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## Alternative Interventions for Children Coping with Chronic Conditions: A Critical Review of the Literature

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## **Alternative Interventions for Children Coping with Chronic Conditions: A Critical Review of the Literature**

### **Acknowledgements**

I would like to thank my mentor and faculty advisor and partner on this project, Dr. Kim Amer, for guiding me through the research process and sharing her infectious passion for advancements in pediatric medicine with me. I would also like to thank the College of Science and Health and the Undergraduate Summer Research Program for granting Dr. Amer and I the permission and funding for this project.

## Alternative Interventions for Children Coping With Chronic Conditions: A Critical Review of the Literature

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**ABSTRACT** Reduction of stressors and anxiety levels in adolescents with chronic illnesses is a critical concept in pediatric health care in America today. The many stressors associated with chronic illness include displaying physical and mental differences, social stigma, financial difficulty, and family stress. These stressors may affect the adolescent's ability to learn and cope in everyday life. The current research was a critical review of the literature examining studies done with adolescents coping with chronic diseases and illnesses. The aim was to analyze the most efficacious and non-pharmacological methods for reducing stressors in adolescents with chronic illness. A critical review of the literature of 10 studies was conducted after searching scholarly databases for articles studying physical interventions and their effects on the symptomology of chronic illnesses in youth. We found that physical activity programs are reported to have positive effects on the symptomology, stressors, and overall wellbeing of many children with illnesses, but concluded that more research needs to be conducted in this area before implementing trials of specific exercise interventions due to the high-risk nature of the youth population.

### INTRODUCTION

Children with chronic conditions have many stressors in day-to-day life. Stressors are defined for the purposes of this study as components of life (usually related to chronic illness in some way) that contribute to feelings of anxiety and discomfort. For youth coping with stressors brought on by the effects of their illnesses, it becomes even more important to investigate nonpharmaceutical interventions to reduce stress so that they have equal opportunity to thrive in both social and academic settings. In school and at home, many adolescents may feel discomfort in having a visible illness or a learning challenge.

Those with visible differences are most at risk for having low self-esteem and poor adaptation skills (Amer, 2009). Even when there is no evidence of difference, the child may be challenged due to cognitive issues, and they may hesitate to ask for help.

Because therapy in the form of medication is typically the first response to treat symptomology induced by chronic illnesses, the benefits of engaging in physical activity programs or classes are often overlooked. However, current research suggests that there are many benefits to children

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participating in physical activity programs (Boas, Danduran, McBride McColley & O’Gorman, 2000, Folleto, Pereira & Valentini, 2016). Exercise can help to boost confidence in adolescents and physical interventions in group settings help to improve social comfort and interpersonal skills (Mortimer, Privopoulos & Kuman, 2014). These benefits are important because they can contribute to decreased feelings of anxiety and stress and an increase in confidence and ability to cope with the realities of illness. In addition, being active is proven to improve the overall health of participants, so applying these interventions to children coping with chronic illnesses had the expectation of reducing general symptomology (Boas & Nevin, 2001).

The benefits of these interventions in adolescents have been previously investigated by implementing pilot exercise programs and studying the physical (musculoskeletal strength and flexibility, endurance, strength, reduce in illness symptomology) and psychoemotional (stress, confidence, comfort, happiness) effects of the exercise (Boas, Danduran, McBride McColley & O’Gorman, 2000 and Folleto, Pereira & Valentini, 2016). However, a definitive therapeutic plan identifying the most advantageous physical activity interventions has yet to be studied and identified.

The purpose of this study was to review and synthesize the current literature studying non-pharmaceutical interventions for children coping with chronic illnesses to help formulate possible plan implementations. The research to date is not consistent or clear on the physical and psychological benefits of exercise such as yoga. There is anecdotal and preliminary pilot study data. To pull together the research done so far, this research proposal was focused on identifying the interventions that may increase coping and health outcomes in children with varying challenges. The primary research question was: Are there benefits to non-pharmacologic, alternative interventions such as physical exercise and yoga in children with chronic physical or mental illness?

## METHOD

The research was conducted in the form of a critical review of literature using Whittmore and Knafl’s method (2005). This method involves a new system of researching, which includes the following steps: identifying the research purpose, searching literature, evaluating sources, analyzing data, and synthesizing findings in a meaningful way and finally presenting the results of the review. However, this method is unique in that it allows for a combination of different primary research methodologies, which better aligns with evidence-based practice initiatives. Whittmore and Knafl’s method was chosen because the research question addressed in this review of literature is currently relatively unexplored. Thus, it is essential to be able to include and synthesize various types of primary research methods to draw a meaningful conclusion on which to base future pilot physical activity programs for youth with chronic illnesses.

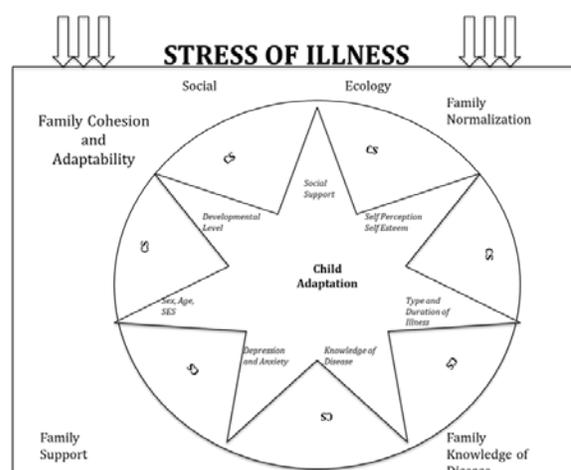
A critical review of literature is a methodology that identifies a concept or clinical phenomenon that needs to be explored and uses the findings of other literature to explain and support the effects of said phenomenon. The general goal was to develop a more comprehensive understanding of a specific health care problem. Studies that had titles that seemed to be related to our focus area were reviewed. Evidence-based practice initiatives have endorsed the use of literature reviews to develop recommendations for best practices. The researcher asks the question of the data, which was the literature that was reviewed. The critical review of literature was the best method to begin this research because there were more risks and challenges with intervening with children with chronic conditions, and thus, it is best to begin with a first step of a critical review of the literature. The following stages of integrative review were adhered to with this research: (1) Problem identification, (2) Literature search, (3) Data evaluation, (4) Data analysis, and (5) Presentation.

The literature search (step 2) was conducted by searching databases in nursing, physical therapy, medicine, health and wellness, and psychology.

The Boolean search method was used, in which multiple terms can be searched at once in the databases to match with specifically relevant articles. Search terms used included: children, adolescents, youth, chronic, illness, disease, disability, physical, exercise, therapy, wellness, health, stress, and anxiety. Data analysis (step 3) involved a methodology used to assess articles for relevance to the topic. Articles which studied the use of non-pharmaceutical interventions (specifically in the form of some sort of physical activity, exercise, program, or therapy) were first located. Biofeedback and cognitive behavioral therapies were not included due to their reliance on brain function and thought processes rather than focusing on physical responses to induced activity. If the effects of employing these physical interventions in these selected studies were evaluated on children (aged 1-18 years), the studies were retained. Next, chosen studies were narrowed down by relevance again by identifying the health of the study participants. Only studies that evaluated children with chronic (not acute) illnesses were chosen for inclusion in the review of literature. Chronic illnesses are those that have effects that last between three months and a lifetime long. Chronic illnesses are not preventable by vaccination or cured by medication, and will not simply subside over time. Thus, if studies used physical interventions to evaluate children with specifically chronic illnesses, they were reviewed. Because the Whitmore and Knalf method was utilized, no specific primary research methodology was selected for inclusion. Instead, controlled experimental and observational studies, meta-analyses, comparative and evaluative studies, and literature reviews were all allowed for inclusion, if relation to the primary research question was deemed relevant. The relevant selected articles were analyzed (step 4) and the critical components were compiled and added to a table (step 5) to be analyzed for the overall success of physical interventions in stress coping for youth with chronic illnesses.

A risk and resistance framework was used to frame and formulate our clinical recommendations. The risk and resistance framework is a systems model that recognizes the many influences on the child's health and coping

strategies. The risk factors include visibility of disease, functional independence, psychological stressors and many more. The resistance factors include social support, economic resources, family environment, culture and family member's adaptation and utilitarian resources (Wallender, 1989). The complexity of children coping with chronic conditions is best understood by the risk and resistance framework because coping with chronic illness is a multifactorial system with many conflicting life components, as seen in faculty sponsor Dr. Kim Amer's model (Figure 1).



**Figure 1.** Model of Influences on Child Adaptation to Chronic Illnesses

On the top of the model there is the downward pressure of the stress of illness that affects all systems. Stressors related to and beyond the illness are viewed as *risk variables*. Positive coping strategies, (CS) flow through all systems, and provide *resistance to stress*. *Risk variables* identified in the model include gender, age, socioeconomic status (SES), development level, lack of social support, duration of illness, and the presence of depression and anxiety. Exercise and non-traditional treatments can build up the resistance to the risks. *Resistance variables*, if present, can mediate or buffer the effect of risk on the child's adaptation to chronic illness. *Resistance variables* include self perception or self-esteem, knowledge of disease, and presence of social support. *Social ecological variables*, which provide resistance to poor adaptation, include family environment, family support,

family cohesion and adaptability, family knowledge of disease, and normalization (Knafl & Deatrck, 1986).

Child adaptation, the center of the framework, can be measured by the children's ability to process stress, their cognitive appraisal, coping strategies and physical, social, and psychological well-being. The model includes select variables that have been studied most frequently in the literature, such as family environment and competence of the child. (Amer, 2009) The physical interventions studied in this project can bolster the child's sense of well being or self esteem potentially.

The child's adaptation, the center of the model, is conceptualized in a comprehensive manner to include the social ecology that includes mental health, social functioning, and physical health. Outcomes, such as the presence or absence of depression, anxiety, level of self-worth and physical health, are influenced by the variables of social ecology of the child's environment, coping strategies, and cognitive appraisal by the child. The child must not be viewed in isolation since there are complex systems operating that are included in the conceptual model.

### **DEFINITIONS OF CONCEPTS**

The following definitions were developed in conjunction with the theoretical framework. The concepts were developed and defined to clarify the relationships between concepts and the primary focus of the framework, child adaptation.

### **STRESS PROCESSING**

The definition of stress for the conceptual model is adapted from Lazarus and Folkman (1984), who define stress as a perception of threat that is appraised by the child as taxing or exceeding his

or her resources and endangering well-being. The stress of having a chronic illness provides a stimulus that requires the child to respond through the process of coping. The coping appraisal of the stress and the individual's response is the first step toward the outcome of adaption to the illness.

### **RESULTS**

The study was a critical review of the literature on physical interventions that were used to help positively affect adolescents coping with chronic illness. The number of articles identified as meeting the criteria for inclusion was ten. The chronic illnesses identified as having research done with non-pharmacological interventions include: autism, pervasive-developmental disorder, Asperger Syndrome, cerebral palsy, cystic fibrosis, musculoskeletal and pulmonary disorders, ADHD, and epilepsy.

The interventions identified as being effective with a reduction in behavioral and academic symptomology, coping, confidence in social interactions, and stress-reduction were jogging and walking, hydrotherapy, exercising before class, aquatic and equine therapies, and yoga programs. Other outcomes measured were increased skill in motor abilities, musculoskeletal and pulmonary fitness, and knowledge expression and decreases in overall symptomology and hospitalizations. The number of studies that showed improvements in these physical parameters was eight. One study included had results that were deemed inconclusive and did not display positive or negative outcomes following implementation of physical activity programs on chronically ill youth (Slaman, 2015). Overall findings are included in Table 1.

**Table 1.** Reviewed literature studying physical interventions for chronic illnesses

Author & Date	Type of study and Illness	Sample size & Age	Tools used	Independent (I) And Dependent (D) Variables	Impact
Hulzebos, Snieder, VanderNet, Helders, Takken (2011)	Experimental Cystic Fibrosis	N=1 Female 16 years old	Cardio- Pulmonary Exercise test (CPET)	Interval training exercise program (I) Cystic fibrosis symptoms (oxygen uptake (D))	Increase in pulmonary function
Schmitz, Goldbeck (2006)	Descriptive Cystic Fibrosis	79 female 51 males 12-22 years old	Life Satisfaction scale (FLZ)	Inpatient rehabilitation(I) Healthy related Quality of Life(D)	Lower quality of life in all dimensions
Boas, Nevin (2001)	Evaluative Cystic fibrosis	Large range	Perceived competence and social acceptance	Exercise testing (I) Symptoms of Pulmonary disease (D)	Regular exercise helps disease recovery time, slows disease progression
Boas, Danduran, McBride, McColley, O’Gorman (2000)	Experimental Cystic Fibrosis	N = 25 8-17 years old	Leukocyte & lymphocytes and Bruininks-Oseretsky Test of Motor Proficiency,	Exercise testing (I) Symptoms of Pulmonary disease (D)	Significant positive changes pulmonary function and tests
Verschuren, Darrah, Novak, Ketelaar, Wiart (2010)	Observation Cerebral Palsy	Patients aged 16-24	Physical activity charts	Physical activity level (I) Condition of Child (D)	Resistance training promoted muscle strength, cardio-respiratory improvement and locomotion
Slaman (2015)	Randomized controlled experimental study Cerebral Palsy	Patients 16-24	Fatigue severity scale (FSS); Checklist of Individual Strength (CIS-20r)	Active Lifestyle (I) Condition of Cerebral Palsy (D)	Fatigue and fitness had no association
Srinivasan, Pescatello, Bhat (2014)	N/A Meta-analysis of ASD, CP, DD, Autism	Range from study to study	Range from study to study	Exercise interventions (I) Behavioral and academic (D)	Exercise promotes musculo-skeletal fitness and improved symptomatology
Folletto, Pereira, Valentini (2016)	Experimental Healthy children	First grade	Perceived self competence and social acceptance	Yoga 12 weeks (I) motor abilities and social behavior (D)	Positive changes in motor abilities scores and positive changes in social acceptance and expressive knowledge
Brondino, Fusar-Poli, Rocchetti, Provenzani, Barale, Politii (2015)	Review of literature Autism Spectrum disorder (ASD)	Wide range	Aberrant Behavioral Checklist Irritability Subscale (ABC)	Yoga (I) Stress level and quality of life (D)	Increased GABA brain levels and decreased ABC scale, increased control of disruptive behaviors
Mortimer, Kumar, Privopoulos (2014)	ASD	N=4 3-12 years old	10-14 Halliwick- based hydrotherapy intervention	Hydrotherapy (I) Social interactions & Behaviors (D)	Hydrotherapy improved social interactions and behaviors

## DISCUSSION

Introducing physical exercise programs into the lives of adolescents with chronic conditions has been shown to have many positive health implications. Several studies observed reduction in overall symptomology, a slow in disease progression, increases in cardiopulmonary and musculoskeletal strength and endurance, and improvements in gross motor skills following implementation of non-pharmaceutical, exercise-based interventions. The compiled studies that were reviewed provide strong evidence of physical activity as a positive intervention for youth coping with chronic illness.

In the future, we will explore designing research and experimental studies on the effects of yoga,

specifically, on the stressors, self-confidence, coping abilities, and social skills of children with chronic conditions such as ASD, cerebral palsy, ADHD, and Asperger syndrome. The wide range of studies of physical activity and calming interventions, different illnesses, and ages of children made it difficult to generalize about benefits of such interventions. However, there is enough positive evidence that physical exercise, including yoga, assisted with both physiologic improvements (as in cystic fibrosis) and psychological or social interactions (such as in Autism Spectrum Disorder). There is a beginning pattern that emerges which justifies investing time in future studies with more subjects and more standardized measures.

## ACKNOWLEDGEMENTS

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