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*Child Development Master’s Degree Thesis:*

# The Impact of Childhood Chronic Illness on Mental Health: A Review of Parent and Child Reports of Stress and Maladaptive Behaviors in a Longitudinal Study

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***Submitted in partial completion of the Master of Arts Degree at Sarah Lawrence College, May 2017***

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# ABSTRACT

An estimated 16 million children live with at least one chronic medical condition in the United States. These children and their parents must contend with a variety of challenges that affect their everyday lives, as well as their future and potential outcomes. This study analyzed the relationship between having a child with a chronic medical condition and the mental health/well-being of both the child and the primary caregiver using data from the Bellevue Project for Early Language, Literacy, and Education Success (BELLE). Parent and child reports of children's socioemotional function, and parent's feelings of stress and depression were used as indicators of mental health/well-being. Forty-three children in this study were identified as having a chronic medical condition; they were compared to a healthy sample (n= 602) from the same data set. Children with chronic medical conditions exhibited aggressive behaviors more than their healthy peers. Regardless of the child's medical condition, these types of externalizing behaviors were associated with parenting stress, and lower levels of cognitive stimulation by the parent. Analysis of covariance controlling for SES, gender, country of origin, and early aggressive behavior suggest that parents who provide cognitive stimulation to their chronically ill children mitigate the likelihood of the children developing aggressive behaviors. In addition to providing an illness-centered care plan, pediatricians should screen chronically ill children for internalizing and externalizing symptoms. Furthermore, given the pivotal role parental mental health/well-being plays in children's developmental outcomes, pediatricians should also screen the parents for symptoms of depression, stress, and/or anxiety in order to safeguard positive parent-child relationships and interactions.

*Keywords*: child, chronic conditions, parenting, externalizing behaviors

## INTRODUCTION

According to the most current estimates available from the Centers for Disease Control and Prevention (CDC), approximately 22.3% of children in the United States experience at least one chronic health condition; this represents a population estimate greater than 16 million children nationwide (NHIS-Child, 2014). Although there is some variability in how "chronic illness" is defined, most definitions concur that it must be a *persistent* condition that causes functional impairment to an individual (Bennett et al., 2015). How long the condition ought to persist in order to be considered chronic is not widely agreed upon, but the overall consensus is that the condition itself or its effects are not transient. The fact that children are in the early stages of growth and development means that even within marginal time frames, the ever-present nature of a chronic condition can have long-term, negative consequences on a child's development, and more generally on a child's life.

In addition to the direct effects on the particular biological system(s) affected by any given condition, chronically ill children and their families have to contend with a variety of challenges affecting their everyday lives, as well as their future potential outcomes. Studies have shown that financial prosperity, academic success, and mental health/well-being are significantly lower for children and families dealing with a chronic condition (Children's Environmental Health Center, 2013; Suryavanshi and Yang, 2016; Wilcox, et al., 2016).

The current thesis seeks to address the relationship between pediatric chronic conditions and the effects this experience has on the primary caregiver's and the child's mental health. The literature shows that children with a chronic condition and their caregivers have to deal with a litany of issues ranging from everyday tasks, like getting to class/work, to serious concerns about their future prospects and stability in just about any aspect of their lives—financial, educational, professional, etc. Using stress and depression as indicators of mental health/well-being, and cognitive stimulation as a measure of parenting this project aims to demonstrate a positive and persisting correlation between pediatric chronic conditions and stress in both the children with the diagnosis and their primary caregiver. Furthermore, when compared to children from similar socioeconomic backgrounds who have not had a chronic condition, one expects to see a clear contrast in reported stress between chronically ill and "healthy" children, and their primary caregivers.

## Theoretical Foundations

It is unsurprising to see that a negative effect on health leads to complications outside the individual body to areas like family structure and peer relations. To understand these cross-systemic effects we can turn to bioecological and biopsychosocial theory. Urie Bronfenbrenner's bioecological model conceptualizes this interaction. He believed that development should be studied within the actual context in which a person lived (Ferguson and Evans, 2017); he termed his original model the "ecology of human development," and described it as "the scientific study of the progressive mutual accommodation between an active, growing human being and the changing properties of the immediate setting in which the developing person lives, as this process is affected by relations between these settings (Bronfenbrenner, 1979, p.21). The individual child is the developing person; when chronic illness emerges it first and foremost affects his/her own health (both physical and mental), but it very quickly creates an ecological transition to his/her microsystem, including family members, peers, teachers and those medical health professionals treating the condition (Bergen, 2008). Interaction amongst those entities (e.g. an increased use of medical services by the child and caregivers) carries the ecological transition into the mesosystem; and when there are connections between settings that do not directly involved the child, but still directly influence him/her (e.g. parents' loss of employment due to absenteeism) the ripple effects of the medical condition have extended to the exosystem (Ferguson and Evans, 2017). Arguably more so than adults', children's bioecological systems are particularly susceptible to changes, due to children's greater dependency on others. It is important for those with a say in how to deal with a chronic illness diagnosis to address potential intersystemic consequences. This bioecological framework exemplifies for us that there are "multiple factors impacting the health and development of children and their families at multiple levels" and in various ways (Ferguson and Evans, 2017, p. 4).

The biopsychosocial model helps clinically account for the aforementioned intersystemic interactions, an area neglected by the more commonly practiced biomedical approach in healthcare (Engel, 1980). In George Engel's biopsychosocial model the individual simultaneously represents "the highest level of the organismic hierarchy and the lowest level of the social hierarchy" (Engel, 1980, p. 537). The model is based on the premise that similar parts (e.g. cells, organs/organ systems, families) can and should be identified as separate levels, but they are nonetheless nestled, and a part of higher systems (e.g. tissues, individual person, communities). A systems-oriented physician would not only acknowledge, but also address in treatment, the effects of a pediatric chronic illness across systems and levels. Studies conducted as recently as 2012 suggest that we still lack an in-depth understanding of how children and parents cope with and/or recover from serious pediatric medical events (Atkins, Colville, and John, 2012). Like their physicians, patients and families also have a preoccupation with the body and disease (Engel, 1980; Atkins, Colville, and John, 2012). While this may be the most obvious area affected, it is not the only one, and sometimes it may not even be the most important one. In cases where full recovery is not a realistic option, like chronic conditions, psychological and social support should be paramount, as these are areas that can themselves improve, but they can also impact the medical condition's progression.

In fact, these theories would argue that such environmental and contextual factors contribute to varying patterns of progress for the same conditions, as trajectory of medical condition can often times be unpredictable. Childhood asthma, for example, can be classified as remitting, periodic, or persistent based on the level of asthma activity reported, though more generally it is still considered chronic (Covar, et. al., 2011). Nonlinear dynamic systems theory of development, with its strong roots in biology, argues that a child's "physical growth dimensions, opportunities for environmental practice, and changes in the neurological structures of the brain all interact dynamically" (Bergen, 2008, p. 232). How a child behaves and develops is nearly impossible to predict, because it is contingent on countless factors to begin with—current situation, "continuous short and long term history of acting, the social situation, and the biological constraints he/she was born with" (Thelen, 2004, p.259-260). Those relationships change over time and space, and can (and will) attract, bifurcate, and recur at different points throughout a child's development.

When we bring illness into the picture, Dr. Esther Thelen (2004) points out that "how one views the etiology of a disorder—and one's implicit and explicit theories of development—can profoundly alter how one treats a child (p.257). Although children and parents may feel that an illness is them, that it has defined who they are, it is essential that those providing care do not fall into the same trap. The human being is composed of infinite complex systems. I believe these theories provide a sensible basis for this. A chronic medical condition inserts itself into the very fabric of an individual, but how it progresses, how it impacts the body, and how its effects ripple throughout a child's different systems and relationships are all equally important when treating a child for a chronic condition.

## Multilevel Impacts

Studies that pertain to chronic medical illness tend to use measurements of "quality of life" (QoL) to assess the general well-being of those chronically ill. The CDC defines quality of life as a "broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life" (CDC.gov/HRQOL Concepts). In pediatric research, measures like the Pediatric Quality of Life Inventory (PedsQL), and the KINDL-R are used to obtain a quantifiable idea of a child's physical, emotional, social, family, and school functioning (Hullman, et al., 2011). The mental health/well-being, of both the caregiver and the child, is often analyzed through this lens of quality of life, or in conjunction with it.

What the literature has shown is that there is a "preoccupation with the body and with disease" that often neglects the patient as a person, and does not address psychological and social recovery from the onset of diagnosis (Engel, 1980, p. 538; Atkins, Colville, and John, 2012). As previously mentioned, the characteristics that distinguish chronic illnesses from more transient conditions— prolonged duration, difficulty to treat, and association with impairment or disability—have negative consequences on the financial prosperity, academic success, and mental health/well-being of both the chronically ill child and his/her family (Bell et al., 2016; Children's Environmental Health Center, 2013; Suryavanshi and Yang, 2016; Wilcox, et al., 2016).

### *Financial Impact*

For parents of chronically ill children, health care costs pose a significant financial burden (Suryavanshi and Yang, 2016; Quach and Barnett, 2015; Szefler et al., 2011). Standard cost of treatment for a child with a chronic condition often includes prescription drugs, special medical devices to monitor the condition, regular office visits, and specialty visits (Suryavanshi and Yang, 2016). In addition to these services, there is a greater use of the healthcare system overall. These families report more emergency room (ER) visits, impatient hospitalizations, out-patient (i.e. walk-in) visits, and greater use of home health care (Suryavanshi and Yang, 2016; Szefler, et al., 2011). This all comes at a direct and indirect cost to the family and society. One Australian study found the mean primary care medical cost to be more than 240% higher for families with a chronically ill child (US$1648) than for those with no chronic illness (US$ 681) over the same period of time (Quach and Barnett, 2015). This does not take into account the extra costs incurred from additional, concurrent illnesses and disorders that children with chronic conditions commonly experience. When those costs are factored in the price tag nearly doubles (Suryavanshi and Yang, 2016).

Other studies have shown that depending on the severity and chronicity of a condition, indirect costs (i.e. cost due to school and work days lost) can account for approximately half of the total cost of care for a chronic condition (Szefler, et al., 2011). This is a significant financial burden on families with chronically ill children, as well as on a society that simultaneously loses productivity output, and gains fiscal responsibility (Szefler, et al., 2011; Wilcox, et al., 2016). In 2003, for example, Medicare and Medicaid covered half of the "total obesity-attributable medical expenditures" nationwide at a total cost of $38 billion dollars (New York State's Children and the Environment, 2013, p. 65).

### *Academic Impact*

There are some chronic conditions whose very nature unquestionably affects a child's cognitive development due to their neuropathological origins and/or processes (e.g. brain tumors and epilepsy). Studies suggest that attention and executive functions are two cognitive abilities predominantly affected by these types of neurologically based chronic conditions (Steck-Silvestri, et al., 2013; Reuner, et al., 2016). What is more, their treatment options also have negative effects on cognitive development. Both radiation/chemotherapy, as well as some epilepsy medications can have neurocognitive side effects, such as: lower working memory, slower processing speeds, and response inhibition deficits (Steck-Silvestri, et al., 2013).

However, even children with non-neurological types of chronic conditions are at risk for poorer academic performance. In some studies, children with asthma have been shown to be 14 times more likely to develop learning and developmental problems (Arif and Korgaonkar, 2015). It is believed that these negative effects on a child's academics are due in large part to the absenteeism associated with chronic conditions. Having a chronic illness requires constant monitoring, and in some cases it may require location and time specific treatments (e.g. chemotherapy or dialysis). For a child this has multiple implications. In terms of just the academic material, a chronically ill child is constantly playing catch-up to his/her peers—assuming that neither the illness nor the treatment/therapy is energy depleting, as is the case with more strenuous treatments like dialysis, radiation/chemotherapy, and physical therapy.

Arguably more important, though, is that chronically ill children miss out on classroom time, not just learning material. They miss out not only on learning, but also on interacting and socializing with peers, on honing skills like attention maintenance and self-regulation that are necessary to be successful in a traditional academic setting. Children with chronic conditions have worse academic outcomes than their peers on standard measures like literacy, and they also score poorly on domains like social competence, emotional maturity, and communication skills (Quach and Barnett, 2015; Bell et al., 2016; Reuner, et al., 2016; Curtis and Luby, 2008). This should perhaps be more worrisome.

### *Social Impact*

Qualitative studies in which both chronically ill children and their parents are interviewed reveal a myriad of pressures felt by both parties that extend beyond the physical challenges directly posed by the illness. Thematically, the topics of:

normalization, conversations about disclosure, and reintegration after isolation emerge repeatedly in the literature (O'Toole et al., 2016; Atkins, Colville, and John, 2012; Engel and Melamed, 2002). Both children and their parents are concerned with being labeled as "ill," and how differently people will treat them due to this experience (Engel and Melamed, 2002). Absenteeism from both work and school, for parents and children respectively, has obvious financial and academic ramifications, but socially speaking reacclimation to 1) a changed environment or 2) the same environment but a "different you" can take its toll on how they are perceived by their peers, and how they perceive themselves.

Social functioning is one of the domains in which children with chronic conditions tend to perform worse than their healthy peers. Unfortunately, when they do return to their typical social settings (i.e. school), chronically ill children are more likely to face rejection and bullying from their peers (Curtis and Luby, 2008; Pinquart, 2012). Self-concept is a vital part of a child's psychological function and socioemotional development, particularly during these early years of life (Pinquart, 2012; Yamamoto, 1972). A child's judgment of self is reliant on how he/she believes to be perceived by those closest to him/her—parents, siblings, teachers, and peers. Understandably, chronically ill children are treated differently. Parents may be more overprotective, teachers may be more or less patient with them, and peers, we know, tend to be more cruel. It follows, then, that sick children exhibit more asocial, distant, and even defensive behaviors (Curtis and Luby, 2008; Yamamoto, 1972).

In a society, like ours, that stresses and places a high premium on individualism and success, the inability to reach those goals sets that person up for failure and social devaluation, making those fears of being labeled and thought of as "less than" well founded. This translates to *self*-devaluation, and leads to even more negative effects on a child's mental health/well-being (Yamamoto, 1972). Feelings of low self-esteem, for instance, are believed to be related not just to poor physical functioning, but also poor social functioning in children with chronic medical conditions (Pinquart, 2012).

### *Impact on the Mental Health of Parent and Child*

Chronic illness impacts both the child's and the caregiver's mental health/well-being. Concern over treating the illness and the physical symptoms, by both physicians and parents, prioritizes the illness at the expense of other areas of health. Retrospective research can provide evidence of this, as well as insight into how to avoid falling into this pitfall. The literature suggests that poor mental health outcomes are more dynamic than A leads to B (i.e. a cause and effect model). Exhibiting poor mental health symptoms should not be considered a simple consequence of having a chronic illness (or having a child with a chronic illness). There are different mediators, like the ones previously discussed that influence, to varying degrees, the mental health status of those coping with the chronic condition.

The word that repeatedly appears for parents is: stress. Grappling with the idea, and the implication, of having a child with a chronic condition can be quite a process. The term "chronic sorrow," first described by Simon Olshansky in 1962, "refers to a pattern of sadness in response to the child's differences" (Shepard and Mahon, 2002, p. 161). As families adapt to the changes and the implications of having a chronically ill child, their "sorrow" also evolves and changes throughout the course of the illness. In addition to sadness, "feelings of anger, guilt, and failure" also form a part of their ever-changing chronic sorrow (p.161). As the medical condition progresses (or continues, as the illness does not need to get worse for the burden of it to feel greater), those implications parents feared may, and often do, become realities.

One of the greatest stressors associated with chronic conditions is the financial burden on a family due to the direct costs of care and treatment, and the indirect costs of lost wages. This, along with any number of accommodations a family must make, puts a strain on the entire family structure—affecting overall functioning, conflict management, and marital status (Swindle, et al., 2015). One can imagine how these issues, independently or in combination with each other, can spill into the caregivers' own physical and mental well-being. Quality of life scores for parents of chronically ill children are lower than their counterparts' with healthy children (Macedo et al., 2015). In some cases, even the coping mechanisms parents adapt become problematic. Turning to smoking or alcohol use (Swindle et al., 2015; Weil, 1999) has a negative effect for healthy people, for already ill and burdened families the consequences can be exponentially worse.

Having all of these feelings, pressures, and responsibilities compound is nothing less than stressful and worrisome. It is said that it takes a village to raise a child, a healthy one at that. Many times parents of chronically ill children are isolated in their struggles, in need of greater social support systems (Macedo et al., 2015; Weil, 1999). If these issues are not alleviated, adequately dealt with, it makes sense for a parent's poor mental health to influence his/her sick child's mental health as well (Ohleyer et al.,

Another significant way in which this can affect chronically ill children's well-being is through changes in parenting behavior. Maternal depression, in particular, has been shown to negatively impact social engagement and regulatory behaviors in children (Feldman, et al., 2009) by disrupting parent-child interactions. Mothers are less likely to adapt to their children's cues, and be verbally responsive if they are suffering from depressed and/or anxiety.

Even very young children interpret, on some level, how their caregivers perceive them (Yamamoto, 1972). As previously mentioned, the building of self-concept is dependent on this very perception. Negative effects on a child's self-image have led researchers to focus their investigative efforts on the comorbidity of chronic medical conditions and mental health disorders in children (Ortega et al., 2002; Steck-Silvestri, et al., 2013; Suryavanshi and Yang, 2016). Those with chronic physical illnesses are up to four times more likely to develop psychiatric symptoms (Bennet, et al., 2015; Pinquart and Shen, 2011). Depression and anxiety, more commonly, but even separation disorders and simple phobias have been reported amongst this population of children (Weil, 1999; Ortega, et al., 2002; Bennet, et al., 2015; Wilcox, 2016).

### *Internalizing vs. Externalizing Symptoms in Pediatric Chronic Illness Research*

There has been a great deal if interest in the internalizing symptoms expressed by caregivers and children (i.e. symptoms of depression, anxiety, and self-esteem issues), for which there are strong and significant findings across varying types of chronic conditions (Bennett, et al., 2015; Cousino and Hazen, 2013; Curtis, et al., 2008; DeWalt, et al., 2015; Macedo, et al., 2015; Moreira, et al., 2013; Oretga, et al., 2002; Pinquart and Shen, 2011). Those studies that do address externalizing symptoms, like fighting and throwing temper tantrums, view these behaviors in the context of social functioning, rather than mental health/well-being (Curtis, et al., 2008). In other words, when data on externalizing symptoms are collected, they are interpreted as mediating factors between childhood chronic illness and poor social/peer relationships. This approach, while logical, fails to address externalizing symptoms as possible indicators of chronically ill children's mental/emotional state, or coping troubles.

Unlike internalizing, externalizing behaviors appear to be more illness-specific. Children with chronic conditions associated with impaired brain function, like cerebral palsy, epilepsy, and migraines (Moreira, et al., 2013; Pinquart and Shen, 2011) tend to have the strongest correlations with externalizing behavioral problems. However, this should not discourage investigation into this aspect of mental health with other medical conditions. In fact, when further analyses are done, externalizing symptoms are found to be associated with a myriad of other variables, like socioeconomic status, school achievement, resilience, and family conflict, even in non-neurological chronic conditions (Kim and Im, 2014; Holmes, Yu, and Frentz, 1999).

It is important to look at what externalizing behaviors children with chronic conditions exhibit, in part because it is an area understudied, at least when compared to the attention given to internalizing symptoms, but also because it seems to be interrelated with many other, important aspects of a child's life. Externalizing behaviors, unlike internalizing ones, are readily visible, and discernable even to an untrained eye. It could be argued that this makes it a more dependable measure of mental health/well-being, because adult reports on these behaviors can be regarded as quite objective, certainly more so than reports of internalizing behaviors (Pinquart and Shen, 2011).

In developmentally delayed, nonverbal pediatric populations (e.g. children with autism spectrum disorders) aggressive behaviors are interpreted as incommunicable frustrations. It is reasonable to propose that the same could be true for children living and dealing with chronic conditions, particularly for younger children who may not yet have the communication skills, even though they have the physical ability, to express similar frustrations. Between the ages of four to seven, typically developing children will resort to crying, screaming, verbal resistance, and increased physical activity (though not necessarily aggressive) as coping mechanisms (Engel and Melamed, 2002). These are externalizing behaviors; and this is the way children that age know best to express themselves and/or deal. As children get older, this of course changes. Between eight and eleven years of age, there is significantly less crying and screaming, greater use of cognitive distractions, and greater use of words to express pain (Engel and Melamed, 2002). As they approach adolescence, children's communicative and coping skills transform from outward manifestation to inward management, from externalizing to internalizing. For younger children with chronic conditions, instruments or even subscales, specifically addressing hyperactivity and aggression could more directly address a relationship between externalizing symptoms and the chronic condition.

## Potential Significance

This current project aims to address two main issues: the effects on parental and childhood mental health of having a child with a chronic condition, and specifically the externalizing symptoms exhibited by children with chronic conditions. Given the number and variety of concerns that families with chronically ill children must contend with, stress would be an adequate indicator of mental health/well-being. Moreover, the population studied as part of the BELLE Project (to be described below) is one of low income and socioeconomic demographics. The present project could potentially provide evidence supporting an adverse, additive effect on mental health/well-being in a population already burdened by other environmental factors. A finding in this direction could help make a case for programs or groups offering no-to-low cost additional support and resources to these kinds of families, who may not otherwise be able to afford the extra psychological help they need.

Based on the literature, it would appear as though a majority of interest lies in the internalizing symptoms expressed by caregivers and children (i.e. symptoms of depression, anxiety, and self-esteem issues). However, children do not, and depending on their age *cannot*, always accurately or clearly relay their feelings. It would therefore make sense to also pay attention to the externalizing symptoms—like aggression, temper, and/or defiance—that children coping with a chronic condition may present. This project will hopefully add to the limited body of work currently available on this specific aspect of mental health in chronically ill children.

Theories that highlight the interdependence and interrelationship amongst the different aspects (i.e. systems) of a child's life point to a dynamic, nonlinear interaction (Thelen, 2005). The question is whether that pattern holds or changes for children with chronic conditions and their families. Findings could provide support for a more biopsychosocially conscious, multifaceted, inter-disciplinary treatment plan for families receiving or coping with a pediatric chronic illness diagnosis.

## METHODS

The current project uses and analyzes data previously collected in a larger IRB-approved, longitudinal study—the Bellevue Project for Early Language, Literacy, and Education Success (BELLE). The BELLE Project aims to deliver a parenting intervention to low-income families in the hopes of improving their children's future developmental and educational outcomes.

### Original Study Design

Mother-child dyads were recruited at birth in an urban public hospital serving low-income families for participation in the BELLE Project—a 3-way randomized controlled trial. The three randomization groups were: video interaction project (VIP), building blocks (BB), and control.

The Video Interaction Project is a "relationship-based intervention" where the children's primary caregivers (typically their mothers) meet with a parent-child specialist who provides the parent(s) with an age appropriate toy or book (e.g. textured baby book, doctor kit, school bus), and makes a video of the parent(s) and the child playing and interacting together (Developmental and Behavioral Pediatrics). This video is burned right away, and reviewed with the parent(s), highlighting different aspects of the child's development, the parent's positive scaffolding, and/or attachment-building practices. The interventionist also discusses and jots down any goals the parent(s) would like to help their baby/child reach in the next session and/or home, and the parent takes home the toy/book they used in the session, a copy of their video, and a customized pamphlet with all of the notes taken during the session. These sessions are scheduled to coincide with the child's well-child medical visits.

The Building Blocks (BB) group received mailed information and learning materials from birth to 36 months of age. Parents in this group received an age-specific parenting newsletter at 6, 9, 11, 14, 16, 19, 24, 30, and 32 months of age, which suggested parent-child activities, and discussed topics such as: safety, developmental milestones, and feeding.  The newsletters were accompanied by a toy or book.

The control families continued to received their child's standard pediatric care in the hospital.  All the families enrolled in the research study, regardless of randomization group, also agreed to come in periodically (every 6 or 12 months) for developmental evaluations that assessed different aspects of the child's development, including but not limited to: language, cognitive, and socio-emotional development.

## Participants

Six hundred and seventy-five mother-child dyads were recruited between 2005 and 2008 in the maternity ward for participation in the BELLE Project.  All children were typically developing, full-term, and healthy at birth. Primary care givers were mothers, at least 18 years of age, who spoke English or Spanish as their primary language, and intended to receive their children's pediatric care at the institution of birth for the next three years.

## Data Source

The current project analyzes data previously collected during the developmental evaluations of the BELLE Project, specifically, parent and child self-reports related to children's emotional and social behaviors, physical health function, as well as parent reports of their own mental health/well-being and parenting behaviors.  Caregivers were asked if the child had any medical and/or neurological problems or diagnoses at the 36-Month, 54-Month, and 72-Month developmental evaluations; if they responded positively they were asked to specify the condition(s).

For the purposes of this present project, children with a parent-reported medical condition during the 36-Month developmental evaluation were considered for the chronically ill sample.  The reported medical problems were individually reviewed, and those determined to be chronic conditions causing functional impairment or considerable disruption to everyday life.  The following medical problems were excluded from analysis on this basis: dental cavities, heart murmurs, broken finger, delayed speech, and environmental allergies, as well as children with neurodevelopmental disorders, such as autism and sensory integration.  This study was exempt from review by the Sarah Lawrence Institutional Review Board per the Common Rule, which specifies that deidentified existing data are exempt.

## Measures

BELLE parent reports did not include a quality of life (QoL) instrument through which assessment of mental health would have been comparable to the existing literature. However, measures related to parenting stress and maternal depression were collected throughout the longevity of the study via the Parenting Stress Index: Parent-Child Dysfunctional Interaction (PSI-PCDI) instrument and the Center for Epidemiologic Studies Depression Scale (CES-D).  In addition, a measure of cognitive stimulation provided to the child by the parent (STIMQ- Preschool) was also included in analyses as a measure of positive parenting behaviors. Measures of children's mental health/well-being were obtained in the last, 72-Month developmental evaluation from parent report of mental health symptoms (Pediatric Symptom Checklist (PSC-17)) and child report of perceived stress (Lewis Stressful Life Events Scale (Lewis, Siegel, and Lewis, 1984)). These measurements, along with subscales related to externalizing behaviors—aggression and hyperactivity—from the Behavioral Assessment System for Children-Parent Rating Scale (BASC-2) helped ascertain mental health/well-being for the children, and differentiate between their internalizing and externalizing symptoms. All measures were collected during the 36-Month developmental evaluation (here forth identified as Early), after the 36-Month developmental evaluations (i.e. 54-Month and/or 72-Month; identified as Later), or both. The Hollingshead Four Factor Index (Hollingshead, 1975) was used to determine SES. The score was calculated on the basis of marital status, parental education, employment status, occupation.

### ***Parental Mental Health/Well-Being***

*PSI-PCDI*: This subscale of the Parenting Stress Index- Short Form, 3rd Edition (PSI-SF; Abidin, 1995) assesses the parent-child relationship, specifically the degree to which parents feel their child and their interactions with their child do not meet their expectations. It consists of 12 items rated on a 5-point Likert scale. The PSI-SF has been demonstrated to have good concurrent and construct validity, as well as satisfactory internal consistency and test-retest reliability (Abidin, 1995; Abidin and Brunner, 1995). It has been adapted in several languages, including Spanish, and has been shown to be psychometrically appropriate in high-risk families, and diverse populations (Barroso, et al., 2016).

*CES-D*: This 20-item self-report questionnaire is a widely used measure of depressive symptomatology, using a cut-off score of 16 to detect mild to moderate depressive symptoms (Radloff, 1977). It has been consistently demonstrated to have robust psychometric properties, including high internal consistency (Cronbach's α coefficients between .85 to .90), as well as adequate test-retest reliability and excellent concurrent validity (Radloff, 1977; Lewinsohn et al., 1997; Barroso, et al., 2016).

### *Parenting Behaviors*

*STIMQ-Preschool*: This structured interview (Dreyer, Mendelsohn, and Tamis-LeMonda, 1996) assesses parenting behaviors important for promoting development in children ages 36 to 72 months. It includes four subscales: availability of learning materials (ALM) in the home, the number and diversity of books read to the child (READ scale), parental involvement in developmental advance (PIDA) (i.e. parental teaching behaviors), and parental verbal responsivity (PVR). The measure is available in both English and Spanish. It has high internal consistency (Cronbach's α coefficients between .88 to .93) and test-retest reliability ($r$ = 0.93; Dreyer, Mendelsohn, and Tamis-LeMonda, 1996).

### *Child Mental Health/Well-being*

*PSC-17*: This measure is an abbreviated version of the PSC-35, which is a validated parent-reported screening questionnaire (Garner et al.,1999; Murphy et al., 2016) used in clinical settings to recognize psychosocial problems in children. High test-retest reliability ($r$ = .84 to .91), and internal consistency (Cronbach's α coefficients = .91) provide psychometric support for its use (Garner et al.,1999; Murphy et al, 1996). This tool assesses: how a child is functioning in his/her different environments (home and school), with different people (friends and family), and the child's own moods and behaviors. Its three subscales—Attention, Internalizing, and Externalizing—reflect these areas of interest. A positive score (> 15) suggests the need for further evaluation by a qualified health or mental health professional.

*Feel Bad Scale:* This assessment asks children to rate both the frequency and severity of common stressors for elementary school aged children, including familial, peer, and school stressors (Lewis, Siegel, and Lewis, 1984). Internal consistency, particularly for the severity questionnaire is high (Cronbach's α coefficients = .82).

*BASC-2*: It is an instrument used to evaluate children's observable behaviors, personality, and emotional disturbance (Reynolds and Kamphaus, 2004). The Parent Rating Scale, rated on a 4-point frequency Likert scale, gathers the parent's perceptions on the child's: social skills, hyperactivity, aggression, and attention problems. Both the English and Spanish versions have been shown to have strong sensitivity and specificity in diagnostic applications. It has high internal consistency (Cronbach's α coefficients > .80) and test-retest reliability.

### Statistical Analysis

Since the sample size for children with a reported chronic condition was not large (n=43), no statistical analyses were conducted within or across chronic health conditions. Instead descriptive analyses compared the chronically ill sample to a healthy sample (n=602) from the same data source—BELLE Project participants—with no reports of chronic illness or behavioral disorders. All analyses were prepared and conducted with IBM Statistical Package for Social Sciences (SPSS) Statistics, version 23.

Correlation analyses were performed to investigate bivariate relationships between the presence of chronic condition and mental health/well-being of both the parent and child. The statistical threshold was set at $p < 0.05$ (two-tailed). Multiple linear regression analysis was done using Later aggression as the dependent variable and the following variables as independent variables: Early aggression, SES, gender, and mother born outside of the US.

## RESULTS

### Demographic Characteristics

Sociodemographic characteristics are presented in Table 1 for: the selected chronically ill sample and the healthy control sample. There were no significant demographic differences between the groups. A majority of the study participants identified as Hispanic/Latino; and more than three-quarters, in each study sample, reported Spanish as the primary language spoken at home. In the chronically ill sample, 95% of families were considered of low socioeconomic status (SES).

**Table1**: Demographic Characteristics of Study Participants

| **Characteristics** | **Chronically Ill**<br>N = 43<br>% | **Healthy Controls**<br>N = 602<br>% | $\chi^{2a}$ | ***p*** |
|---|---|---|---|---|
| Male | 46.5 | 50.8 | .15 | .70 |
| Ethnicity | | | .32 | .57 |
| Hispanic/Latino | 95.3 | 91.7 | | |
| Other | 4.7 | 8.3 | | |
| Home language | | | .00 | 1.00 |
| English | 23.8 | 23.3 | | |
| Spanish | 76.2 | 76.7 | | |
| Low socioeconomic status | 95.0 | 89.8 | .63 | .43 |
| Parents married | 79.1 | 83.6 | .30 | .58 |
| Mother non-US born | 79.1 | 83.9 | .37 | .54 |
| Mother unemployed | 86.0 | 80.4 | .50 | .48 |
| Mother's education level | | | | |
| High school degree/GED | 39.5 | 44.2 | .19 | .66 |

a. Chi-square with Yates' Continuity Correction reported for comparisons with exactly two levels.

### Descriptive outcome

All measures, with the exception of the Feel Bad Scale, were collected in an interview format via parent report. The Feel Bad Scale responses were obtained from the child during the child's 72M developmental evaluation. For descriptive data of the scores for each measure and subscale used in this project, see Table 2. Chronically ill children scored significantly higher in both Earl and Later Aggression, and in Later Pediatric Internalizing symptoms than their health peers.

**Table 2**: Variables' mean scores, standard deviation, and range of responses.

| **Measure** | | | **Chronically Ill** | **Healthy Controls** | ***t*** |
|---|---|---|---|---|---|
| **Maternal Depression (CES-D)** | Early | Mean (SD) | 7.58 (8.97) | 6.61 (8.84) | -.665 |
| | | Range | 0 – 41 | 0 – 45 | |
| | | Possible Range | 0 – 60 | 0 – 60 | |
| | Later | Mean (SD) | 7.91 (8.93) | 6.92 (10.00) | -0.55 |
| | | Range | 0 – 37 | 0 – 51 | |
| **Parenting Stress (PSI-CDI)** | Early | Mean (SD) | 18.86 (6.72) | 17.52 (5.03) | -1.53 |
| | | Range | 12 – 38 | 12 – 34 | |
| | | Possible Range | 12 – 60 | 12 – 60 | |
| | Later | Mean (SD) | 20.06 (7.74) | 18.21 (6.56) | -1.49 |
| | | Range | 12 – 52 | 12 - 48 | |
| **Cognitive Stimulation (STIMQ)** | Early | Mean (SD) | 26.58 (8.89) | 26.25 (8.18) | .05 |
| | | Range | 2 – 42 | 4 – 46 | |
| | | Possible Range | 0 – 46 | 0 – 46 | |
| | Later | Mean (SD) | 38.32 (10.39) | 36.11 (10.21) | -1.18 |
| | | Range | 16 – 56 | 3 – 59 | |
| | | Possible Range | 0 – 60 | 0 – 60 | |
| **Child Hyperactivity** (BASC-Hyperactivity) | Early | Mean (SD) | 56.19 (13.32) | 52.64 (11.76) | -1.79 |
| | | Range | 35 – 96 | 33 – 94 | |
| | | Possible Range | 0 – 100 | 0 – 100 | |
| | Later | Mean (SD) | 51.97 (8.87) | 51.34 (10.89) | .323 |
| | | Range | 35 – 75 | 31 – 95 | |
| **Child Aggression** (BASC-Aggression) | Early | Mean (SD) | 48.88 (11.27) | 44.89 (8.59) | -2.67** |
| | | Range | 33 – 87 | 33 – 80 | |
| | | Possible Range | 0 – 100 | 0 – 100 | |
| | Later | Mean (SD) | 46.21 (7.10) | 43.63 (6.96) | -2.01* |
| | | Range | 35 – 61 | 35 – 74 | |
| **Later Pediatric Internalizing** (PSC-17 INT) | | Mean (SD) | 2.59 (1.73) | 1.81 (1.44) | -2.02* |
| | | Range | 0 – 5 | 0 – 6 | |
| | | Possible Range | 0 – 10 | 0 – 10 | |
| **Later Pediatric Externalizing** (PSC-17 EXT) | | Mean (SD) | 2.82 (2.04) | 2.68 (2.41) | -0.24 |
| | | Range | 0 – 7 | 1 – 11 | |
| | | Possible Range | 0 – 14 | 0 – 14 | |
| **Later Childhood Stress** (Feel Bad Scale) | | Mean (SD) | 53.32 (28.23) | 59.23 (30.54) | 0.79 |
| | | Range | 12 – 129 | 4 – 135 | |
| | | Possible Range | 0 - 380 | 0 – 380 | |

*$p < .05$, **$p < .01$

## Bivariate Relationships

There were a number of expected associations within parental mental health symptoms (depression and stress), children's mental health symptoms (internalizing and externalizing symptoms), and children's externalizing behaviors (aggression and hyperactivity) (see Table 3). Parenting stress and maternal depression were significantly related when reported at the 36M developmental evaluation, as well as at a future point. Similarly, children's later internalizing and externalizing symptoms were highly correlated when reported concurrently; and there was an even stronger association between specific externalizing behaviors of aggression and hyperactivity at both early and later points.

Longitudinal relationships were also observed between those items repeatedly assessed. Regardless of children's medical health conditions, reports of maternal depression, parenting stress, and children's hyperactive and aggressive behaviors persisted in mothers and their children.

Positive associations were found between children's medical health status and their externalizing behaviors. Aggressive behavior, per parent report, was significantly related to having a chronic medical condition, not just at 36 months but at later ages as well. This relationship was not just observed in children's future externalizing behaviors, but also in their internalizing symptoms. As expected, children's externalizing behaviors were related to caregiver's mental health—particularly in parenting stress. And there was a strong negative correlation between self-reported parental stress and the cognitive stimulation offered to the child.

## Multiple Linear Regression Analysis

A multiple linear regression analysis was completed in order to determine how certain traits predicted aggressive behavior later in life for chronically ill children. Analysis of covariance controlling for SES, gender, country of origin, and early aggression were conducted. Step one included: SES, child's gender, mom's country of origin, early aggressive behavior, presence of a chronic medical condition, and later parental cognitive stimulation. The initial model predicted 22% of the variance in child aggressive behavior ($R^2$= .218). In step two, the interaction between chronic medical condition and later parental cognitive stimulation was added. This addition significantly improved the model ($\Delta R^2 = .02$, $\Delta F = 4.48$, $p < .05$). The interaction term was a significant predictor of later aggression, indicating that cognitive stimulation significantly influenced future aggressive behavior in children with chronic medical conditions. Chronically ill children who are provided less cognitive stimulation are more likely to exhibit aggressive behaviors. Inversely, the more cognitive stimulation is given to the child by the parent, the more aggressive behaviors are suppressed. Additionally, when there is a high level of cognitive stimulation provided by the parent, the relationship between chronic medical condition and aggressive behavior was no longer significant (see Figure 1).

**Table 3**: Correlations among study variables

| | 1. | 2. | 3. | 4. | 5. | 6. | 7. | 8. | 9. | 10. | 11. | 12. | 13. | 14. |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1.Chronic Condition | -- | | | | | | | | | | | | | |
| 2.Early Maternal Depression | .039 | -- | | | | | | | | | | | | |
| 3. Later Maternal Depression | .034 | .461** | -- | | | | | | | | | | | |
| 4. Early Parenting Stress | .090 | .255** | .158* | -- | | | | | | | | | | |
| 5.Later Parenting Stress | .092 | .217** | .210** | .453** | -- | | | | | | | | | |
| 6. Early Cognitive Stimulation | -.003 | -.166** | -.049 | -.315** | .333** | -- | | | | | | | | |
| 7. Later Cognitive Stimulation | .073 | -.142* | -.194** | -.241** | .352** | .634** | -- | | | | | | | |
| 8.Early Child Hyperactivity | .105 | .263** | .125* | .339** | .149* | -.193** | -.086 | -- | | | | | | |
| 9. Later Child Hyperactivity | .020 | .259** | .176** | .290** | .259** | -.079 | -.178** | .567** | -- | | | | | |
| 10. Early Child Aggression | .156** | .299** | .142* | .338** | .178** | -.223** | -.089 | .575** | .382** | -- | | | | |
| 11.Later Child Aggression | .124* | .203** | .216** | .263** | .409** | -.174** | -.230** | .309** | .547** | .438** | -- | | | |
| 12.Later Child Internalizing | .173* | .207* | .229* | .049 | .67 | .053 | .005 | .085 | .024 | .132 | .023 | -- | | |
| 13.Later Child Externalizing | .021 | .216* | .105 | .219* | .117 | -.109 | -.272** | .289** | .301** | .323** | .234* | .323** | -- | |
| 14. Later Child Stress | -.068 | -.028 | -.017 | .075 | -.031 | -.051 | -.060 | -.028 | -.141 | .071 | .013 | .150 | .180* | -- |

* $p < .05$, ** $p < .01$

**Table 4**: Regression analysis predicting later childhood aggression from demographic and medical condition variables

| Variable | *B* (SE) | β | *t* | *p* |
|---|---|---|---|---|
| **Model 1** | | | | |
| SES | -2.41 (1.81) | -.080 | -1.33 | .19 |
| Gender | -.64 (.83) | -.05 | -.77 | .44 |
| Mother non-US born | -2.28 (1.60) | -.09 | -1.42 | .16 |
| Chronic Medical Condition | 2.10 (1.23) | .10 | 1.71 | .09 |
| Early Childhood Aggression | .31 (.05) | .40 | -1.42 | .16 |
| Later Cognitive Stimulation | -.13 (.04) | -.20 | -3.30 | < .01 |
| **Model 2** | | | | |
| SES | -0.30 (1.80) | -0.08 | -1.28 | .20 |
| Gender | -0.73 (.83) | -0.05 | -0.88 | .38 |
| Mother non-US born | -2.65 (1.60) | -.10 | -1.66 | .10 |
| Chronic Medical Condition | 11.94 (4.81) | 0.58 | 2.48 | < .05 |
| Early Childhood Aggression | 0.31 (.05) | 0.41 | 6.84 | < .001 |
| Later Cognitive Stimulation | -0.10 (.04) | -0.15 | -2.33 | < .05 |
| Chronic Medical Condition x Later Cognitive Stimulation | -.26 (.12) | -.50 | -2.12 | < .05 |

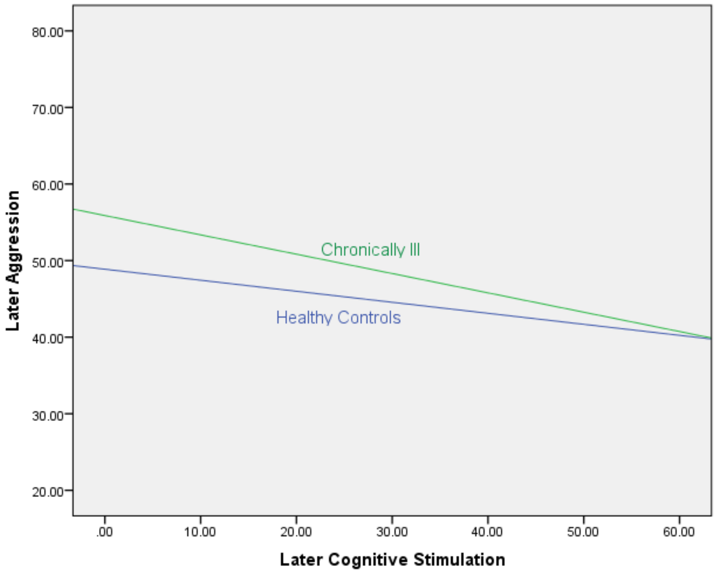

**Figure 1**: Linear regression model comparing parental cognitive stimulation and later child aggression between chronically ill and healthy children.

## DISCUSSION

This study used parent reports of chronic medical conditions in their children to examine the association between childhood chronic illness and the mental health/well-being and maladaptive behaviors of both the primary caregiver and the chronically ill child. The data collected over time suggests that children with a chronic medical condition exhibit a variety of behavior issues, including greater internalizing symptoms, greater externalizing behaviors, such as aggression and hyperactivity, than their healthy peers. Moreover, this relationship appears to persist beyond the age of diagnosis. In addition, parents who report feelings of depression and stress, independent of their children's physical health, also continue to experience these sentiments over time. Although these issues were not directly related to children's chronic illness, they were related to levels of cognitive stimulation provided to the child. However, if the parent of a chronically ill child provides him/her with greater cognitive stimulation, the effects of having a chronic medical condition on externalizing symptoms appear to be suppressed by their parental involvement.

Parenting stress and maternal depression, and aggression and hyperactivity were used as indicators of poor parental mental health and of children's externalizing behaviors respectively. As expected, there were positive and significant relationships within each set of indicators. Parenting stress was viewed specifically as it related to parent-child interaction via the PSI's Parent-Child Dysfunctional Interaction subscale, which assesses the degree to which parents feel their child and their interactions with their child do not meet their expectations. Parents who reported greater feelings of depression also scored higher on the PSI-PCDI, indicating that their interactions with their children did not meet their expectations, causing them concern in regards to their roles as parents. Similarly, children who were considered to be more aggressive by their primary caregivers were also thought to be more hyperactive. Unsurprisingly, these relationships persisted over time, suggesting that psychological issues also have elements of chronicity, in that unless they are addressed they can continue or reoccur in both the near and distant future.

One aspect of these relationships that *was* surprising was that they were not related to children's physical health. A possible explanation for this is the sociodemographic homogeneity between groups. Participants in both the chronically ill and the healthy groups were overwhelmingly Spanish-speaking Hispanic/Latino immigrant families of low SES. It is therefore likely that participants in both groups faced the same stresses and challenges in their everyday life—including but not limited to: urban poverty, lack of childcare, housing instability, high level of unemployment, and less access to resources (Bartlett, et al., 1999)—affecting their mental health/well-being in equal ways (Kim and Im, 2014).

However, despite these similarities, sociodemographics did not confound the relationship between chronic medical conditions and externalizing behaviors in children. This study's data suggest that young children with a chronic illness are more likely to have externalizing symptoms, expressed specifically through aggression, well after the age of diagnosis. Although the relationship is not very strong, it is statistically significant. Thus it was enough of a discernable pattern in a relatively small sample size to indicate that having a medical condition ever-present in the life of a young child and his/her family can lead to behavioral problems for the child.

After controlling for demographic predictors (SES, gender, and country of origin), multiple linear regression analyses demonstrated that medical condition and lack of cognitive stimulation provided to chronically ill children were significant predictors of aggressive behavior in these children later on in life. Moreover, bivariate analyses showed significant negative relationships between cognitive stimulation and parental mental health. The correlation coefficients for these associations varied in strength, ranging from -.142* to -.352** (* $p < .05$, ** $p < .01$). The strongest relationship was between self-reported parenting stress after diagnosis of the child's medical condition and lack of parental cognitive stimulation during that same time period. In other words, parents who felt concern or pressure about how they interact with their children, because they didn't feel it was meeting their expectations of what that interaction should be, were also reporting less availability of learning materials, less shared reading, and less verbal responsivity on their part.

These results provide support for some of the literature that does address externalizing symptoms in children with chronic medical conditions (Curtis and Luby, 2008; Holmes, Yu, and Frentz, 1999; Kim and Im, 2014; Moreira, et al., 2013; Ohleyer, et al., 2007; Pinquart and Shen, 2011). Overwhelmingly, research tends to focus on signs of depression, anxiety, and self-esteem issues—internalizing symptoms (Arif and Korgaonkar, 2016; Bennett et al., 2015; Curtis and Luby, 2008; DeWalt et al., 2015; Macedo et al., 2015; Muhammed, et al. 2016; Ortega et al., 2002; Pinquart, 2012; Wilcox et al., 2016)—even when young children's coping mechanisms are more likely to be external (Engel and Melamed, 2002), if only because of their developmental capacities. These data pointing specifically to aggression ought to encourage further research into externalizing symptoms and the different behaviors through which they are expressed. This study used parental reports of aggression and hyperactivity, but a combination of other behaviors, such as temper tantrums, crying, screaming, and pouting, should also be simultaneously considered (Curtis and Luby, 2008; Engel and Melamed, 2002) when thinking about chronically ill children's mental health/well-being.

Perhaps one of the most interesting findings of this study is the role and importance of parental involvement in cognitive stimulation for children with a chronic medical condition. Previous studies have emphasized that there is a preoccupation with the disease itself by both physicians and parents of chronically ill children (Engel, 1980; Atkins, Colville, and John, 2012).

This has the potential to leave other areas of a child's development neglected. The data in the present study suggest that parents/mothers who provide cognitive stimulation to these children, by engaging in developmentally advantageous activities like reading, playing, and talking together, are protecting the children from developing aggressive behaviors as a maladaptive coping mechanism. In fact, high levels of cognitive stimulation appear to disrupt that relationship between chronic medical illness and aggressive behavior.

These relationships are remarkable, because they are essentially a manifestation of theory. It was hypothesized that development and illness, and parent and child well-being would interact dynamically to explain some of the mental health issues that children with chronic medical conditions may develop. These preliminary findings have implications for care and treatment planning in medical practice, as well as for intervention design in research.

We know that children growing up and developing with a chronic medical condition are at a higher risk of experiencing a number of challenges in various aspects of their lives—economically, academically, socially, emotionally, physically, psychologically and developmentally. It is incumbent upon physicians to approach care in a more holistic and biopsychosocially conscious manner, given the plethora of information demonstrating the interactions between systems and groups of people in a child's life. In *addition to,* not in lieu of, providing an illness-centered care plan, pediatricians should be vigilant and perhaps even screen their chronically ill patients for both internalizing and externalizing symptoms. Moreover, although parents/mothers are not pediatricians' primary "customers," their well-being is just as important as the child's own health. Children do not grow up in a bubble, independently; in fact, they are arguably the most dependent and impressionable people. Therefore, making sure that a child's mother (because she is most likely to be the child's primary caregiver) has the structural and emotional support needed to lead a healthy and productive life, should be something addressed by pediatric medical staffs. Pediatricians and pediatric nurses should be trained in spotting signs of depression, anxiety, and stress in caregivers, but the responsibility of care for the adult should not fall on them. It is with the help of a multidisciplinary team—including but not limited to: social workers, psychologists, child life specialists, nutritionists, and even lawyers— that a pediatric specialist can improve the quality of life for his/her chronically ill patient by improving those other important components in a child's life that are not within the child's own self.

Effective interventions do not need to directly target the child in order to have a positive effect on his/her health and/or future outcomes. This study's findings signal an opportunity to improve a chronically ill child's behavioral and psychological outcomes through their mothers. One way would be to provide them with information and guidance on how to have more developmentally meaningful interactions with their children, thus promoting the protective factor that cognitive stimulation seems to provide. Another way to approach intervention via parental mediation is by providing mothers with additional socioemotional support (Macedo et al., 2015). Mothers who reported greater stress and depressive symptoms were less likely to engage in meaningful interactions with their children in this study and others (Kim and Im, 2014). This suggests that protecting the *parent's* mental health status is another way to positively influence the chronically ill child's quality of life. Interventions should focus on empowering and encouraging mothers. It may be helpful to develop a network of other parents with sick children, and even further cater to those groups with specific illnesses to foster comradery and mutual support amongst people undergoing similar challenges. This sort of organization would really rely on the empathy that those experiencing the same problems can provide; and on the guidance and advice that those who have already overcome those same problems can offer.

## Study Limitations

This study had a number of limitations. First, the sample sizes used were less than ideal. The chronically ill (CI) sample was both generally and relatively small ($CI_n$ = 43 v. $Healthy_n$ = 602). Future studies should ensure a comparable number of participants in each group. Second, chronic medical conditions were measured solely through parental report, and not medical records. This may lead to purposeful reporting bias, in which the parent chose not to disclose a child's medical condition, as well as unintentional withholding of information if the parent simply did not perceive the condition to be a reportable medical problem (Quach and Barnett, 2015). The latter was partially avoided by individually examining parents' responses over the entire study period to determine if the medical condition was reported in greater detail that would suggest chronicity at earlier or later points. Still, studies have shown that there can be significant discordancy between maternal reports of childhood chronic illness and medical records (Miller, Gaboda, and Davis, 2001).

Identifying or rather defining which reported medical conditions would be considered chronic for this study was also a challenge. There were clear examples of what should count as a chronic condition (e.g. epilepsy, leukemia) and what would definitely not be counted (e.g. cavities), but less severe conditions like eczema, allergies, and constipation had to be assessed more carefully. In the end, it was decided that conditions that caused functional impairment (e.g. repeatedly reported otitis media) or considerable disruption to everyday life (e.g. food allergies, eczema) would be considered for analysis.

Given the sociodemographic makeup of the population studied, these findings may not be generalizable. Furthermore, BELLE Project participants were also not a specifically chronically ill pediatric population. This posed a challenge in several regards. Although participants were asked about the children's medical diagnoses at nearly every assessment point, some of the measures used in the present study to analyze parents' and children's mental health/well-being (i.e. BASC, PSI, CES-D) were not administered at all the assessments.  It was therefore not possible to look at relationships spanning the entire 7+ years of the parent study.  As previously mentioned, the sample size of the chronically ill group was also a matter of concern.  Since it was not possible to use other data from all 6 assessment points, a specific age of interest had to be selected for the reported medical conditions.  Ultimately, only chronic medical conditions reported during the 36-Month developmental evaluation were considered for analysis, because the sample size was large enough, *and* because the PSI, the CES-D, the STIMQ, and the BASC were administered both at that assessment point as well as during the assessment immediately after (i.e. 54-Month developmental evaluation) which was necessary in order to analyze any possible predicting trends.

Finally, standard measures used in other research to analyze well-being in children with chronic conditions assess overall and specific aspects of the children's quality of life.  No such quality of life measures were used during the BELLE Project's study period.  This limited the ways in which the present study's findings could be compared to existing literature on chronic illness in children.

## Study Strengths

This study also had some important strengths.  One of the most appealing aspects of this entire data sample is the longitudinal collection of the same information for a substantial time frame.  These children have been followed from *birth* through middle childhood (> 7 years). As previously mentioned, this study was not meant to research chronically ill pediatric populations.  In fact, in order to be eligible for enrollment into the BELLE Project, children had to have been born typically developing. However, a small and significant number of children eventually developed chronic conditions. Not all medical problems reported by parents were analyzed for the present study, but a total of 138 families did report some kind of medical diagnosis throughout the entire study period. This comes out to approximately 21.4% of the BELLE Project sample, a percentage surprisingly close to the CDC's most recent population estimate of 22.3% (NHIS-Child, 2014), indicating the sample was representative of the population as a whole, at least in some respects. Because the majority of the participating children were considered to be healthy, no quality of life measurements were used in the BELLE Project. However, when researching QoL measurements it became obvious that there was significant overlap between the questions asked in those measures and many of the questions asked in other instruments that *were* used for this study's parent project. Some questions were even identical; a cross-reference of some of those questions can be seen in Appendix D.

Overall, the present study provides unique insight on parent-child interactions specifically for families with chronically ill children. The benefits of shared reading and bonding between parent and child are well studied and documented in the field of child development. However, within pediatric medical care parent-child interactions may fall beyond the purview of what is generally discussed in the doctor's office. Because managing physical health is thought to be the most important aspect of care, both physicians and parents may feel that adequate medical control is enough to help a child overcome challenges posed by their chronic condition. However, this study offers preliminary data supporting the idea that parents' positive involvement in non-illness related interactions can mediate the effects on aggressive behaviors that dealing with a chronic medical conditions can have on a young child.

Often times we look at when, how, and why children fail to succeed, or to overcome a specific challenge. Childhood resilience studies, though, seek to understand when, how and why high-risk children *are* able to thrive *despite* the serious challenges they face. This study's findings, though not focused on the theme of resilience, provide some supporting data to the field in suggesting that cognitive stimulation can act as a protective factor against future behavioral problems for children with a chronic illness. Interestingly, these other themes of cognition and behavioral problems are topics generally viewed and studied through the lens of education. The present study provides a fresh perspective in that it ties cognition and cognitive stimulation to parental mental health, and child aggression in the context of chronic illness.

## Future Directions

Future studies conducted with chronically ill pediatric populations should analyze in greater depth those direct and indirect relationships observed in this project's findings related to parent and child mental health/well-being. For instance, it would be interesting to study the predominance of externalizing versus internalizing symptoms in chronically ill children as they age, to see if and/or when there is a switch in how children's psychological issues are manifested. Additionally, as previously suggested, other forms of externalizing behaviors should also be studied in addition to hyperactivity and aggression, like bullying, defiance, and delinquency. Although parent reports are perhaps the most convenient way of collecting data on this subject matter, children's self-reports could offer promising complementary information. Ideally, behavioral assessments by an objective evaluator would also figure into the analysis to provide a more complete view—objective and subjective—of what is going on behaviorally with a chronically ill child. In this study, parental mental health was linked to parents' participation in cognitively stimulating their children. Future research should consider assessing other aspects of parenting and parenting practices, such as: discipline, household nutrition, and school involvement.

As previously discussed, the theoretical premises for this thesis project argue that there are dynamic interrelationships amongst different aspects of a child's life, aspects both within his/her own body as well as with his/her ecological systems (i.e. family, society, school, etc…). This study's findings draw some of those lines of connectivity, but one question that remains is the directionality of the mechanisms at play. The emporal relationships provide some insight into the directionality, but some of the studies aforementioned limitations prevented more detailed analyses. Nevertheless, it is an important inquiry for future consideration, because evidently there is a "pattern of reciprocal influences " (Weil, 1999). We know that the relationships between parental mental health and children's mental health symptoms exist for children with chronic medical conditions, and we know that they *do not* occur in a unilateral linear manner. Studying the ways in which they *do* or *can* unfold is important for both practical and theoretical reasons. Theory supports practice. Understanding a possible theoretical model would help design interventions and devise presumably more effective and cost-efficient care procedures benefitting chronically ill children, their families, and more broadly, the society that supports them.

## CONCLUSION

This thesis project found data to suggest that children with chronic medical conditions are likely to develop aggressive behaviors that persist over time. Parents can mitigate these symptoms by engaging in developmentally advantageous activities, like reading, playing, and talking with their chronically ill children. Children who are cognitively stimulated by these types of positive parent-child interactions are less likely to develop aggressive behaviors, suggesting that cognitive stimulation can act as a protective factor against future behavioral problems for children with a chronic illness.  This finding has important implications for pediatric care.  Physicians should approach management of an illness in a holistic, biopsychosocially-conscious manner, realizing that parents have an important role in their children's health that is not directly attached to managing the condition and its symptoms.  The medical community's advocacy can go a long way as doctors are often viewed as voices of authority in matters concerning health care.  It is therefore imperative that pediatricians monitor different aspects of their patients' lives, not just their physical health.  This would include vigilance over parents' mental health/well-being, which is a significant determinant of parental cognitive stimulation.  Pediatric medical staffs should be trained in identifying mental health symptoms in adults, specifically parents.  Parent and child's physical and mental health are intrinsically intertwined; they run parallel to each other.  Childhood chronic illness is a multifaceted, dynamic phenomenon that needs a multidisciplinary team to treat not just the child's symptoms, but parents' and children's mental health/well-being as well.

## REFLECTIONS

Over the last four years I have been a part of a multi-disciplinary behavioral research team functioning out of a large urban public hospital serving low-income families. Our lab, named after the central project— the Bellevue Project for Early Language, Literacy, and Education Success (BELLE), aims to deliver a relationship-based parenting intervention to low-income families in the hopes of improving their children's future developmental and educational outcomes. As a research assistant on the study my main responsibility was to collect data through child assessments and parental reports. Using a variety of standardized measures I assessed school-aged children on different aspects of their development, including but not limited to: language, cognitive, and socio-emotional development. I also had the opportunity to engage with the participating mothers and learn more about their children's current life experiences directly from a primary caregiver. As a study, we gained insight into the parent-child relationship, parental involvement, household habits, routines, challenges, as well as parents' perspectives on their own and their children's behaviors, attitudes, and feelings.

As one can imagine from this description, there was a plethora of data to analyze. My academic interest has always lain in atypically developing children, and the medical causes and effects of failure to reach specific developmental milestones. Professionally, I was more invested in those measures related to children's mental health, particularly because I was very involved in the introduction of these measures as an additional component to the main longitudinal study. I was part of this addendum study from its inception, helping strategize and pilot the best way to encourage participation and to collect reliable data. Although medical well-being was not extensively examined in these studies there were a few targeted questions regarding developmental and medical diagnoses.

At the time, it seemed more intuitive than anything to me that there would be an association between persistent, and/or reoccurring illness and poor mental health symptoms.  Children would not express these symptoms the same way adults do, but that does not mean they do not experience them.  With these two interests in mind, I became curious about the relationship between having an illness as a child and the potential toll this may take on mental health.  I conducted a literature review on this topic, focusing on persistent pediatric illnesses, known as *chronic* conditions, but maintaining broader criteria for the findings addressing mental health.

Most of the findings in my initial literature search were unsurprising.  Looking into this topic, there were some preconceived notions about the adverse effects that experiencing a chronic condition in childhood might have on the child's mental health.  The more I searched and read, I realized studies were not just focused on the child's mental health, but also on that of his/her nuclear family, specifically parents and siblings alike (though siblings were not discussed in the paper).  Moreover, although I was familiar with the term, I had not previously come across measures of "quality of life" in research.  It is surprising not just to repeatedly see these specific types of measures being used, but also seeing them used to study mental health.  In other words, it was mental health through the lens of quality of life.

I also noticed that there was a heavy emphasis on certain internalizing symptoms of poor mental health, specifically depression, anxiety, and self-esteem issues for both parents and chronically ill children.  On the other hand, externalizing symptoms seemed woefully understudied in the initial literature review I completed.  Considering that there is an entire branch of pediatric studies focused on behavioral issues, I was surprised to not come across more investigations addressing behaviors like aggression, hyperactivity, defiance, and delinquency.

The literature indicated that there were relationships between having a chronic illness and parent and child mental health/well-being. However, in developing my own thesis proposal I saw the lack of emphasis on externalizing behaviors in chronically ill children as a gap in the literature that I could help fill. In addition, because the same information was collected longitudinally for my lab's central research study, I hoped to use data regarding parental mental health, childhood mental health, and both parenting behaviors and children's behaviors to draw some conclusions about the temporal relationship between childhood chronic illness and mental health/well-being.

The greatest advantage to having access to these archival data was that the data collection step, which can often times be the most time-consuming part of a research study, was already done. Moreover, the information acquired at each assessment point provided a treasure trove of data covering a variety of topics, from infant feeding practices to bilingual expressive language. However, despite the quantity and variety of information available, the information itself was perhaps the most limiting factor, because in choosing to use archival data I was limited to analyzing the information that had already been collected, how it had been collected, and when it had been collected, without the opportunity to change any aspect to better understand certain relationships and answer certain specific questions. This was a significant impediment in my attempt to study the patterns' reciprocity between childhood chronic illness and poor mental health symptoms, because not all of the same measurements were collected throughout the study period.

Still I was fortunate enough to work with two advisers, one in my lab and one at my college, who helped me narrow my focus to a specific group of chronically ill children and target externalizing symptoms of mental health and maladaptive behaviors. They also helped me tremendously to understand the statistics involved in arriving at my findings, from running the necessary algorithms to understanding standard statistical jargon. My background in statistics is limited, and as such it was a significant personal limitation for the amount of data analysis I was able to do independently.  This added another challenge—coordinating meetings and the topics of discussions at two different sites.  It was important that I keep each adviser up-to-date on what I last consulted with the other adviser, without making the entire meeting a catch-up session.

In the end, though, I was pleasantly and genuinely surprised to have significant findings with such a small and impromptu sample.  Because of this study's numerous limitations, the data analysis period lasted much longer than I had anticipated.  There were several considerations that had to be taken into account to simply separate out the chronically ill sample from the healthy sample.  And although the effect size and statistical strength of some of my findings were small, this study's significance lies more in what the findings suggest for pediatric patient care.

For me this project was a perfect capstone that melded together the teachings I learned over the last three years and the work I do on a daily basis in research and intervention implementation.  I truly take to heart my study's implications for pediatric practice, a field that I hope to enter now better prepared by this experience.  I would hope that this knowledge would help me be a more holistic practitioner who not only monitors and treats her patients' medical conditions and guards for behavioral symptoms, but who also acknowledges their parents' needs.  It is important to practice vigilance for subtle signs of parental depression, stress, and anxiety, knowing full well that these feelings are affecting the children's present well-being and their future outcomes.  My greatest take home message is that children's health is so dynamic and multidimensional that it radiates beyond the child, to his/her parents, to his/her siblings, to his/her society, and eventually those effects, positive or negative, boomerang back around to impact the child's present and future.

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*A mi padre, Edgar E. Raak, que desde el cielo me continua guiando y protegiendo le agradezco por haberme heredado su inteligencia y tenacidad.  Y por ultimo, a mi madre, Carmen M. Herrera, a quien le debo todo lo que tengo y todo lo que soy.  Le agradezco por todos los sacrificios que ha hecho y sobrellevado a lo largo de mi vida para ayudarme a conquistar mis metas, y por su infinito amor y apoyo.*

# BIBLIOGRAPHY

A Report from the Children's Environmental Health Center. (2013, December). Retrieved from https://www.mountsinai.org/static_files/MSMC/Files/Patient Care/Children/Childrens Environmental Health Center/NYS-Children-Environment.pdf

Abidin, R.R. (1995). *Parenting Stress Index Manual* (3rd ed). Charlottesville, VA: Pediatric Psychology Press.

Abidin, R. R., & Brunner, J. F. (1995). Development of a parenting alliance inventory. *Journal of Clinical Child Psychology*, 24(1), 31-40. doi:10.1207/s15374424jccp2401_4

Arif, A. A., & Korgaonkar, P. (2016). The association of childhood asthma with mental health and developmental comorbidities in low-income families. *Journal of Asthma,* 53(3), 277-281. doi:10.3109/02770903.2015.1089277

Atkins, E., Colville, G., & John, M. (2012). A 'biopsychosocial' model for recovery: A grounded theory study of families' journeys after a Paediatric Intensive Care Admission. *Intensive and Critical Care Nursing, 28*(3), 133-140. doi:10.1016/j.iccn.2011.12.002

Bartlett, S., Hart, R., Satterthwaite, D., De la Barra, X., & Missair, A. (1999). *Cities for Children: Children's Rights, Poverty, and Urban Management*. London: Earthscan Publications Ltd.

Barroso, N. E., Hungerford, G. M., Garcia, D., Graziano, P. A., & Bagner, D. M. (2016). Psychometric properties of the Parenting Stress Index-Short Form (PSI-SF) in a high-risk sample of mothers and their infants. *Psychological Assessment,* 28(10), 1331-1335. doi:10.1037/pas0000257

Bergen, D. (2008). *Human development: Traditional and contemporary theories*. Upper Saddle River, NJ: Pearson Prentice Hall.

Bell, M. F., Bayliss, D. M., Glauert, R., Harrison, A., & Ohan, J. L. (2016). Chronic Illness and Developmental Vulnerability at School Entry. *Pediatrics, 137*(5). doi:10.1542/peds.2015-2475

Bennett, S., Shafran, R., Coughtrey, A., Walker, S., & Heyman, I. (2015). Psychological interventions for mental health disorders in children with chronic physical illness: A systematic review. *Archives of Disease in Childhood Arch Dis Child, 100*(4), 308-316. doi:10.1136/archdischild-2014-307474

Brofenbrenner, U. (1979). *The ecology of human development.* Cambridge, MA: Harvard University Press.

Canfield, C. F., Weisleder, A., Cates, C. B., Huberman, H. S., Dreyer, B. P., Legano, L. A., . . . Mendelsohn, A. L. (2015). Primary Care Parenting Intervention and Its Effects on the Use of Physical Punishment Among Low-Income Parents of Toddlers. *Journal of Developmental & Behavioral Pediatrics, 36*(8), 586-593. doi:10.1097/dbp.0000000000000206

Cousino, M. K., & Hazen, R. A. (2013). Parenting Stress Among Caregivers of Children With Chronic Illness: A Systematic Review. *Journal of Pediatric Psychology, 38*(8), 809-828. doi:10.1093/jpepsy/jst049

Covar, R. A., Strunk, R., Zeiger, R. S., Wilson, L. A., Liu, A. H., Weiss, S., . . . Szefler, S. J. (2011). Predictors of remitting, periodic, and persistent childhood asthma. *Journal of Allergy and Clinical Immunology*, 125(2), 359-366. doi:10.1016/j.jaci.2009.10.037

Curtis, C. E., & Luby, J. L. (2008). Depression and Social Functioning in Preschool Children with Chronic Medical Conditions. *The Journal of Pediatrics, 153*(3), 408-413. doi:10.1016/j.jpeds.2008.03.035

DEVELOPMENTAL & BEHAVIORAL PEDIATRICS. (n.d.). Retrieved September 08, 2016, from http://www.med.nyu.edu/pediatrics/developmental/research/the-belle-project

Dewalt, D. A., Gross, H. E., Gipson, D. S., Selewski, D. T., Dewitt, E. M., Dampier, C. D., . . . Varni, J. W. (2015). PROMIS® pediatric self-report scales distinguish subgroups of children within and across six common pediatric chronic health conditions. *Qual Life Res Quality of Life Research, 24*(9), 2195-2208. doi:10.1007/s11136-015-0953-3

Dreyer, B. P., Mendelsohn, A. L., & Tamis□Lemonda, C. S. (1996). Assessing the Child's Cognitive Home Environment Through Parental Report; Reliability and Validity. *Early Development and Parenting*, 5(4), 271-287. doi:10.1002/(sici)1099-0917(199612)5:4<271::aid-edp138>3.3.co;2-4

Engel, G. L. (1980, May). The Clinical Application of the Biopsychosocial Model. *The American Journal of Psychiatry,* 137(5), 535-544. doi:10.1093/jmp/6.2.101

Engel, R. G., & Melamed, B. G. (2002). Stress and Coping in Children at Risk for Medical Problems. In L. L. Hayman, M. M. Mahon, & J. R. Turner (Eds.), *Chronic Illness in Children: An Evidence-Based Approach* (pp. 171-198). New York, NY: Springer Publishing Company.

Feldman, R., Granat, A., Pariente, C., Kanety, H., Kuint, J., & Gilboa-Schechtman, E. (2009). Maternal depression and anxiety across the postpartum year and infant social engagement, fear regulation, and stress reactivity. *Journal of the American Academy of Child & Adolescent Psychiatry, 48(9),* 919-927. doi: 10.1097/CHI.0b013e3181b21651

Ferguson, K. T., & Evans, G. W. (in press 2017). Family systems and family psychology in bioecological and bioecocultural perspective. In Fiese, B. H. (Ed.), APA Handbook of Contemporary Family Psychology.

Gardner, W., J. M. Murphy, G. Childs, K. Kelleher, M. E. Pagano, M. S. Jellinek, T. McInerny, M. Wasserman, P. Nutting and L. Chiapetta (1999). The PSC-17: A brief pediatric symptom checklist with psychosocial problem subscales. A report from PROS and ASPN. *Ambulatory Child Health* **5**: 225-236.

Health-Related Quality of Life. (2016). Retrieved from http://www.cdc.gov/hrqol/index.htm

Holmes, C. S., Yu, Z., & Frentz, J. (1999). Chronic and discrete stress as predictors of children's adjustment. *Journal of Consulting and Clinical Psychology*, 67(3), 411-419. doi:10.1037//0022-006x.67.3.411

Hollingshead, A. A. (1975). *Four-factor index of social status*. Unpublished manuscript, Yale University, New Haven, CT.

Hullmann, S. E., Ryan, J. L., Ramsey, R. R., Chaney, J. M., & Mullins, L. L. (2011). Measures of general pediatric quality of life: Child Health Questionnaire (CHQ), DISABKIDS Chronic Generic Measure (DCGM), KINDL-R, Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales, and Quality of My Life Questionnaire (QoML). *Arthritis Care & Research*, 63(S11), S420-S430. doi:10.1002/acr.20637

Kim, D. H., & Im, Y. J. (2014). Resilience as a protective factor for the behavioral problems in school-aged children with atopic dermatitis. *Journal of Child Health Care*, 18(1), 47-56. doi:10.1177/1367493512468360

Lewis, C. E., Siegel, J. M., & Lewis, M. A. (1984). Feeling bad: Exploring sources of distress among pre-adolescent children. *Am J Public Health American Journal of Public Health, 74*(2), 117-122. doi:10.2105/ajph.74.2.117

Macedo, E. C., Silva, L. R., Paiva, M. S., & Ramos, M. N. (2015). Burden and quality of life of mothers of children and adolescents with chronic illnesses: An integrative review. *Revista Latino-Americana De Enfermagem Rev. Latino-Am. Enfermagem, 23*(4), 769-777. doi:10.1590/0104-1169.0196.2613

Miller, J. E., Gaboda, D., & Davis, D. (2001). Early childhood chronic illness: comparability of maternal reports and medical records. *Vital and health statistics. Series 2, Data evaluation and methods research,* (131), 1-10.

Moreira, H., Carona, C., Silva, N., Frontini, R., Bullinger, M., & Canavarro, M. C. (2013). Psychological and Quality of Life Outcomes in Pediatric Populations: A Parent-Child Perspective. *The Journal of Pediatrics,* 163(5), 1471-1478. doi:10.1016/j.jpeds.2013.06.028

Muhammad, S., Milford, D. V., Carson, A., Young, H., & Martin, C. R. (2016). Coping In Young People With Chronic Kidney Disease (Ckd). *Journal of Renal Care*, 42(1), 34-42. doi:10.1111/jorc.12131

Murphy, J. M., C. Ichinose, R. C. Hicks, D. Kingdon, J. Crist-Whitzel, P. Jordan, G. Feldman and M. S. Jellinek (1996). Utility of the Pediatric Symptom Checklist as a psychosocial screen to meet the federal Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) standards: A pilot study. *The Journal of Pediatrics* **129**(6): 864-869.

Murphy J.M., Bergmann P., Chiang C., Sturner, R., Howard, B., Abel M.R., Jellinek, M. (2016) The PSC- 17: Subscale Scores, Reliability, and Factor Structure in a New National Sample. *Pediatrics*. doi:10.1542/peds.2016-0038

National Health Interview Survey – Child Component. Data query from the child and adolescent health measurement initiative, data resource center for child and adolescent health website. Children with 1 or more current chronic health conditions. NHIS-Child 2014. Retrieved from http://www.childhealthdata.org/browse/survey/results?q=3371&r=1

Ohleyer, V., Freddo, M., Bagner, D. M., Simons, L. E., Geffken, G. R., Silverstein, J. H., & Storch, E. A. (2007). Disease-related stress in parents of children who are overweight: relations with parental anxiety and childhood psychosocial functioning. *Journal of Child Health Care*, 11(2), 132-142. doi:10.1177/1367493507076065

Ortega, A. N., Huertas, S. E., Canino, G., Ramirez, R., & Rubio-Stipec, M. (2002). Childhood Asthma, Chronic Illness, and Psychiatric Disorders. *The Journal of Nervous and Mental Disease, 190*(5), 275-281. doi:10.1097/00005053-200205000-00001

Pinquart, M. (2012). Self-esteem of children and adolescents with chronic illness: A meta-analysis. *Child: Care, Health and Development Child Care Health Dev, 39*(2), 153-161. doi:10.1111/j.1365-2214.2012.01397.x

Pinquart, M., & Shen, Y. (2011). Behavior Problems in Children and Adolescents With Chronic Physical Illness: A Meta-Analysis. *Journal of Pediatric Psychology*, 36(9), 1003-1016. doi:10.1093/jpepsy/jsr042

Quach, J., & Barnett, T. (2015). Impact of Chronic Illness Timing and Persistence at School Entry on Child and Parent Outcomes: Australian Longitudinal Study. *Academic Pediatrics, 15*(1), 89-95. doi:10.1016/j.acap.2014.08.004

Radloff, L. S. (1977). The CES-D Scale: A Self-Report Depression Scale for Research in the General Population. *Applied Psychological Measurement*, 1(3), 385-401. doi:10.1177/014662167700100306

Reuner, G., Kadish, N. E., Doering, J. H., Balke, D., & Schubert-Bast, S. (2016). Attention and executive functions in the early course of pediatric epilepsy. *Epilepsy & Behavior, 60*, 42-49. doi:10.1016/j.yebeh.2016.04.011

Reynolds, C.R, & Kamphaus, R.W. (2004) *Behavior assessment system for children* (2nd ed.). Bloomington, MN: Pearson Assessments.

Shepard, M.P., & Mahon, M.M. (2002). Family Considerations. In L. L. Hayman, M. M. Mahon, & J. R. Turner (Eds.), *Chronic Illness in Children: An Evidence-Based Approach* (pp. 143-170). New York, NY: Springer Publishing Company.

Steck-Silvestri, E.L., Phelps, L., MacAllister, W.S., Ensign, J., Crevier-Quintin, E., Hale, J.B., (2013). Chronic pediatric medical conditions and comorbid psychopathology. In L.A. Reddy, A.S. Weissman, & J.B. Hale (Eds.), *Neuropsychological Assessment and Intervention for Youth An Evidence Based Approach to Emotional and Behavioral Disorders*. (pp.299-323). Washington: American Psychological Association.

Suryavanshi, M. S., & Yang, Y. (2016). Clinical and Economic Burden of Mental Disorders Among Children With Chronic Physical Conditions, United States, 2008–2013. *Preventing Chronic Disease Prev. Chronic Dis., 13*. doi:10.5888/pcd13.150535

Swindle, T. M., Shapley, K., Kyzer, A., Cheerla, R., & Whiteside-Mansell, L. (2015). Familial Risk in Low-Income Children With Chronic Illness Exposed to Passive Smoke. *Clinical Pediatrics, 54*(9), 840-846. doi:10.1177/0009922815589927

Szefler, S. J., Zeiger, R. S., Haselkorn, T., Mink, D. R., Kamath, T. V., Fish, J. E., & Chipps, B. E. (2011). Economic burden of impairment in children with severe or difficult-to-treat asthma. *Annals of Allergy, Asthma & Immunology, 107*(2). doi:10.1016/j.anai.2011.04.008

Thelen, E. (2005). Dynamic Systems Theory and the Complexity of Change. *Psychoanalytic Dialogues, 15*(2), 255-283. doi:10.1080/10481881509348831

Thelen, E., Ulrich, B. D., & Wolff, P. H. (1991). *Hidden skills: A dynamic systems analysis of treadmill stepping during the first year* (1st ed., Vol. 56, Ser. 223). Chicago, IL: University of Chicago Press.

Van Cleave, J., Gortmaker, S. L., & Perrin, J. M. (2010). Dynamics of obesity and chronic health conditions among children and youth. *Jama, 303*(7), 623-630.

Weil, C. M., Wade, S. L., Bauman, L. J., Lynn, H., Mitchell, H., & Lavigne, J. (1999). The Relationship Between Psychosocial Factors and Asthma Morbidity in Inner-City Children With Asthma. *Pediatrics, 104*(6), 1274-1280. doi:10.1542/peds.104.6.1274

Wilcox, H. C., Rains, M., Belcher, H., Kassam-Adams, N., Kazak, A., Lee, R., . . . Wissow, L. (2016). Behavioral Problems and Service Utilization in Children with Chronic Illnesses Referred for Trauma-Related Mental Health Services. *Journal of Developmental & Behavioral Pediatrics, 37*(1), 62-70. doi:10.1097/dbp.0000000000000236

Yamamoto, K. (1972). *The Child and his image; self concept in the early years*. Boston: Houghton Mifflin.

# APPENDICES

## **Appendix A:** Literature Review Summary Table

| First Author, Year, Journal | Sample Description | | | Type of Study | Illness Characteristics | | | Outcomes | | Evaluation Period | Findings | Notes/ Critiques |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Sample Size | Demographics | Sample Age | | Definition of Chronic Illness | Illnesses Reviewed | Diagnosis Confirmation | Assessment Measures | Outcome of Interest | | | |
| Bell, 2016 PEDIATRICS | 22,890 (2,879 studied) | Western Australian (WA), population-level | 5.5 y | Cross-sectional analysis | Physical health conditions that are prolonged in duration, difficult to treat, and ass. With impairment or disability. | Chronic otitis media, chronic respiratory disease, epilepsy, anemia, etc (ICD-10-AM) | ED & Hosp Morbidity databases; ICD-10-AM chronic illness code | Australian Early Development Census (AEDC): school readiness measure | AEDC Domains (5): Physical health and well-being, social competence, emotional maturity, language and cognitive skills, communication skills and general knowledge | 48 – 83mos<br>1 evaluation point | Children with chronic illness are at increased risk of dev vulnerability in all (5) dev domains. Particularly in social and emotional capacities. Multiple chronic illnesses had increased risk of dev. vulnerability, but NOT significantly greater than single chronic illness. | Evidence of delays in school readiness already at entry. Suggests EI services eligibility should be broadened. Chronic Otitis media overwhelmingly prominent. (Due to country's pastime? No regional differences) |
| Ortega, 2002 J Nerv Ment Dis | 1,295 | Community-based Multi-racial; Four sites (Atlanta, New Haven, New York, Puerto Rico) | 34.9% 9-11 y<br>65.1% 12-17 y | Cross-sectional analysis | NONE | Asthma, cancer [excluded], other [cardiac problems, diabetes, sickle cell anemia] | Parent report on Service Utilization and Risk Factors Interview (SURF) | National Institute of Medical Health (NIMH) Diagnostic Interview Schedule for Children v2.3 (DISC 2.3):<br>SURF | Psychiatric disorders according to DSMIII-R: anxiety disorder; mood disorder; disruptive disorder; miscellaneous disorder (e.g. eating, tic disorders) | Asthma reports were lifetime reports (>10 years)<br>Psychiatric disorder past 6 -12 months | Children with a history of asthma were more likely to have any anxiety disorder, simple phobia, separation anxiety, and overanxious disorder than children without history of asthma | Relationship between anxiety disorder and chronic illness is specific to asthma, and not other chronic conditions. Severe asthma (hospitalization) even more likely to have anxiety disorder<br>Small *N* for "other chronic illnesses" |

| First Author, Year, Journal | Sample Size | Demographics | Sample Age | Type of Study | Definition of Chronic Illness | Illnesses Reviewed | Diagnosis Confirmation | Assessment Measures | Outcome of Interest | Evaluation Period | Findings | Notes/ Critiques |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Swindle, 2015<br>Clinical Pediatrics | 902 | Head Start in a Southern state; Urban area<br>Majority African-American | UNK | Cross-sectional analysis | A mental or physical health problem or illness that requires regular, ongoing care | NON-SPECIFIC | Parent report | Family Map risk areas of: Basic Needs, Family Stress, Caregiver Mental Health | Familial risk in terms of meeting basic needs (difficulty paying utilities, rent, health care, and transportation); having family problems (stress, conflict, lack of cohesion); caregiver's mental health (depression, hostility, and anxiety) | 2 mos;<br>1 evaluation point | Children with chronic illness and passive smoke exposure were most at risk across all areas of family risk<br>Followed, in order by children with: NCI-PS, CI-NPS, NCI-NPS | Specific chronic illnesses not recorded<br>Cyclic effects, because smoking may be a coping mechanism to deal with challenges of having a child with chronic illness, but exposure to passive smoke may worsen health, which is worsening financial and emotional demands on the family<br>Including mental health in the definition of child's chronic illness |
| Pinquart, 2012<br>Child: care, health, and development | 621 studies<br>809 samples<br>58281 subjects | Convenient sample (clinical sample) | 12.30 y | Systematic Review and Meta-Analysis | NONE | NON-SPECIFIC [Obesity, arthritis, diabetes, cancer, asthma, epilepsy, etc…] | No documentation of physician diagnosis within each study was required. | VARIED [Child Health Questionnaire, Coopersmith, SPPC/SPPA, Rosenberg's Self Esteem Questionnaire, Piers-Harris Self Concept Questionnaire, etc…] | Child and adolescent self-esteem as reported by: patient, parent, clinician/ teacher | N/A | Type of illness (affecting function), age (adolescence), gender (females), rater (other than child), country (less developed), year of publication (<2000), and target of comparison (vs. control) were significant predictors of self-esteem of children with chronic illnesses. | Children with chronic fatigue syndrome, and chronic headaches had lowest levels of self-esteem, possibly due to lower levels of physical and social functioning due to symptoms. Parents/others tend to report more self-esteem problems than children. |
| Quach, 2015<br>Academic | 4983 (4464 | Australian nationally | 4.3 – 5.2 y.o. | Longitudinal | Any medical | NON-SPECIFIC | Parent-report | Language, Literacy, & | Child's: learning, | 7 yrs | Largest differences | Causal role of chronic illness |

| First Author, Year, Journal | Sample Size | Demographics | Sample Age | Type of Study | Definition of Chronic Illness | Illnesses Reviewed | Diagnosis Confirmation | Assessment Measures | Outcome of Interest | Evaluation Period | Findings | Notes/ Critiques |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Pediatrics | chronic illness data) | representative | at age of enrollment | | conditions or disabilities that have lasted, or are likely to last, for 6 months or more. | | | Mathematical Thinking subscales from Academic Rating Scale from the Early Childhood Longitudinal Study (ECLS) for teacher-reports;<br>Approach to Learning subscale from Social Rating Scale of ECLS for teacher-report;<br>Teacher-Child Relationship Scale-Short form teacher-report;<br>Wechsler Intelligence Scale for Children IV-Matric Reasoning subset;<br>Peabody Picture Vocabulary;<br>Strengths and Difficulties Questionnaire parent & teacher reports;<br>Parent-proxy Pediatric Quality of Life Inventory 4.0;<br>Kessler-6 parental self-report | approach to learning, relationship w/ teacher, nonverbal cognition, verbal cognition receptive vocabulary, behavior, health-related quality of life; parental mental health; health care cost | | were noted for "persistent" chronic illnesses (vs. none, resolved, & incidental) in all measures, except fathers' mental health. Largest differences for parent-reported behavior, child psychosocial functioning, and teacher reported child literacy.<br>Costs aligned with increased health care burden | supported by temporal relationships (implicit in categories: never, resolved, incident, & persistent). Timing and persistence associated with learning and well-being outcomes for children, and mothers' psychological stress & well-being.<br>No record of chronic illnesses |
| Steck-Silvestri, 2013<br>Neuro-psychological Assessments and Interventions … [BOOK] | N/A | N/A | <18 y | Literature review | NONE | Neonatal stroke, cerebral palsy, neoplasms/ tumors, concussion /mild brain injury, traumatic brain injury, viral/ bacterial encephalitis, HIV/AIDS, FASD, lead exposure, epilepsy | N/A | N/A | Neuro-psychological (e.g. memory, attention, visual-spatial deficits), and neuro-psychiatric characteristics (e.g. ADHD, mood and anxiety disorders) | N/A | Early age of onset, greater frequency, poor response to medication can be predictors of executive deficits<br>Mood disorders are common in pediatric epilepsy<br>Children with chronic conditions face | This was NOT a study, but rather a chapter relating to chronic pediatric medical conditions and comorbid neuro-psychological and neuro-psychiatric characteristics. |

| First Author, Year, Journal | Sample Size | Demographics | Sample Age | Type of Study | Definition of Chronic Illness | Illnesses Reviewed | Diagnosis Confirmation | Assessment Measures | Outcome of Interest | Evaluation Period | Findings | Notes/ Critiques |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | | challenges | |
| Macedo, 2015 Rev. Latino-Am. Enfermagem | 22 studies, 15-787 subjects per study | Convenient samples, mothers | UNK | Systematic Review and Meta-Analysis | NONE | Broncho-pulmonary dysplasia, cerebral palsy, asthma, eating disorders, hemophilia, autism, sickle cell anemia, cancer, myelomeningo-cele, obesity, and inborn errors of metabolism | Parent report | Caregiver scales: Zarit Burden Interview, Montgomery-Borgatta Caregiver Burden Scale-Revised Quality of Life scales: WHOQOL, Self-reports, SF-36, Ulm Quality of Life Inventory, Pediatric Asthma Caregiver Quality of Life, Nottingham Health Profile | Quality of sleep, mental health, stress, anxiety, depression, perception of child's illness, impact of coping strategies and self-efficiency, ethnic & regional differences, and socio-demographic | Articles 2010-2014 | Most powerful predictors of QoL: hours of sleep, little/no perception of self-efficiency, lack of perceived social support, limitations of maternal role, little vitality, high levels of depression & anxiety, functional compromise, low coping capacity, non-adaptation in family, and care burden | Absence of partner, low educational level, multi/bi-racial background, insufficient income, unemployment, reduced social co-existence, more children, presence & degree of depression & anxiety symptoms, &tensions in daily life increase burden. |
| Bennett, 2015 Arch Dis Child | 10 studies, 209 subjects | Intervention based on cognitive-behavioral framework | <18 y (8-18) | Systematic review | Physical illnesses lasting for at least 3 m and causing functional impairment. | Asthma, cystic fibrosis, diabetes, epilepsy, inflammatory bowel disease (IBD) | N/A | Varied: Cognitive-behavioral therapy (CBT), Treatment for Adolescents with Depression Study, Primary and Secondary Control Enhancement Training | Mental health outcome (anxiety, depression); physical health outcome (specific to disease: blood glucose monitor, glycaemic control) | 3 – 12 mos | Children may benefit from CBT for depression and anxiety, in the context of comorbid chronic physical health problem. Lack of evaluations of treatment for psychiatric symptoms children with chronic illnesses Current evidence base is weak; there's a need for more randomized-controlled trials | Studies where psychiatric symptoms were directly related to the physical illness (e.g. interventions for anxious breathing in asthma) were excluded presumably to eliminate a confounder. Cancer surviving children were also excluded, due to "last 3 mos" of function Impairment definition. No RCTs focused on anxiety. |

| First Author, Year, Journal | Sample Size | Demographics | Sample Age | Type of Study | Definition of Chronic Illness | Illnesses Reviewed | Diagnosis Confirmation | Assessment Measures | Outcome of Interest | Evaluation Period | Findings | Notes/ Critiques |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Curtis, 2008 The Journal of Pediatrics | 273 Dyads (children-mothers) | Biological mothers, racially/ ethnically, economically diverse | 4.02 y (3.0-5.2) | Cross sectional analysis | Unspecified; Medical conditions that limit physical activities or require frequent absences. | Chronic ear infections, respiratory infections, asthma, bowel diseases, chronic urinary infections, blood diseases, lung disease, eczema, birth defects, congenital heart disease, Hep A, other | Parent report Positive response to whether their child has "ever had" any of 17 chronic medical conditions (per HBQ) | Parent scales: MacArthur Health and Behavior Questionnaire-Parent Version (HBQ 1.0), Global Physical Health and Chronic Medical Conditions.<br>Child assessment: Pre-school and Early Childhood Functional Assessment Scale (PECFAS), Daycare/Preschool Role Performance subscale, Behavior Towards Others subscale | Physical and social well-being for young children, social functioning, physical functioning, children's psychometrics (psychosocial functioning and impairment), children's internalizing, peer rejection, fulfillment of societal defined roles, inappropriate behavior ( temper tantrums, fighting, pouting, teasing, peer avoidance) | 3.0 -5.2y; 1 evaluation point | Chronic illness is significantly ass. with early-onset depressive symptoms and impairment in several social functioning domains, even after controlling for SES/family income. Children with chronic illnesses also experienced higher frequency of peer rejection and bullying. | Depressive mediated the relationship between illness and asocial behavior. Higher depression scores, frequency of asocial behavior, and impairment in daycare role cooperation and behavior towards other were evident for number of chronic conditions—some more than others (Table 3). |
| Wilcox, 2016 J Dev & Behavioral Pediatrics | 9885; 2103 chronic illness | Geographically, and racially/ ethnically diverse | 10.7 y | Cross-sectional analysis | Chronic or recurrent condition that affects the child's ability to function. | Chronic illnesses not recorded;<br>13 traumatic experiences (sexual abuse, sexual assault, physical abuse, physical assault, emotional abuse, neglect, domestic violence, illness/medical trauma, serious injury, traumatic loss, impaired caregiver, community violence, school violence). | Caregiver report | Trauma History Profile (THP), Post-traumatic Stress Disorder (PTSP) Reaction Index (RI) for the DSM- IV, and the Trauma Symptom Checklist for Children, Alternate version (TSCC-A), Child Behavior Checklist (CBCL), | Frequency of PTSD symptom reoccurrence, posttraumatic symptoms in children, child emotional and behavioral symptoms (internalizing, externalizing, and total behavioral problems) | 2004-2011 National Child Traumatic Stress Network (NCTSN) core data set (CDS) | Children with "medical problems/ disabilities" have a different profile; they're more likely to be: male, black/ African American, receiving public assistance, not residing with parent.<br>They are more likely to experience specific types of trauma exposures, not all 13. | Specific traumas include: illness/ medical trauma, serious injury, traumatic loss, physical assault, neglect, separation & bereavement. Lower rates of exposure to: sexual abuse, domestic violence, impaired caregiver, school violence<br>Findings re: anxiety, conduct, and separation disorders and depression |

| First Author, Year, Journal | Sample Size | Demographics | Sample Age | Type of Study | Definition of Chronic Illness | Illnesses Reviewed | Diagnosis Confirmation | Assessment Measures | Outcome of Interest | Evaluation Period | Findings | Notes/ Critiques |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
|  |  |  |  |  |  |  |  |  |  |  |  | contradict other findings |
| Weil, 1999<br>PEDIATRICS | 1528?<br>1260 (complete data) | Female caretakers;<br>75% Black/African American<br>Lower SES | 6.18 y (4-9) | Longitudinal | NONE | Asthma | Unclear | Child Behavior Checklist (CBCL), Brief Symptom Inventory (BSI), CAGE, Clock Child Rearing Practices (modified) Report, Social Support Questionnaire, Psychiatrics Epidemiology Research Interview (PERI) Life Events Scale, Functional Status II Revised | Child's mental health and adjustment, Adult psychological symptoms, adult alcohol use, parenting practices, availability of emotional, information, & practical support, incidence of stressful life events, Contribution of illness to child's daily functioning | 9 mos,<br>3 evaluation points | Caretaker's psychological adjustment was the most sig. factor predicting hospitalizations due to asthma.<br>Child functioning sig. related to child's mental health even (after control) | Healthcare utilization was not strongly related to wheezing and functional status, suggesting that parents seek care for reasons other than child symptoms.<br>Study couldn't test reciprocal relationship between adjustment & asthma morbidity, because mental health assessments over time were not included/ available. |
| Suryavanshi, 2016<br>Prev Chronic Dis | 42,130;<br>4,640 with chronic physical condition | Nationally representative sample,<br>More boys than girls | 10.98y | Cross-sectional analysis | NONE | 21 Chronic Physical Conditions: Juvenile rheumatoid arthritis, asthma, epilepsy, diabetes mellitus, infantile cerebral palsy, Spina bifida, congenital anomalies, sickle-cell disease, cystic fibrosis, visual problems, hearing loss, cancer(s)<br>11 Mental Disorders: Affective psychoses, anxiety, depression, conduct disorders, ADHD, | International Classification of Disease, 9th Revision, Clinical Modifications (ICD-9-CM) codes<br>The Clinical Classification Codes (CC) | Medical Expenditure Panel Survey (MEPS) | Chronic physical conditions, healthcare use: hospital inpatient stays, emergency department visits, outpatient visits, office-based medical provider visits, prescription medicine files, dental visits, and home health files | 2008-2013,<br>1 evaluation point | Boys, white, and/or recipients of public health insurance were significantly more likely to have a mental health disorder diagnosis.<br>An additional cost of $2874.57 for families of children with concurrent presence of chronic illness and mental health. | Under-diagnosis is believed to be the main reason minorities (Hispanic, black, and Asian), & the uninsured were less likely to have a mental health disorder diagnosis.<br>No analysis of specific diseases, or severity of the disease. |

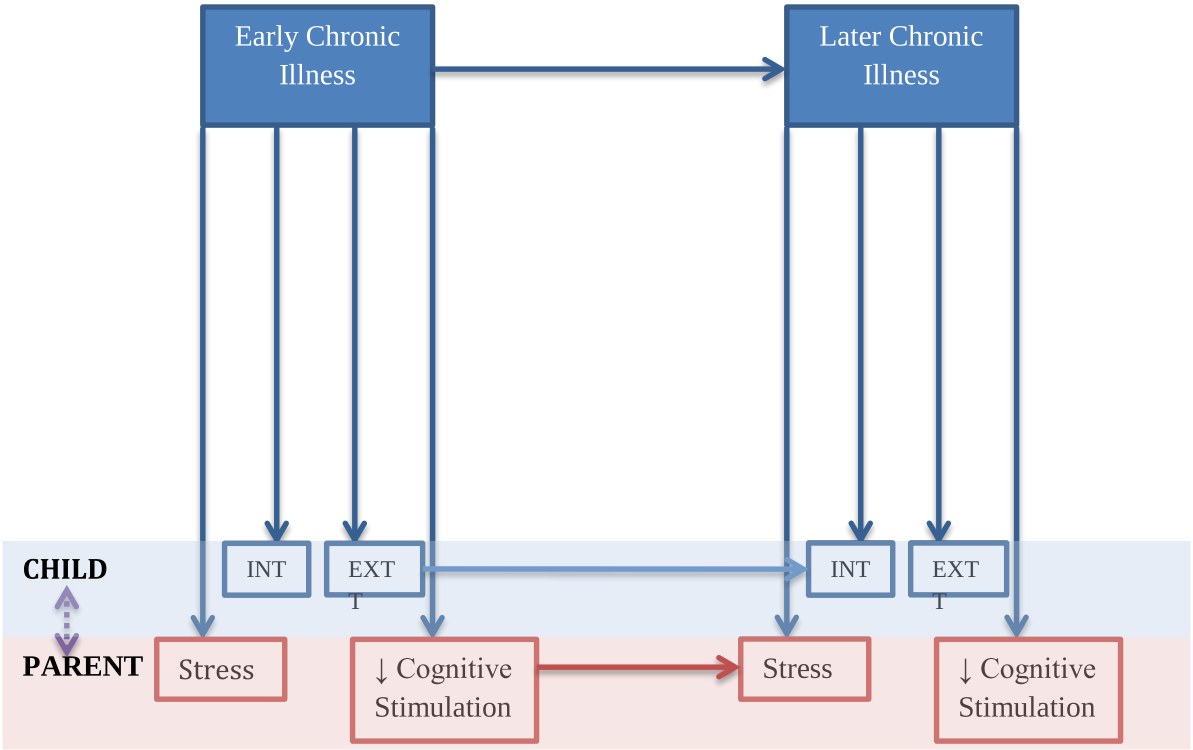
| First Author, Year, Journal | Sample Size | Demographics | Sample Age | Type of Study | Definition of Chronic Illness | Illnesses Reviewed | Diagnosis Confirmation | Assessment Measures | Outcome of Interest | Evaluation Period | Findings | Notes/ Critiques |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | oppositional-defiant disorders, personality disorders, acute stress, adjustment disorders, delusions, other pyschoses disorders | | | | | | |
| DeWalt, 2015<br>Qual Life Res | 1454 | Multi-site; Majority Caucasian and African American | 12.59y (8-17) | Cross-sectional analysis | NONE | Asthma, cancer, chronic kidney disease, obesity, rheumatic disease, sickle cell disease | Physician diagnosis; NIH Patient Reported Outcomes Measurement Information Systems (PROMIS) | PedsQL, Health-related quality of life (HRQOL) | PROMIS domains: mobility, upper extremity functioning, depressive symptoms, anxiety, anger, peer relations, pain interference, and fatigue | 2009-2010, 1 evaluation point | Children who had higher disease severity showed worse outcomes. Children with recent hospitalizations (in last 6 months) were significantly worse in all PROMIS domains, except anger. | Demographics of participants calculated per health condition, not overall. Additional and/or specific measurement were used for each condition (e.g. asthma control test, glomerular filtration rate, etc…) to help determine severity |
| O'Toole, 2016<br>Epilepsy & Behavior | 34 parents | Neurology dept. (major children's hospital) and National epilepsy association referrals | 11y7m<br>6-16 | Qualitative | NONE | Epilepsy | Medical diagnosis<br>Prescription for antiepileptic drugs (AED) | Interview format | Challenges in communication | 1 evaluation point | 5 themes: normalizing epilepsy, invisibility of epilepsy, information concealment, fear of misinforming child, and difficulty discussing epilepsy-related issues. | Family communication is a key coping strategy for family adaptation to childhood chronic illness<br>Lack of resources specifically showing parents how to communicate about illness. |
| Van Cleave, 2010<br>JAMA | 5001<br>(3 cohorts) | Nationally representative<br>Majority white/Caucasian | 4.62y (mean of means)<br>2-8 | Longitudinal | A health condition that limited activities or schooling or required medicine, specialized health services, | 4 categorizations:<br>Asthma, obesity, Other physical conditions, and behavioral/learning problems. | Caregiver report | Interview format | Body Mass Index (BMI). | 6 years (biennial) | Greater odds of prevalence amongst: black and Hispanic, children, males, Associations between maternal obesity and | Having a chronic condition was dynamic over time.<br>Prevalence of chronic conditions increased by 10% with each |

| First Author, Year, Journal | Sample Size | Demographics | Sample Age | Type of Study | Definition of Chronic Illness | Illnesses Reviewed | Diagnosis Confirmation | Assessment Measures | Outcome of Interest | Evaluation Period | Findings | Notes/ Critiques |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | and lasts at least 12 months. | | | | | | having a chronic condition. | cohort. Increased prevalence may be explained by greater access to medical care. |
| Reuner, 2016<br>Epilepsy & Behavior | 115 | University Children's Hospital wards, outpatient clinic patients | 12.47y<br>6-17 | Longitudinal | NONE | Epilepsy | Hospital chart<br>Validated by medical doctor (JHD) | EpiTrack Junior (assesses: speed, inhibition, working memory, verbal fluidity, and planning) | Attention, Executive function | 3 months 1 evaluation point | Children with new-onset epilepsy had impaired cognitive function at higher proportions than healthy children, but significantly lower than children with chronic epilepsy<br>Biophysiological dysfunctions affect cognitive performance in an early phase of epilepsy. | Epilepsy-related variables, but not socio-demographics, were associated with lower chance of improvement, and higher chance for deterioration. Can't distinguish if children with new-onset epilepsy had EF deficits, prior to medication, or whether said dysfunctions indicate more global cognitive deficit |
| Szefler, 2011<br>Ann Allergy Asthma Immunol. | 628 | Majority white, male<br>Community and academic sites | 9.3 y<br>6-12 | Longitudinal observational, prospective | Asthma is a chronic (long-term) lung disease that inflames and narrows the airways. | Asthma | Health care utilization;<br>TENOR study criteria | Pediatric Asthma Quality of Life Questionnaire with Standardized Activities;<br>Spirometry;<br>Asthma Therapy Assessment Questionnaire;<br>Work Productivity and Activity Impairment | Symptoms, nighttime awakenings, and interference;<br>lung function;<br>medication adherence;<br>school/work absence;<br>healthcare utilization (hospitalizations, ED visits, unscheduled physician visits) | 24 months, 3 evaluation points | Mean annual asthma cost more than twice as high for "very poorly controlled" group<br>Persistence of poor control associated with higher costs. Inverse also true. | Total asthma costs in children are higher than those in adults.<br>Small control sample size |
| Arif, 2016 | 398 | Low income | 5.9 y | Cross | NONE | Asthma | Clinically | Pakistan | Mental health | 7 months | Children with | Asthma |

| First Author, Year, Journal | Sample Size | Demographics | Sample Age | Type of Study | Definition of Chronic Illness | Illnesses Reviewed | Diagnosis Confirmation | Assessment Measures | Outcome of Interest | Evaluation Period | Findings | Notes/ Critiques |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| J Asthma | | families in outskirts of Karachi, Pakistan; Baluch ethnic minority | 2-14 | sectional analysis | | | diagnosed, based on reported signs and symptoms | Demographics and Health Survey 2006-07 | (anxiety, attention, depressive disorders), and developmental (learning, sleep and speech problems, hearing impairments) comorbidities | | asthma had 18 times greater for children with asthma Developmental problems were more than 14 times greater for children. More than twenty times the odds of sleep disturbance in children with asthma | attacks can trigger anxiety, which may cause patients to hyperventilate, further aggravating asthma symptoms.<br>In US rural population there were > 8-fold elevated odds of hearing impairment/ deafness |
| Muhammad, 2016<br>J of Renal Care | 14 | Children recruited from a children's hospital, & youth club in the UK. | 11.5y/ 14y<br>12-18 | Phenomeno-logical Qualitative | NONE | Chronic kidney disease (CKD) | Pediatric nephrology clinic nurse | Semi-structured questions | Coping strategies | N/A | 11 different coping themes: anticipating a challenging scenario, close relationships, coping strategies (lying down, sleeping), Demonstrating resilience, exercise, making decisions, pastimes, peer pressure, relaxation-relief, stress triggers, worst case scenario- on the extreme. (problem-focused, emotion-focused, avoidant-focused) | Good support system can help young people cope with challenges. Communicating with CKD peers could be beneficial. Exercise was a positive copying strategy to relieve stress and anxiety. Common stress triggers: frustration, inability to express feelings |
| Children's Environmental Health Center, 2013<br>Icahn School of Medicine | N/A | New York State children | N/A | Environmental and Health report | NONE | Asthma, birth defects, developmental disorders, primary brain cancer, childhood | N/A | N/A | Most common diseases in NYS, environmental hazards, economic costs | 2013 | About $4.35 bil/year is spent on diseases with environmental origins. | Children's unique vulnerabilities: greater exposure, unique |

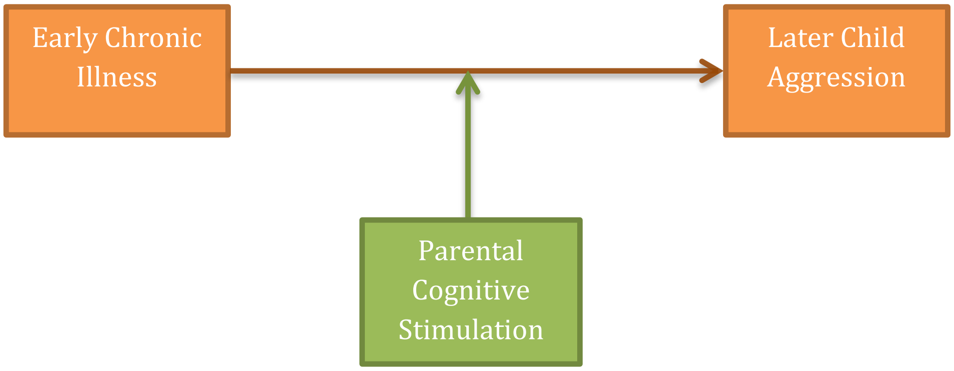
| | | | | |
|---|---|---|---|---|
| | leukemia, childhood obesity, lead poisoning | | 475K children had asthma in NYS in ‘08 Obesity has quadruples in the last 10 years. | behaviors, immature metabolisms, rapid growth and development, long future lives. |

**Appendix B:** Original Conceptual Model



INT = Internalizing Symptoms
EXT = Externalizing Symptoms

**Appendix C:** Mediating Effect Model of Parental Cognitive Stimulation on Later Child Aggression for Chronically Ill Children



**Appendix D:** Quality of Life Cross-Reference between Standardized QoL Measures and BELLE Project Data Available

| **Literature** | **Question** | **BELLE Measure/Section [Assessment]** |
|---|---|---|
| **Physical Health Function** | | |
| KIDSCREEN-27 | Overall, how would you describe your child's health? | Difficult Life Circumstances [36M, 54M] |
| Weil, 1999 | No. ER visits/unscheduled visits | MR |
| ComQoL-S5 | No. Specialty/doctor visits | MR |
| Weil, 1999 | No. Hospitalizations | MR |
| | Physical Therapy Y/N | Child Care & Educational Programs [14M, 24M, 36M, 54M, 1G] |
| Macedo, 2015<br>ComQoL-S5 [Qo Sleep] | Hours of sleep | Home Routines & Sleep Patterns [54M, 1G] |
| **Material Well Being** | | |
| ComQoL-S5 | Which best describes the building in which your child lives? | Difficult Life Circumstances [6M, 24M, 36M, 54M] |
| ComQoL-S5 | Do you… 1-own, 2- rent, 3- live w/ family or friends | Difficult Life Circumstances [6M, 24M] |
| ComQoL-S5 | How much did you and your partner bring home in the most recent calendar month? /Estimated Income | Job Earnings [14M, BL] |
| | No. Public Assistance Programs | Public Assistance Programs [14M] |
| | Availability of Learning Material (ALM) score | STIMQ [14M, 24M, 36M, 54M] |
| **Emotional Functioning** | | |
| PedsQL, KIDSCREEN-27 | Feels sad, unhappy | PSC-17 [1G] |
| PedsQL, KIDSCREEN-27, ComQoL-S5 | Worries a lot | PSC-17 [1G] |
| KIDSCREEN-27 | Seems to be having less fun | PSC-17 [1G] |
| PedsQL; Curtis, 2008 | Loses temper too easily | BASC- Aggression [36M, 54M, 1G] |
| YQOL-R | Argues when denied own way | BASC- Aggression [36M, 54M, 1G] |
| Curtis, 2008 | Hits other children | BASC- Aggression [36M, 54M, 1G] |
| Curtis, 2008 | Fights with other children | BASC- Aggression [36M, |

| | | |
|---|---|---|
| | | 54M, 1G]; PSC-17 |
| Curtis, 2008 | Teases others | BASC- Aggression [36M, 54M, 1G]; PSC-17 [1G] |
| PedsQL | Is easily soothed when angry | BASC- Adaptability [36M, 54M, 1G] |
| **Social Functioning** | | |
| | Does not understand other people’s feelings | PSC-17 [1G] |
| PedsQL | Pays attention | BASC- Attention [36M, 54M, 1G] |
| Bell, 2016; YQOL-R | Tires new things | BASC- Adaptability [36M, 54M, 1G] |
| | Cannot wait to take turn | BASC- Hyperactivity [36M, 54M, 1G] |
| | Interrupts others when they are speaking | BASC- Hyperactivity [36M, 54M, 1G] |
| ComQoL-S5? | On average, during the school years, how many days/week does your child spend playing with friends outside of school? | Parental Involvement with and Monitoring Homework [1G] |
| PedsQL | Shares toys or possessions with other children | BASC- Adaptability [36M, 54M, 1G] |
| **Other** | | |
| ComQoL-S5 | Hours of TV/day | Media Logs [6M,14M, 24M, 36M, 54M, 1G] |

*Note:* BL = Baseline; 6M = 6-Month Assessment; 14M = 14-Month Assessment; 24M = 24-Month Assessment; 36M = 36-Month Assessment; 54M = 54-Month Assessment; 1G = 72-Month Assessment; MR = Medical Record