligations and penalties as outlined in the attached research contract;

OR

AND WHEREAS the Investigator wishes to extend the completion date of the contract from ----------- to ----------- in order to properly complete the research and analysis as outlined in the attached research contract;

OR

AND WHEREAS the Investigator wishes to have access to the following datasets:
- (Name of dataset or datasets) as a new data set to be used for the data output in the original contract in order to properly complete the research and analysis as outlined in the attached research contract;
IN WITNESS WHEREOF, this amendment has been signed on the dates indicated below.

**FOR STATISTICS CANADA**

<table>
<thead>
<tr>
<th>Witness</th>
<th>Date</th>
<th>Manager, Research Data Centres Program</th>
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**FOR THE INVESTIGATOR**

<table>
<thead>
<tr>
<th>Witness</th>
<th>Date</th>
<th>Investigator (could indicate: signing for the team)</th>
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<th>Witness</th>
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<th>Co-Investigator</th>
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APPENDIX 6 - SAMPLE DISCLOSURE REQUEST FORM

Research Data Centre
Disclosure Request Form

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date:</th>
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<tbody>
<tr>
<td>Email address:</td>
<td>Phone number:</td>
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<tr>
<td>Project number or title:</td>
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These few simple checks can facilitate the release of disclosure requests:

<table>
<thead>
<tr>
<th>Check that the following is complete:</th>
<th>Yes / Not Applicable</th>
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</thead>
<tbody>
<tr>
<td>Variables are clearly labelled, particularly recoded variables. *</td>
<td></td>
</tr>
<tr>
<td>Cell sizes below the minimum requirement are collapsed or re-categorized.</td>
<td></td>
</tr>
<tr>
<td>Mistakes in the output are corrected.</td>
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</tr>
<tr>
<td>Specific disclosure issues for the survey (e.g., rounding of EDS output) are addressed.</td>
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</tr>
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* If Applicable, please provide variables information file: S:\Project number\Disclosure\Pending\Folder name

Directory of files to be vetted: S:\Project number\Disclosure\Pending\Folder name

Output for Release:

<table>
<thead>
<tr>
<th>File Name</th>
<th>Survey Name and cycle(s) used</th>
<th>Weighting (e.g., population, fractional/adjusted/sample, bootstrap)</th>
<th>Types of Methods (Insert number(s) from list below or specify)</th>
<th>Subsample Characteristics (e.g., gender, age range, regional distribution, etc.)</th>
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41
<table>
<thead>
<tr>
<th>File Name</th>
<th>Survey Name and cycle(s) used</th>
<th>Weighting (e.g., population, fractional/adjusted/sample, bootstrap)</th>
<th>Types of Methods (Insert number(s) from list below or specify)</th>
<th>Subsample Characteristics (e.g., gender, age range, regional distribution, etc.)</th>
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Types of Methods:
1. **Descriptive methods** (e.g., Frequencies, Cross-tabular analysis, means and distributions)
2. **Scaling methods** (e.g., Factor Analysis)
3. **Graphs** (e.g., histograms)
4. **Regression methods** (e.g., OLS, ANOVA, Logistic, Probit, Tobit)
5. **Complex methods of modeling** (e.g., Structural equation modeling, Hierarchical Linear Modeling, Growth analysis, Survival analysis, Event History Analysis, Simultaneous-equations Models, Fixed Effects Models, Random Effects Models)

Supporting Documentation Files:

- Includes information to address disclosure issues but is not for release:
  - A clearly labelled un-weighted version of the tabular data.
  - The necessary supporting cross-tabulations of binary variables for variance-covariance matrices.
  - Clear indication of the source of the data if contextual information has been merged with the dataset.
Residual Disclosure:

A re-release of the same output after slight modifications greatly increases the risk of residual disclosure. Statistics Canada strongly recommends that researchers submit as few versions of the output as possible for release from the RDC.

<table>
<thead>
<tr>
<th>Check:</th>
<th>Yes / No / Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has a version of this output has been previously released?</td>
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</tr>
<tr>
<td>Have variables been recoded or modified affecting only a few respondents since a previous release?</td>
<td></td>
</tr>
<tr>
<td>Have individual outliers or cases have been dropped from the analysis since a previous release?</td>
<td></td>
</tr>
<tr>
<td>Has the sub-sample or target population has changed slightly from a previous release?</td>
<td></td>
</tr>
</tbody>
</table>

If the answered is ‘yes’ to any one of these questions, the output is at risk for residual disclosure. Please consult with the RDC Analyst for solutions and strategies.

Please list any other comments or concerns you may have for your disclosure request:
Appendix B: UBC Behavioural Research Ethics Board Certificate of Approval

The University of British Columbia  
Office of Research Services  
Behavioural Research Ethics Board  
Suite 102, 6190 Agronomy Road, Vancouver, B.C. V6T 1Z3

CERTIFICATE OF APPROVAL - MINIMAL RISK

<table>
<thead>
<tr>
<th>PRINCIPAL INVESTIGATOR:</th>
<th>INSTITUTION / DEPARTMENT:</th>
<th>UBC BREB NUMBER:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kadriye Ercikan</td>
<td>UBC/Education/Educational &amp; Counselling Psychology, and Special Education</td>
<td>H06-03719</td>
</tr>
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INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:

<table>
<thead>
<tr>
<th>Institution</th>
<th>Site</th>
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<tbody>
<tr>
<td>N/A</td>
<td>N/A</td>
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</tbody>
</table>

Other locations where the research will be conducted:  
British Columbia Inter-university Research Data Centre (BCIRDC)

CO-INVESTIGATOR(S):  
Jennifer Shapka

SPONSORING AGENCIES:  
N/A

PROJECT TITLE:  
Psychological and Educational Effects of Childhood Chronic Illnesses

CERTIFICATE EXPIRY DATE: February 6, 2008

DOCUMENTS INCLUDED IN THIS APPROVAL:  

<table>
<thead>
<tr>
<th>Document Name</th>
<th>Version</th>
<th>Date</th>
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</tbody>
</table>

The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:

Dr. Peter Suedfeld, Chair  
Dr. Jim Rupert, Associate Chair  
Dr. Arminee Kazanjian, Associate Chair  
Dr. M. Judith Lynam, Associate Chair