UNIVERSITY OF CALGARY

The Psychosocial Implications of Physical Activity for Children with Juvenile Arthritis

By

Kerry Coupland

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE

DEGREE OF MASTER OF SCIENCE

FACULTY OF KINESIOLOGY

CALGARY, ALBERTA

SEPTEMBER, 2005

UNIVERSITY OF CALGARY

FACULTY OF GRADUATE STUDIES

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "The Psychosocial Implications of Physical Activity for Children with Juvenile Arthritis" submitted by Kerry Coupland in partial fulfilment of the requirements of the degree of Master of Science.

S. Nicole Culos-Reed Ph.D., Supervisor
Faculty of Kinesiology

David Paskevich Ph.D.
Faculty of Kinesiology

Lorraine Watson Ph.D.
Faculty of Nursing

Sept 2, 2005
Date

Abstract

Increasing attention is being focused on the psychosocial benefits of physical activity (PA) for children. However, there remains a paucity of literature on the impact PA may have on populations with special health concerns. This preliminary research investigated relationships between PA and self-efficacy, self-esteem, HRQL, pain perception, functional disability, and social functioning in youth with juvenile arthritis (JA). The Exercise and Self-Esteem Model provided the framework from which this investigation was based. Using a one time cross-sectional survey methodology, questionnaires were mailed to children and adolescents being treated at The Alberta Children's Hospital rheumatology clinic. Although mainly descriptive, results suggest a positive relationship between a child with JA's level of PA and his or her self-efficacy, self-esteem, and social functioning. No relationship was demonstrated between PA and HRQL, pain, or functional disability. Additional prospective experimental studies are needed to further examine the relationships found in a larger JA sample.

Acknowledgements

There are a number of individuals who deserve recognition for their contribution to my studies and my ability to complete this Masters of Science degree.

My family (Dad, Mom, Tara, and Devon) and my friend Erynn for their unwavering support and encouragement when things felt too monumental to overcome – I can not express to you how important your role has been. Thank-you.

Melanie Keats, my colleague, co-worker, and friend, for your invaluable guidance, tireless answers to seemingly silly questions, and for your enthusiasm for mailroom and food court breaks. Your presence was instrumental and without which I am certain this would have been an even bumpier and far more confusing ride.

To the Rheumatology Clinic doctors, nurses, and staff and in particular Dr. Paivi Miettunen who recognized the merits of this project and were fundamental to its existence.

Dr. Doug Lawson for his passionate endorsement of me, and my project, and for his role in liaising with The Arthritis Society Calgary Chapter who graciously funded part of this study.

To my committee members: Dr. David Paskevich and Dr. Lorraine Watson who despite being extremely busy agreed to participate and share their wealth of information and experience.

Lastly, I would like to thank my supervisor Dr. Nicole Culos-Reed for her direction and support in the timely completion of my degree. Thank-you.

Table of Contents

Approval Page ii
Abstract iii
Table of Contents v
List of Tables viii
Epigraph xi

INTRODUCTION 1
CHAPTER ONE: LITERATURE REVIEW 3
1.1 Physical Activity and Physiological and Physical Benefits 3
1.1.1 Physical Activity and Cardiovascular Disease 3
1.1.2 Physical Activity and Obesity 3
1.1.3 Physical Activity and Future Health 4
1.1.4 Physical Activity and Healthy Bones 5
1.2 Physical Activity and Psychological Benefits 5
1.2.1 Physical Activity and Stress 6
1.2.2 Physical Activity and Social Relationships 6
1.2.3 Physical Activity, Anxiety and Depression 7
1.2.4 Physical Activity and Self-efficacy 8
1.2.5 Physical Activity and Self-esteem 9
1.2.6 Physical Activity and Health Related Quality of Life 10
1.3 What is Juvenile Arthritis? 11
1.3.1 Definition of Juvenile Arthritis 11
1.4 Juvenile Arthritis and Health Concerns 13
1.4.1 Physical and Physiological Concerns 13
1.4.2 Psychosocial Concerns 15
1.5 Physical Activity's Role in Alleviating Physical and Psychosocial Concerns 26
1.6 Physical Activity for Juvenile Arthritis 32
1.7 Potential Physical Benefits of Physical Activity for Juvenile Arthritis 33
1.8 Potential Psychosocial Benefits of Physical Activity for Juvenile Arthritis 34
1.9 Theories of Physical Activity 35
1.9.1 Theory of Planned Behaviour 36
1.9.2 Transtheoretical Model 39
1.9.3 Self-Efficacy Theory 41
1.10 Conclusion 45

CHAPTER TWO: METHOD 48
2.1 Participants 48
2.2 Design 48

2.2.1 Demographics 48
2.2.2 Godin Leisure Time Exercise Questionnaire. 49
2.2.3 Physical Self-Description Questionnaire. 49
2.2.4 Confidence to Engage in Physical Activity Scale (CTEPA) 50
2.2.5 PedsQL. 50
2.2.6 Pain Visual Analog Scale 51
2.2.7 Child Health Assessment Questionnaire 51
2.2.8 Physical Activity Behaviour and Interests 52
2.3 Procedure 53

CHAPTER THREE: RESULTS 54
3.1 Statistical Analyses 54
3.2 Participant Characteristics 54
3.3 Quantitative Analysis 59
3.3.1 Physical Activity and Psychosocial Well-being 59
3.3.2 Psychosocial Variables 62
3.4 Physical Activity Level Results (Past Week) 66
3.4.1 Total physical activity 66
3.4.2 Strenuous physical activity 66
3.4.3 Moderate and mild physical activity 67
3.4.4 Correlations between psychosocial variables and leisure score index (LSI) 67
3.5 Physical Activity Group Differences 67
3.5.1 Relationship Between Physical Activity and Physical Self-Concept 71
3.5.2 Relationship Between Physical Activity and Confidence to Engage in Physical Activity 71
3.5.3 Relationship Between Physical Activity Participation and Self-Esteem 71
3.5.4 Relationship Between Physical Activity Participation and Quality of Life 71
3.5.5 Relationship Between Physical Activity Participation and Social Functioning72
3.5.6 Relationship Between Physical Activity Participation and Functional Disability72
3.5.7 Relationship Between Physical Activity Participation and Perceived Pain 72
3.6 Qualitative Analysis 74

CHAPTER FOUR: DISCUSSION 82
4.1 The Role of PA Level and Amount 87
4.2 Model – Utility for Future Research 88
4.3 Limitations 89
4.4 Conclusion and Future Directions 91

REFERENCES 94

APPENDICES

Appendix A - Diagram of Arthritic Joint.....110
Appendix B – Diagrams of Forms of Juvenile Arthritis.....111
Appendix C – Diagram of Cycle of Disuse.....113
Appendix D – Theory of Reasoned Action/Theory of Planned Behaviour.....114
Appendix E – The Transtheoretical Model.....115
Appendix F – Self-Efficacy Theory/ Exercise & Self-esteem Model.....117
Appendix G – Questionnaire Package.....118

List of Tables

Table 1. Studies Examining Psychosocial Well-Being and Juvenile Arthritis 19

Table 2 Studies Examining Physical Activity and Juvenile Arthritis (including PA interventions) 27

Table 3 Demographic Characteristics of the Study Participants 56

Table 4 Reasons for Compliance with Medication Regime 57

Table 5 Demographic and Medical Characteristics of Participants 58

Table 6 Physical Activity Frequency and Duration Before and After Diagnosis 60

Table 7 Organized Sport Involvement Before and After Diagnosis 61

Table 8 Pearson Correlations Between Physical Activity (LSI) and Psychosocial Variables 64

Table 9 Significant Correlations Between Physical Activity and Psychosocial Variables Based on Group Membership 71

Table 10 T-Test of Differences Between Group Means of LPAG and HPAG 70

Table 11 Pearson Correlations of Psychosocial Variables within High and Low Physical Activity Groups 73

Table 12 Response Categories to the Advantages of Physical Activity 76

Table 13 Response Categories to the Disadvantages of Physical Activity 78

Table 14 Response Categories to Question "What Prevents Youth From Participating in Physical Activity 80

Table 15 Response Categories to Question "What Would Encourage Youth Like You To Participate in Physical Activity..... 81

List of Symbols, Abbreviations and Nomenclature

CHAQ.....Child Health Assessment Questionnaire
CTEPA.....confidence to engage in physical activity
GLTEQ.....Godin Leisure Time Exercise Questionnaire
HPAG.....high physical activity group
HRQL.....health related quality of life
JA.....juvenile arthritis
LPAG.....low physical activity group
PA.....physical activity
PSDQ.....Physical Self-Description Questionnaire

Epigraph

Health is the vital principle of bliss, and exercise of health

- James Thomson

INTRODUCTION

Since the inception of Little League and PeeWee divisions, physical activity and sport involvement has been viewed by the general public and academics alike as a legitimate past time for children (Eppright, Sanfacon, Beck, & Bradley, 1997). The assumption held is that sports and physical activities kept children out of trouble and certainly could not be bad physiologically. It was not until the last part of this century that science tested this common sentiment and began to investigate the relationship between physical activity and children's physical health. Not surprisingly, academia found that physical activity is good for a child.

A plethora of evidence exists linking healthy physiological functioning of children to physical activity (Baranowski et al., 1992; Boreham & Riddoch, 2001; Sallis, 1995; Sallis & Patrick, 1994). Benefits include, but are by no means limited to, improvements in cardiovascular fitness and motor ability, and research also indicates that physical activity is essential for proper growth and maturation (Kohl III & Hobbs, 1998). Along with these physiological findings, it is known that skeletal integrity through life is contingent upon sufficient peak bone mass being accumulated in one's growing years (McDonagh, 2001). Strong scientific evidence also demonstrates the physiological risks associated with not being physically active, such as obesity, which is a predictor for coronary heart disease, hypertension, and diabetes in adulthood (Bailey & Martin, 1994; Biddle & Mutrie, 2001; Boreham & Riddoch, 2001).

The relationship between physical activity and psychological well-being in children is not as well-documented, but the research that exists on the topic suggests physical activity may also provide a number of important psychological benefits (Field,

Diego, & Sanders, 2001; Kirkcaldy, Shepard, & Siefen, 2002; Sorensen, 1991). These benefits are discussed in the following sections, including stress reduction, promotion of social relationships, decrease in depression, and an increase in self-efficacy and self-esteem. Physical activity is also a significant contributor to overall health-related quality of life.

Understanding and exploring means for improving the health related-quality of life of children is increasingly being recognized as a legitimate research interest, and of great clinical importance (Rejeski, Brawley, & Schumaker, 1996). This remains true for children with juvenile arthritis. Children with this chronic illness encounter a number of physical and psychological challenges related to their disease experience (Duffy, Arsenault, Watanabe, Paquin, & Strawczynski, 1997). The role physical activity may play in mediating a child's experience of this disease is largely unexplored, thus necessitating further study.

CHAPTER ONE: LITERATURE REVIEW

1.1 Physical Activity and Physiological and Physical Benefits

While prolific scientific evidence exists clearly defining the role physical activity and exercise assume in keeping adult bodies healthy and disease free, a less delineated relationship exists with respect to physical activity and children (Biddle, Gorely, & Stensel, 2004). The lack of clarity on this issue is the result of fewer studies, inconsistent measures, and methodological inconsistencies (Biddle et al., 2004). However, the literature suggests some important associations.

1.1.1 Physical Activity and Cardiovascular Disease

It is well understood that cardiovascular disease has its origins in childhood and that risk factors are carried through into one's adult life (McGill et al., 2000; Nicklas, von Duvillard, & Berenson, 2002). Empirically sound randomized studies measuring the effect exercise has directly on cardiovascular disease predictors in children, such as blood pressure and lipid profiles, are lacking, and therefore it is too early to make any definitive assertions (Riddoch, 1998; Tolfrey, Jones, & Campbell, 2000). However, what seems to be apparent from large-scale multinational trials is that youth physical fitness and activity is associated with a more positive and healthy cardiovascular profile in later life (Boreham, Twisk, Neville et al., 2002; Janz, Dawson, & Mahoney, 2002; Lefevre, Philippaerts, Delvaux, 2002; Ribeiro et al., 2004a; Trost, Saunders, & Ward, 2002).

1.1.2 Physical Activity and Obesity

Globally, childhood obesity is becoming a pandemic problem (Ohki, Kishi, Orimo, & Ohkawa, 2004; Ribeiro, Gurerra, Oliveira, Andersen, Durate, & Mota, 2004b). It is well understood that obese children are more likely to become obese adults, increasing

their risk for numerous health troubles including coronary hearth disease, hypertension, and diabetes (Biddle & Mutrie, 2001). Physical activity likely is a variable in the expression of obesity. Although some argue the evidence to be inconclusive (Biddle et al., 2004), a link between physical inactivity and the development of obesity in children is abundant in academic literature (Steinbeck, 2001; Ribeiro, Gurerra, Oliveira, Andersen, Durate, & Mota, 2004b). In fact, a recent large scale study conducted with 12 year olds in France demonstrated that the larger the size of a child's waist, the lower their structured physical activity levels (Klien-Platat et al., 2005). Additionally Klien-Platat et al. found sedentary activities were associated with larger body mass indexes, and children who participated mainly in non-vigorous activities were heavier than their peers who participated in fewer sedentary activities. Both of these relationships indicate that physical activity is associated with total adiposity of adolescents, and specifically with waist circumference, a known risk factor for cardiovascular disease and diabetes.

1.1.3 Physical Activity and Future Health

Furthermore, while physical activity in childhood sets the foundation for current health, it also decreases the risk of health problems in adulthood. Although a controversial assertion, the research is generally supportive that active children lead active adult lives (Malina, 2001; Trudeau, Laurencelle, & Shepard, 2004; Telama, Laakso, Yang, Vnkari, 1997). For example, a cross-sectional sample of Finnish children and adults found a statistically significant correlation between being physically active as a child and adolescent, and being active as an adult (Telama et al., 1997). Trudeau and colleagues found weak but statistically significant correlations between PA as an adult and PA as a child in a semi-longitudianl quasi-experimental study conducted in Quebec (2004). Furthermore, their results revealed that organized PA in childhood was a

significant predictor of current PA. In addition, Malina's 2001 review of the relationship between activity as a child and activity as an adult indicated at least a low to moderate relationship. This is likely an underestimation of the true relationship, as methodological differences between the studies reviewed made comparisons difficult. Thus, the literature generally supports the premise that physical activity in childhood is not only imperative for current health, but also important for adult health and lifelong well being.

1.1.4 Physical Activity and Healthy Bones

Physical activity is essential in the promotion of peak bone mass in children and adolescents (Biddle et al., 2004; Boreham and Riddock, 2001). Skeletal integrity throughout life is contingent upon achieving sufficient peak bone mass in one's growing years (Kohl II & Hobbs, 1998). One fourth of final adult bone mass is accrued in the two years surrounding puberty in both boys and girls (Bailey, 1997). In addition to this important fact, bone density accretion is determined in part by mechanical loading factors or weight bearing activities (Bailey & Martin, 1994). The failure to accumulate adequate peak bone mass in childhood places individuals at a higher risk for osteoporosis in adulthood. This makes exercise and physical activity in childhood and adolescence extremely important in its prevention of future bone problems.

1.2 Physical Activity and Psychological Benefits

The function of physical activity in the maintenance and promotion of mental and emotional health in children has been gaining scientific interest over the last decade (Calfas & Taylor, 1994; Kirkcaldy et al., 2002). Similar to physical activity and physical benefits, this research is hindered by inconsistent measures and methodological conflicts

(Calfas & Taylor, 1994; Sallis, Prochaska, & Taylor, 1999). However, the literature suggests some important associations.

1.2.1 Physical Activity and Stress

Combating the apparent increase in stress levels in today's children has become an important community health objective (Sorensen, 1991). Physical activity is a long-known and well-documented stress buffer in adult populations (Cotton, 1990; Crews & Lander, 1987; Stein, 2001; Taylor, 2000). Less well-known is physical activity's relationship to stress in children. In one of the few studies on stress and physical activity in children, Sorensen (1991) found physical activity was related to psychological health. The researcher concluded that physical activity acts as a stress buffer and a coping mechanism in children. He also advised that social support is another buffer for stress in children, and that physical activity is associated with social relationships, which are necessary for social support.

From a psychobiological perspective, exercise in children modifies stress and immune and inflammatory mediators (Cooper, Nemet, & Galassetti, 2004). Such mediators include peripheral blood mononuclear cells and circulating pro and anti-inflammatory cytokines, known to be important factors in pediatric diseases. Cooper and colleagues' review of exercise in children found substantial evidence to propose that physical activity is highly involved with diseases such as asthma and arthritis in children because of its major position in changing stress, inflammation, and leukocyte function.

1.2.2 Physical Activity and Social Relationships

Interpersonal relationships are important for a variety of psychological health reasons. First, they provide social support, which acts as a buffer, countering life stressors

(House, Landis, & Umberson, 1988; Schwarzer, 1998; Wills & Filler, 2000). Second, relationships foster a sense of belonging and acceptance (Rodin & Salovary, 1989). And last, quality social relationships teach children the social norms and the appropriate social skills for successful navigation of one's society and culture (Janssens & Dekovic, 1997). Social skills also strengthen peer relations and increase self-esteem, while inadequate social skills are associated with loneliness and social anxiety (Hartup & Stevens, 1999; Meiger, Sinnema, Bijstra, Mellenbergh, & Wolters, 2000). Thus, social skills have the potential to make a significant impact on psychological health and well being.

A positive correlation between healthy social relationships and sport involvement is illustrated by Field and colleagues (2001), who found that self-reported adolescent high exercisers noted more intimacy with their parents, more perceived support, and a higher frequency of physical contact. While somewhat supportive, the research remains relatively inconclusive as to the role physical activity plays in the formation and continuance of social relationships (Brettschneider, 1999; Sanders, Field, Diego, & Kaplan, 2000).

1.2.3 Physical Activity, Anxiety and Depression

A clearer relationship emerges when one reviews literature regarding physical activity's association with the reduction of anxiety and depression. Several surveys have established that physical activity in children and adolescents is correlated with less anxiety and depression (Kirkcaldy et al., 2002; Saunders et al., 2000). Athletic adolescents report themselves to be less anxious, nervous, sad, and depressed and have fewer thoughts of suicide (Brosnahan, Steffen, Lytle, Patterson, & Boostrom, 2004; Ferron, Narring, Cauderary, & Michaud, 1999). Furthermore, Page and Tucker (1994)

demonstrated that exercise frequency was inversely related to feelings of loneliness, shyness, and hopelessness. One of the few experiments to investigate the anxiety/depression relationship in children utilizing an exercise intervention found that intense exercise weakened the relationship between perceived stress, anxiety, and depression (Norris, Carroll, & Cochrane, 1992). Overall, the results strongly support the premise that physical activity is a positive influencing variable on the prevalence of anxiety and depression (Brown, Welsch, Labbe, Vitulli, & Kukarni, 1992; Covey & Feltz, 1991; Strauss, Rodzilsky, Burack, & Colin, 2001). While these results must be considered in view of the small sample size and quasi-experimental design, thus limiting the generalizability, two separate reviews also found support for the negative correlation between depression and physical activity (Calfas & Taylor, 1994; Sallis et al., 1999).

In addition to these positive changes in anxiety and depression, physical activity has also been positively associated with self-efficacy and self-esteem in children.

1.2.4 Physical Activity and Self-efficacy

Self-efficacy is defined as the belief in one's ability to accomplish a particular objective (Bandura, 1997); for a complete discussion of self-efficacy, see the section on self-efficacy theory. Trost, Pate, Dowda, Ward, Felton, and Saunders (2002) investigation of adolescent girls found that self-efficacy perceptions were strongly correlated with girl's intention to be physically active, and intention to be physically active was significantly related to physical activity. Importantly, moderate-to-vigorous physical activity was strongly related to self-efficacy perceptions. Thus, girls who were confident in their physical abilities were more active.

1.2.5 Physical Activity and Self-esteem

Self-esteem is defined in many ways, but the overarching conceptualization of this construct is that it determines if we feel positively or negatively about ourselves (Diener, 2000; Passer & Smith, 2002). It is an evaluative psychological state likely influenced by multiple situation-specific judgments. Self-confidence, along with body image and self-efficacy, are believed to be contributors to overall self-esteem. It is an important concept for emotional well-being, as high self-esteem is associated with being less susceptible to social pressure, demonstrating fewer interpersonal difficulties, and reports of greater happiness (Brown, 1998; Diener, 2000). Likewise, individuals with low self-image are more susceptible to anxiety, depression, impoverished social relationships, and physical illness (Passer & Smith, 2002). Common belief maintains that a healthy self-esteem is essential for emotional adjustment and overall psychological well-being.

Participation in organized sports, recreational activities, and physical activity in general is positively associated with children's self-esteem (Boyd & Hrycaiko, 1997; Brettschneider, 1999; Dekel, Tenenbaum, & Kudar, 1996). Calfas and Taylor's meta-analytic review (1994) concurs with these findings, noting that the most unwavering effect of physical activity was for self-esteem/self-concept variables. Specifically, nine out of ten studies addressing self-esteem, self-concept, or self-efficacy found a positive relationship.

While a more recent review by Sallis et al. (1999) found no such association between physical activity and body image or self-esteem, discrepant review methodology may help to account for the differences in findings. Specifically, the earlier review (Calfas & Taylor, 1994) included only studies with participants falling within the 11-21

year age range, whereas Sallis et al. (1999) included participants aged 3-18 but analyzed the data separately for children 3-12 years old and for adolescents 13-18 years old. As well, Calfas and Taylor's review (1994) included 20 studies of which 12 were randomized controlled or quasi-experimental study designs, whereas Sallis et al. (1999) reviewed 54 cross-sectional and prospective studies.

While the findings for both self-efficacy and self-esteem in relationship to physical activity are generally positive, it is the potential interaction between the two that is most intriguing. Enhancing physical self-efficacy beliefs with physical activity strengthens children's self-esteem and self-concept. According to Calfas and Taylor (1994), the improvement in self-esteem/self-concept is generally reported as a result of improving self-efficacy through mastery experiences and success information. This is supported by Boyd and Hrycaiko's (2001) experimental physical activity intervention in which American students with low self-esteem participated in a six-week physical activity intervention and demonstrated enriched self-esteem and self-concept. Comparable effects have been confirmed in other samples of children (Brown et al., 1992; DiLorenzo, Bargman, Stucky-Ropp, Brassington, Frensch, & LaFontaine, 1999; Ferron et al., 1999; Holloway, Beuter, & Duda, 1988). This substantial body of evidence confirms the notion that exercise and physical activity are salient factors impacting self-efficacy, thereby leading to improved self-esteem and self-concept.

1.2.6 Physical Activity and Health Related Quality of Life

Physical activity influences one's physical and mental health, which positively contributes to the subjective evaluation of one's quality of life (Berger & Motl, 2001). Health related quality of life (HRQL) is a multidimensional component of overall quality

of life and is generally defined as the subjective perception of one's health (Bullinger, Petersen, Schmidt, Baars, & the Disabkids Group, 2002; Matza, Swesen, Flood, Secnik, & Leidy, 2004; Rejeski et al., 1996). This concept speaks to aspects of the self that may be enhanced or lessened by health-related behaviours, such as physical, emotional, mental, social, and functional factors.

Until recently, children's quality of life has been relatively unexplored, but researchers are increasingly becoming aware that if one aims to improve a child's well-being and functioning, then the importance of understanding the determinants of children's quality of life is crucial (Bullinger et al., 2002).

It is apparent that there are a number of both physical and psychological benefits for children from physical activity participation. While even less is known about the impact of physical activity on populations with specific illnesses, it would appear that children with specific health concerns may have even more to gain by regular physical activity participation due to their initial health deficits (Rejeski et al., 1996). The following section is an exploration of the benefits of physical activity for the chronically ill population of children with juvenile arthritis (JA).

1.3 What is Juvenile Arthritis?

1.3.1 Definition of Juvenile Arthritis

Before exploring the association between JA and physical activity one must first understand the nature of the disease. Chronic JA is a heterogeneous group of diseases. All of the diseases falling under the category of JA are characterized by two predominant symptoms: joint inflammation and joint stiffness (LeBovidege, Lavigne, Donenberg, & Miller, 2003). Inflammation and stiffness are the result of an over-stimulated synovium. An autoimmune

disruption causes the synovium, the site for production of synovial fluid, to become inflamed and coagulated. This incites the manufacturing of more fluid, which contains inflammatory cells, thus generating warm, stiff, and swollen joints (Laxer, 1998) (see Appendix A for a diagram depiction). For children living with JA, functioning and quality of life are dictated by periods of flare, when the synovium over produces synovial fluid, and quiescence, when the disease is in remission (Schanberg, Anthony, Gil, & Maurin, 2003). During times of flare, pain, fatigue and stiffness may transform the most routine activities into the most arduous of tasks; the simple act of buttoning up one's shirt or walking around a mall becomes burdensome and painful. The cause of JA remains unknown and there currently exists no cure. Thus, pain management is the primary focus of treatment (Murray & Lovell, 2002).

JA is not adult rheumatoid arthritis (RA) experienced by children. There are a number of features that differentiate JA from adult arthritis, including the possibility of growth abnormalities, vision and eye problems, rash, and an unpredictable disease course (Laxer, 1998). In addition, unlike adult arthritis, JA manifests itself in a variety of patterns (see Appendix B for an illustration of the differences). It can be pauciarticular, indicating that four or fewer joints are affected. This type generally begins in children under the age of four and primarily affects girls. Systemic-onset pattern is a more severe form characterized by spiking fever, rash, swollen lymph glands, and flares that last for a longer duration. Inflammation of a child's internal organs may also occur in this type of JA, resulting in painful stomach and intestinal cramps. Fortunately, systemic-onset pattern does not produce permanent internal damage. A third form is the polyarticular type. This designation denotes that five or more joints are affected, but there is no accompanying rash or fever. Psoriatic Arthritis is yet another pattern. Here, the identifying trait is the presence of psoriasis, a skin disease, in conjunction with arthritis. The fifth is

spondyloarthropathy. This tends to begin in children over the age of ten and is the only form of chronic arthritis that is more common in boys than girls. A child's hips are a commonly affected area but pain may also travel into the back or heels. This form of JA frequently persists into adulthood. The last type of arthritis is adult-type rheumatoid arthritis. Generally, this adult pattern of arthritis occurs in older girls and can be identified with a blood test. More severe joint damage occurs with this disease as compared to the others.

1.4 Juvenile Arthritis and Health Concerns

1.4.1 Physical and Physiological Concerns

The need for physical activity is evident when one understands the "cycle of disuse" prolific in this population. Brostrom, Nordlund, and Cresswell (2004), Lindehammar and Backman (1995) and Klepper (2003) reported that children with JA maintained lower than normal muscle strength. This muscle weakness, in addition to joint stiffness and inflammation, decreased the sufferer's mobility, thereby perpetuating a cycle of disuse (Brostrom et al., 2004; Noll, Kozlowski, Gerhardt, Vannatta, Taylor, & Passo, 2000). Poor flexibility, muscle weakness, and muscle atrophy cause pain. To avoid pain, the child avoids exercise; lack of exercise exacerbates those problems by further decreasing muscle size, muscle strength, and joint flexibility, now rendering activity even more strenuous. The child again limits his or her activity, thus continuing the destructive pattern (see Appendix C for illustration). An explicit example of the cycle of disuse may be seen in plantar and dorsiflextor strength. Brostrom and her research team found that ankle and flexor strength in children with JA was 40-50% less than in healthy age and gender matched controls (Brostrom et al., 2004). The authors asserted that such elevated functional weakness likely causes the children to be inactive, which would lead to further inactivity and further losses in strength, thus beginning a downward spiral. Consequently,

physical activity is necessary to cease the functional descent of these children by increasing flexibility and strength, thereby improving the ease of mobility (Brostrom et al., 2004; Klepper, 2003).

A notoriously poor aerobic capacity catapults children with JA into a high-risk category for future adult health problems (Klepper, 2003). Children with JA participate in fewer strenuous activities and sleep more than their peers (Henderson, Specker, Sierra, Campaigne, & Lovell, 2000). Given this sedentary pattern, it is understandable that these children have decreased cardiovascular integrity. An inactive lifestyle lends itself to muscle disuse and muscle atrophy, and this weakness renders aerobic activity a laborious chore (Klepper, 2003). A lack of cardiovascular fitness is constantly associated with risk factors for cardiovascular disease, including high blood pressure, elevated lipid levels, and a larger body mass index (Sallis, Patterson, Buono, & Nader, 1988; Sallis, 1995). Hence, a program incorporating aerobic conditioning whereby children participate in moderately vigorous activity improves the physical stamina and aerobic capacity of JA sufferers and sets the foundation for positive future health behaviours (Takken, Van Der Net, & Helders, 2001).

Another health concern specific to this disease is the relationship between JA and osteopenia (Henderson et al., 2000). The defining characteristic of osteopenia is the bone mineral content for the individual's age is less than what is required for optimal life long bone health. Over the course of one's life, the largest increase in bone mineral content occurs between the ages of 11 and 17 (McDonagh, 2001). By having a higher bone mass as a child and young adult, one decreases the serious risk of suffering from osteoporosis as an older adult. Thus, prevention of osteopenia requires physical activity and weight bearing activities to build bone mineral density (McDonagh, 2001).

Between fifteen and fifty percent of children with JA suffer the comorbid condition of osteopenia, and it is not strictly a result of receiving corticosteroid medication (Henderson et al., 2000; McDonagh, 2001). Along with this alarming percentage of children who suffer this condition, adults with a history of childhood arthritis demonstrate lower bone mineral density and higher bone turnover in comparison with healthy controls and thereby are at greater risk for osteoporosis, and at a younger age (Zak, Hassager, Lovell,et al., 1999). Inasmuch as children with JA have a larger lifetime fracture probability, a physical activity program that includes weight-bearing exercises is essential.

Sleep quality in children with JA is troubled (Labyak, Bourguignon, & Docherty, 2003). Twice the number of sleep disturbances in children with JA is reported than in their healthy peers. They experience more night awakening, parasomnias, sleep anxiety, sleep-disordered breathing, early morning awakenings, and daytime sleepiness. In fact, some studies have found 79% of participants with JA report having nightmares or bad dreams, while the control group reported only 38%. Polysomnography studies have also uncovered a disturbing trend. Specifically, children with this illness spend significantly less time in stages 2 and 3 non-rapid eye movement and rapid eye movement sleep. Additionally, they also demonstrate a significantly larger number of transfers from deep to lighter stages of sleep. Whether this is a result of medications, anxiety, or a factor inherent in the disease itself is unknown, as is the exact effect this single variable has on children with JA. However, it seems intuitive that such sleep quality problems could have large scale repercussions both with both the physical and mental self.

1.4.2 Psychosocial Concerns

On-going debate exists in the JA literature as to whether children with JA are at a greater risk for experiencing psychosocial difficulties than their age-matched peers (LeBovidge et al.,

2003; Noll et al., 2000; Reiter-Purtill, Gerhardt, Vannatta, Passo, & Noll, 2003; Ungerer, Horgan, Chaitow, & Champion, 2001). Part of the difficulty in assessing this lies in the multiple methodology, measures, and the varied use of controls (see Table 1 for an overview). As sanctioned by the United Nations, improving the quality of life for all children not only encompasses the physical dimension, but also the mental and social (as cited in Seid, Varni, Rode, & Katz, 1999). Therefore, whether or not children with JA experience more or the same level of psychosocial difficulties as other children, it remains important to champion their mental and social health along with their physical well-being.

In a descriptive study by Konkol, Lineberry, Gottlieb, Shelby, Miller III, and Lorig (1989) children with JA were asked a series of questions regarding their illness experience. One question inquired about the most troublesome aspect of their disease. Replies included such descriptions as pain, suffering, agony, and embarrassment. When asked if they had any questions they were afraid or embarrassed to pose about their illness, responses contained such ideas as did they appear funny when they ran and did people think they were trying to make them feel guilty or sorry for them. Perhaps the most exemplary answers elucidating the psychological burdens these children face were to the researchers' inquiry on what caused them the most difficulty at school. Being laughed at, teased, name calling, and the inability to run and play like the others were frequent responses. Sixty-seven percent of the 50 children in the study were concerned about peer reactions and peer acceptance, and sixty-four percent were bothered by their physical limitations. This qualitative study's findings imply that there are psychological implications to living with JA, be it shame, guilt, or decreased self-esteem, and possibly a connection exists between the social functioning of these children and their physical abilities at school.

Pain is a significant problem for children with JA (Schanberg, Lefebvre, Keefe, Kredich, & Gil,1997). Researchers have found that even children in established medical care report pain as a problem. Furthermore, one quarter of them describe their pain intensity as belonging in the middle or high range (Schanberg et al., 1997). This is important to understand, as it has been found that pain is associated with a reduction in school and social activities which are central in growing up (Schanberg et al., 2003). The authors suggested that one essential means of improving the quality of life of children with arthritis is in the exploration of child coping mechanisms.

The reporting of pain is inconsistently correlated with an individual's disease activity. Instead of being a strict representation of the severity of the disease, pain is the result of an interaction with an individual's psychosocial environment (Akikusa & Allen, 2002). To advance the understanding of the relationship between mood, stressful life events and perception of pain, Schanberg and colleagues (2003) had children with JA complete self-report questionnaires. The children then kept a diary of their mood, their disease symptoms, and daily events. The results demonstrated that daily mood and daily stressful events significantly predicted daily symptoms of fatigue and stiffness and additionally, daily mood predicted reports of pain. For example, on Friday stiffness and fatigue were lowest and this low level was carried through until Monday, when once again physical symptoms rose. One interpretation offered for this pain pattern was that Friday is the last day of school before the weekend begins. Weekends are fun, children are more-or-less free to do as they please, and thus these days are less stressful than weekdays. But with Monday comes five more days of school and the associated stress with attending school. A child must interact with other children, some of whom a child will not like, and he or she must do what for many is a laborious chore - schoolwork. Although this descriptive study's sample was very

small, it illustrates that pain experienced by children with JA can be influenced by psychological factors. Other researchers have found similar results (Ross, Lavigne, Hayford, Berry, Sinacore, Pachman, 1993). Thus, further investigation of the role physical activity may play in mood and stress management may be useful in treating symptoms and helping children with JA navigate their pain.

Table 1. Studies Examining Psychosocial Well-Being and Juvenile Arthritis

Citation	Study Design/Sample	Purpose	Data Collection/Variables/Measure	Results/Conclusions	Limitations/Strengths
Brace, M.J., Smith, M.S., McCauley, E., & Sherry, D.D. (2000)	Descriptive, non-experimental 16 JA, 10 chronic fatigue syndrome, 14 healthy controls (11-17 yr.) USA	Investigate what contributes to illness symptoms and psychosocial disability in chronically ill	Questionnaire and Interview Variables: depression, internalising patterns, psychosocial functioning, family cohesion. Measures: Children's Depression Review of Symptoms-Revised, Archenbach's Youth Self-Report Form and Child Behaviour Checklist, FACES II, Illness Behaviour Encouragement Scale.	JA children missed an average of 10 +/- 10.2 days of school compared to 3.4 +/- 1.8 in controls. They experienced statistically significantly greater withdrawal than controls but were not statistically significantly different on somatic subscales, anxiety, and depression.	Very small sample, non-experimental design, based on self-report data, the interviewer was not blinded to the child's condition, and recruitment was through a care clinic. Had a control group and used validated measures.
Daltroy, L.H., Larson, M.G., Eaton, H.M., Partridge, A.J., Pless, I.B., Rogers, M.P., & Liang, M.H. (1992).	Descriptive, non-experimental 102 US families (4-16 years) 101 responders were the mothers	Follow-up to pilot study findings that JA children feel isolated from peers because of physical restrictions. To help clarify level of psychosocial adjustment.	Questionnaire Variables: disease activity, disease severity, disease duration, behaviour problems and social competence, parent mood Measures: primary physician rated disease activity, parents rated severity and duration. Child Behaviour Checklist assessed behaviour problems/social competence; Profile of Mood States assessed parental mood.	Young boys had fewer behaviour problems than the normative data but older boys had more. For girls social competence was viewed as similar to population norms when they were younger but demonstrated more severe behaviour problems and less social competence as they got older. For boys, the youngest showed the greatest competence and the oldest the least. All ages had higher internalising behaviour (more fearful, inhibited, overly controlled). Mild disease activity was associated with the most behaviour problems.	Results reflect parental self-reported perceptions of their child rather than child's perception of psychosocial functioning or other sources. It was a descriptive study, used a mailout questionnaire, and it used population norms rather than age matched control groups. And families were recruited from one rheumatology clinic and one children's hospital. The Child Behaviour Checklist and POMS are well validated and standardised measures.

Citation	Study Design/Sample	Purpose	Data Collection/Variables/Measure	Results/Conclusions	Limitations/Strengths
Konkol, L., Lineberry, J., Gottlieb, J., Shelby, P.E., Miller III, J.J., & Lorig, K. (1989).	Descriptive, non-experimental 50 US families with a JA child.	To conduct as needs assessment to guide educational programming.	Questionnaire Three questionnaires were mailed to each family with open-ended questions asking the children with JA, their parents, and their siblings questions like what is the "most difficult thing about having JA" or the "most difficult thing about having a child with JA" or the "most difficult thing about having a brother or sister with JA". Questions focused on psychosocial and physical functioning at home and school.	51% of children reported psychological distress, 61% reported limited physical capabilities, and 41% reported pain as being some of the difficulties with having JA. When asked if arthritis had caused problems at school 67% said it had an impact on peer reaction and peer acceptance and 64% reported physical limitations at school being problematic. (Responses included "not being able to play and run", "kids laughing at me") Parents never mention physical problems as a difficulty having a family member with JA (but 2/3 of JA children did). 69% of parent s felt physical limitations were a problem at school.	It was a convenience sample recruited from two clinics in Northern California and thus finding are suggestive and not generalizable. There could possible exist a rater response bias as interpretation of open-ended questions is subjective. No control group. Asked children, parents, and sibling opinions rather than just parents. Open-ended questions allow for more freedom in responses.

Citation	Study Design/Sample	Purpose	Data Collection/Variables/Measure	Results/Conclusions	Limitations/Strengths
LeBovidge, J.S., Lavigne, J.V., Donenberg, G.R., & Miller, M.L. (2003).	Meta-analysis 21 studies on JA and psychosocial functioning were reviewed	To systematically review the current findings on the psychological adjustment of children with JA.	To be included in the review studies had to be published in English, children had to be younger than 20 years, psychological adjustment must have been measured, and the studies had to present effect sizes for all groups measured (JA group along with the control group if they had one). 11 or 21 had control groups. Psychological adjustment problems were reported in 9 studies, 13 reported internalising symptoms, 13 reported externalising symptoms, and 9 discussed self-concept.	JA children had statistically significantly greater adjustment problems and demonstrated significantly more internalising symptoms. There was no difference in externalising symptoms. Type of control group used influenced significance of findings. In research with study-recruited controls JA children had significantly more adjustment problems compared to studies using normative data. JA and controls did not statistically differ on self-concept. However again there were differences between study-recruited and normative data with normative data underestimating self-concept problems with JA. Using a statistical procedure, the Fail-Safe N, it was calculated that 7 additional studies with non-significant results would be needed to reduce the average effect size to small for total adjustment problems. 18 non-significant studies would be required to reduce internalising problem effect size to small.	Only using published research, which is generally biased towards significant results. A large portion of the studies used the Child Behaviour Checklist to measure adjustment, argued to be biased toward somatic complaints, which would contribute to JA experiencing more adjustment problems. There is a potential for rater bias as reports of adjustment come from parents. Reviewed a large number of studies. Had strict inclusion criteria.

Citation	Study Design/Sample	Purpose	Data Collection/Variables/Measure	Results/Conclusions	Limitations/Strengths
Noll, R.B., Kozlowski, C.G., Vannatta, K., Taylor, J., & Passo, M. (2000)	Non-experimental, case-controlled correlational 64 JRA families and 64 matched controls in USA	To better understand the social, emotional, and behavioural functioning of Children with JRA by gathering data from peers, teachers, parents, and the children.	Questionnaire Variables: behavioural reputation/peer relationships, emotional well-being (depression, anxiety, loneliness, self-concept), cognitive ability, and ratings of behaviour (externalising behaviour) Measures: Revised Class Play, Three Best Friends, Like Rating Schale, Child Behaviour Checklist, Children's Depression Inventory, Roberts Apperception Test for Children, Dimensions of Temperament Survey-Revised, Loneliness and Social Dissatisfaction Questionnaire, Self-Perception Profile for Children, and WISC-R.	There were no significant main effects for social functioning. The only statistically significant difference in the realm of emotional well being was the JRA children reported higher academic self-concept than controls even though scores on WISC were similar. Mothers' reports of mood and internalising behaviour were significantly different for children with JRA. Their mothers scored them as being less happy and less adaptable. No statistically significant differences in behaviour ratings.	Although had power to detect moderate effect sizes, the sample size was too small and thus insufficient power to detect small effect sizes. The generalizability is limited because the children are from only one treatment centre. The researchers recruited almost every child examined in one clinic. They used age and demographically matched controls. Data was obtained from a variety of sources rather than just parents. Measures included standardised objective measures as well as projective tests.

Citation	Study Design/Sample	Purpose	Data Collection/Variables/Measure	Results/Conclusions	Limitations/Strengths
Reiter-Purtill, J., Gerhardt, C.A., Vannatta, K., Passo, M.H., & Noll, R.B. (2003)	Case-control, cross-sectional correlational Initial phase 74 (8-15 yr.). Two year follow-up 57 (10-17 yr.). USA	To longitudinally follow peer relationships of JRA children and to investigate whether JRA, severity, and activity influences social functioning.	Questionnaire Variables: Social reputation (sociability/leadership, aggressive/disruptive, sensitive/isolated), social acceptance, and disease severity. Measures: Revised Class Play, Three Best Friends, Like Rating Scale, Paediatric Rheumatologist's disease severity rating.	No significant differences were found in social reputation, social acceptance, disease severity, activity, and duration. Significant main effect for participant type was found. JRA were chosen by teachers for prosocial roles more than controls. Children with mild disease severities self-reports of the aggressive/disruptive dimension of the social reputation increased significantly over the two years. Like rating decreased significantly for children with moderate or severe disease ratings. And children with active disease were picked fewer times as a best friend than those JRA children in remission.	Participants are from one treatment centre. No control group. Problem of spurious finding because of the number of statistical procedures computed on the data. Correlational data. Investigators used multiple sources of information. It was a longitudinal design. They used age and demographically matched controls. The measures used are objective and well validated.

Citation	Study Design/Sample	Purpose	Data Collection/Variables/Measure	Results/Conclusions	Limitations/Strengths
Schanberg, L.E., Anthony, K.K., Gil, K.M., & Maurin, E.C. (2003).	Descriptive, correlational 41 JA (8-18yrs) USA	To describe daily pain/symptoms and their relationship to psychological adjustment, demographics, and disease severity.	Joint count, physical exam, questionnaires, and diary. Variables: daily symptoms, activity, functional status, disease severity, and psychological adjustment. Measures: Paediatric Pain Questionnaire, Visual Analog Scale, Likert scale of amount of activity per day, Childhood Health Assessment Questionnaire, physician rating, active joint count, The Children's Depression Inventory, and the Revised Children's Manifest Anxiety Scale.	Pain was reported on average 73% of the 60 days. Statistically significant relationship between decreased function and increased daily symptoms. Those reporting greater impairment also reported greater pain. Increased anxiety was associated with increases in daily symptoms (including fatigue and pain ratings). Ten percent of the sample was deemed to have clinically significant levels of anxiety. Participation in activities at school and in social arena outside of school decreased significantly with increases in symptomology.	Limited generalizability, as the sample is predominantly white American children, recruited through on medical centre. The small sample size is also a concern. As is the source of information only coming form the children rather than a variety of sources. No control group. Self-report data is considered more reliable when recorded on a daily basis, which was the case for this study.
Schanberg, L.E., Sandstorm, M.J., Starr, K., Gil, K.M., Lefebvre, J.C., Keefe, F.J, Affleck, G., & Tennen, H. (2000).	Descriptive, correlational study. 12 JRD American children (7-15 yr.)	To describe the changes in mood, stressful events, and symptoms that occur on daily basis and determine if daily stressful events are predictors for disease symptomology.	Questionnaire and diary. Variables: mood, stressful events, and symptoms/functioning. Measures: Facial Affective Scale, Daily Events Inventory, visual analog scale, and Paediatric Pain Questionnaire.	There was great change in symptoms, mood, and number of stressful events throughout the week. Daily mood and the frequency of stressors were related to disease symptoms on a daily basis. Fatigue was scored as problematic but children did not restrict their activities.	Diary was only kept for seven days. The sample size was very small and the participants were recruited from one clinic. These limit the generalizability of results. Evidently a correlational study does not allow for causal conclusions. No control group. Measured fatigue, pain, and reported symptoms rather than relying on one to determine functioning.

Citation	Study Design/Sample	Purpose	Data Collection/Variables/Measure	Results/Conclusions	Limitations/Strengths
Ungerer, J.A., Horgan, B., Chaitow, J., & Champion, G.D. (1988).	Descriptive, correlational. 363 JA children and parents in Australia (7-20 yr.)	To determine variables related to psychosocial adjustment in children with JA.	Questionnaire Variables: social contact, leisure activities, self-concept, and disease severity. Measures: research team developed own questionnaire assessing social contact and leisure activities, Self-Descriptive Questionnaire III, Piers-Harris Children's Self-Concept Scale, parental report of disease severity.	Self-concept scores were not significantly different from normative samples for primary school children but were for high school students. For both ages those with lowest self-concept rated themselves feeling lonelier and being teased about their arthritis. They were also less frequently responded that they liked most people in their class. Disease severity was related to lower self-concept for both age groups.	Researchers used normative data rather than age and demographically matched controls. The authors did not explain how they recruited their sample. And parents rather than a physician rated disease severity. The sample size was large for JA research. Both parents and children answered questionnaires.

1.5 Physical Activity's Role in Alleviating Physical and Psychosocial Concerns

The traditional sentiment among health professionals treating children with JA has been that aerobic physical activity exacerbates a child's symptoms and thus should be avoided (Akikusa & Allen, 2002). However, opinion has slowly changed as health professionals are increasingly suggesting that physical activity is one of the only 'certain' aspects in the treatment of JA (Akikusa & Allen, 2002; Laxer, 1998). Perhaps the intuitive appeal of such a seemingly obvious 'truth' has lead to a paucity of scientific testing. After a comprehensive literature search, it appears that little research on JA and physical activity exists (a review of the literature can be seen in Table 2). However, what has been conducted has identified both the benefits of physical activity for this population, as well as highlighted needs for future research.

Enhancing the quality of life of children with JA is an increasing concern for health professionals (Akikusa & Allen, 2002). Imagine that you are ten years old. It is recess. A carefree rush of freedom should be upon you as you run and play and jump and laugh. Instead, aching pain forces you to be a spectator, watching your peers from the sidelines, isolated and apart from the group. This is the reality for approximately 1 in 1000 children in Canada enduring a life with JA (Laxer, 1998). Understanding the role that physical activity can play is central for promoting an enhanced quality of life in this population.

Table 2 Studies Examining Physical Activity and Juvenile Arthritis (including PA interventions)

Citation	Study Design/Sample	Purpose	Data Collection/Variables/Measure	Results/Conclusions	Limitations/Strengths
Bacon, M.C., Nicholson, C., Binder, H., & White, P.H. (1991).	Descriptive 11 JRA children (4-13 yrs) USA.	To examine the effects of a 6 week aquatic exercise on lower extremity range of motion and strength.	Physical Fitness Assessment Variables: range of motion, gait, balance, functional mobility of lower extremities, heart rate. Measures: timed single-limb stance, forward heel-to-toe walking step assessment, timed 25-foot run, 100-foot walk, and 13-step-climb, time change from supine to standing position, gait velocity, cadence and stride length, heart rate monitoring.	Significant improvement in bilateral internal and external hip rotation and right hip flexion with knee extension. No statistically significant difference in balance or timed tests.	It was a small sample of children. It was not randomized and it did not have a control group. In addition it was a relatively short intervention and the range of the ages of the children was quite large. As a pilot project it demonstrated important trends. It provides direction for future research.
Henderson, C.J., Lovell, D.J., Specker, B.L., Campaigne, B.N. (1994).	Descriptive comparison 23 JRA children and 23 healthy controls (5-11 yrs) USA.	Prospectively investigate whether there are differences in physical activity between JRA and controls. Also determine factors that may influence physical activity in JRA.	Questionnaire and Activity measuring equipment Variables: physical activity, anthropometric measurements, and functional abilities. Measures: Juvenile Arthritis Functional Assessment Report, Caltracs, University of Cincinnatic Motion Sensor, physical activity log.	Physical activity was significantly lower in JRA children. But daily movement was similar between the groups. JRA children slept significantly more than controls. Children with JRA also spent significantly less time engaged in organized sport and less time engaged in strenuous activity than controls.	Did not use direct observation to ascertain the amount of physical activity the children engaged in. Caltrac monitors needed to be removed during swimming activities and it is not able to detect body movement on bikes. Both swimming and biking are frequent activities recommended for children with juvenile arthritis. It tried to overcome Caltrac limitation with the use of UCMS.

Citation	Study Design/Sample	Purpose	Data Collection/Variables/Measure	Results/Conclusions	Limitations/Strengths
Klepper, S.E. (1999)	Descriptive, quasi-experimental. 25 children (M =12) USA.	Study the implications of a weight bearing activity program on JRA severity and activity.	Questionnaire and Physical Fitness Assessment Variables: disease activity, pain, aerobic endurance, 8 week physical conditioning program. Measures: articular severity index, pain VAS, 9-minute walk test.	No significant differences in pain perception (although a 16% decrease from start to end of program). Significant decrease in articular severity index scores and in joint count. Also a significant increase in walk test scores. Conclusion: research must identify the best means of helping children with JA maintain lifelong physical activity.	Very small sample, non-experimental design, based on self-report data, the interviewer was not blinded to the child's condition, and recruitment was through a care clinic. Had a control group and used validated measures.
Oberg, T., Karsznia, B., Gare, A., & Lagerstrand, G. (1994).	Descriptive, age matched comparison. 10 children with JA (M = 10.4) and 10 healthy controls (M = 10.8) Sweden	Investigate the impact of a physical training program on force, endurance, and electromyographic response to muscle fatigue in children with JA and their healthy peers.	Physical Fitness Assessment Variables: maximum isometric torque, gymnastic and pool training physical activity program. Measures: Maximum torque testing of shoulder muscles and knee extensors, EMG signals.	No significant difference between JA and controls for force or endurance before or after training. Both made significant improvements	Very small sample. However it did include an age matched healthy control comparison.

Citation	Study Design/Sample	Purpose	Data Collection/Variables/Measure	Results/Conclusions	Limitations/Strengths
Shun-Wai Fan, J., Wessel, J., & Ellsworth J. (1998)	Descriptive, cross – sectional 20 girls with JRA. USA	Identify the relationship muscle strength has on functional ability in JRA.	Questionnaire and Physical Assessment Variables: muscle strength, functional ability, pain. Measures: Kin-Com, 50 m run, CHAQ, Pain VAS.	Primarily minimal functional disability but despite this very poor run performance in the 50m. The relationship between strength and function was moderate. Conclusion: participation in a physical activity program that includes strength training may be beneficial for JRA. Girls with no functional disability may still experience problems in p.e. classes and recreational activities, daily activities, and participate less in peer activities due to their poor running abilities.	Results reflect parental self-reported perceptions of their child rather than child's perception of psychosocial functioning or other sources. It was a descriptive study, used a mailout questionnaire, and it used population norms rather than age matched control groups. And families were recruited from one rheumatology clinic and one children's hospital. The Child Behaviour Checklist and POMS are well validated and standardised measures.

Citation	Study Design/Sample	Purpose	Data Collection/Variables/Measure	Results/Conclusions	Limitations/Strengths
Takken, J., Van Der Net, J., & Helders, P.J.M. (2003).	Cross-Sectional 18 children with JA (M = 10.7) Netherlands.	Examine the association between aerobic and anaerobic physical fitness and functional ability in children with JA.	Questionnaire and Physical Fitness Assessment Variables: joint range of motion, BMI, skinfold measurements, maximal oxygen uptake, phosphate use, and functional ability. Measures: Pediatric Escola, Paulista de Medicina range of motion scale, graded maximal exercise to volitional exhaustion on cycle erogmeter and calibrated metabolic cart, Wingate Anaerobic Test, Childhood Health Assessment Questionnaire.	JA children overall had moderately impaired function. There was a low correlation between aerobic fitness and functional ability. But a large correlation between anaerobic fitness and functional ability. Conclusion: A particular level of anaerobic fitness may be required to participate in activities of daily living and should be considered when devising an exercise intervention.	There was no healthy comparison group. And the sample size was relatively small and was cross-sectional. The indices of physical fitness used are excellent. And the novelty of the research make it a very important contribution to the literature.

Citation	Study Design/Sample	Purpose	Data Collection/Variables/Measure	Results/Conclusions	Limitations/Strengths
Takken, T., Van Der Net, J., Kuis, W., & Helders, P.J.M. (2003).	Randomized Experiment 54 children with JIA (Netherlands)	To assess whether a 20 week aquatic exercise program would help children with JIA.	Questionnaire and Physical Fitness Assessment. Variables: participation in a 20 week aqua program, functional ability, quality of life, joint status, and physical fitness. Measures: Childhood Health Assessment Questionnaire, Juvenile Arthritis Functional Assessment Scale, Juvenile Arthritis Quality of Life Questionnaire, Child Health Questionnaire, Paediatric Escola Paulista de Medicina Range of Motion Scale, maximal exercise test, and submaximal 6-min walking test.	No significant results were found for any of the variables. The aqua group did experience improvements in their Child Health Assessment Questionnaire but this did not reach statistical significance. They also demonstrated less swollen and tender joints but again it was not statistically significant. It appears that improving physical fitness in this population is difficult.	The measures of physical fitness did not correspond to the type of physical activity engaged in during participation in the exercise program. It was a randomized double blind experiment. They tracked attendance and drop outs and took all possible precautions to ensure a safe and effective program. The duration of the program was six months.
Takken, T., Van Der Net, J., & Helders, P.J.M. (2001).	Descriptive, non-experimental 25 children with JRA (Netherlands)	Determine whether a 15 week significant aquatic training would assist significant endurance abilities, functional ability, and health related quality of life of children with JRA.	Questionnaire and Physical Fitness Assessment. Variables: joint status and mobility, health related quality of life, aerobic endurance, pain, functional ability. Measures: joint count, Pediatric Escola Paulista de Medicina Range of Motion Scale, Childhood Health Assessment Questionnaire, 6 minute walk test, Juvenile Arthritis Quality of Life Questionnaire, pain VAS.	Functional ability demonstrated a trend towards improvement. There was no statistically significant increase in walk test distances and there was no statistically significant improvement in quality of life. However the three month follow up showed significant decrease in quality of life after the end of the program. General symptoms did improve significantly. Conclusion: aquatic training had positive results but did not significantly improve endurance or functional ability.	It was a convenience sample recruited from two clinics in Northern California and thus finding are suggestive and not generalizable. There could possible exist a rater response bias as interpretation of open-ended questions is subjective. No control group. Asked children, parents, and sibling opinions rather than just parents. Open-ended questions allow for more freedom in responses.

1.6 Physical Activity for Juvenile Arthritis

Exercise is increasingly becoming a recognized component of a comprehensive treatment program for children with JA (Akikusa & Allen, 2002; Laxer, 1998). Extraordinarily, in the last ten years, only four physical activity interventions have been conducted with this population (Klepper 1999; Takken et al., 2001; Takken, Van Der Net, & Helders, 2003; Takken, Van Der Net, Kuis, & Helders, 2003). Three were aqua-exercise studies the other one was a land-based aerobic class. Not surprisingly then, very little education is devoted to assisting a child and his or her family to understand what the recommended "daily activity" for their child entails or in exploring the general benefits of physical activity (Akikusa & Allen, 2002). Instead, time is devoted to other important aspects of care such as teaching the family how to splint, cast, how to lie, as well as in physical therapy (Laxer, 1998). While these elements are important, the role of exercise cannot continue to be neglected. Initial support for the potential role of physical activity can be gleaned from the adult arthritis literature.

Specifically, research indicates that physical activity for adult sufferers of rheumatoid arthritis has been successful in helping improve locomotor abilities, improving cardio respiratory functioning, and in pain management (Harkcom, Lampman, Branwell, & Caster, 1985; Huang, Lin, Yang, & Lee, 2003). Research has found, however, that many adult arthritis patients lack the confidence to self-manage and therefore cope with their pain (Huang et al., 2003). They often remain passive participants, viewing medical treatment as the only means of assistance (Schanberg et al., 2000). Research continues to demonstrate that physical activity as a self-management tool does decrease pain and functional disability, and increase physical fitness indices like walking speed (Huang et al., 2003). For example, Huang and his colleagues found that adult sufferers of painful osteoarthritis of the knee profited from an 8-week therapeutic

exercise program. These improvements all occurred without any adverse affects to the individual.

If the empirical findings on adult arthritis can be applied to children with JA, physical activity demonstrates immense promise in building children's confidence in their ability to cope with their pain, while facilitating a decrease in the pain itself. Thus, a discussion of the physical activity interventions that currently exist for children with juvenile arthritis as well as an examination of research needs in this area follows.

1.7 Potential Physical Benefits of Physical Activity for Juvenile Arthritis

Physician's personal belief and anecdotal evidence, partly supported with research, has found that water-based activity is only beneficial to a limited degree (Klepper, 2003; Klepper, 1999). The justification behind promoting aqua exercise is that the buoyant properties of water place less stress on joints, thus making exercise less painful while still improving physical fitness (Klepper, 2003). Takken and colleagues (2001) investigated whether an aerobic water exercise program would help improve the endurance abilities of children with JA. They found it did indeed have a positive overall effect, with children reporting fewer disease symptoms, but it did not produce a statistically significant difference in functional ability. Although the water reduces the stress on joints and bones, weight-bearing activity is necessary for increasing bone density, which is a requisite for the prevention of osteoporosis. Therefore, while aqua-based programs remain a physical activity option for children with JA, children may benefit from other land-based, weight-bearing physical activity interventions.

Klepper's 1999 study was the first published work to investigate whether weight-bearing activities, like aerobics classes, could improve the cardiovascular functioning of children with JA. The participants in this study were children age 8-17. They partook in an hour-long physical-

conditioning program three times per week for eight weeks. Activity in the classes consisted primarily of low-impact aerobics and muscular strengthening activities. Klepper concluded that land-based exercise programs have the potential to be equally or more valuable than water based programs. Disease severity and reported pain significantly decreased and there was a significant improvement in aerobic endurance. In addition, this preliminary research found that compared to aqua training, children in land-based programs demonstrated greater improvements in functional abilities and statistically significant decreases in severity of joint signs and symptoms (Klepper, 1999; Klepper, 2003).

It is well acknowledged that this population of children lead inactive lives, contributing to their functional deterioration, thereby placing them at increased risk for disability in adulthood (Klepper, 2003; Takken et al., 2001). A physical activity program needs to address the significant cardiovascular and musculoskeletal deficits, the diminished aerobic capacity of these children, and the reality that their performance on standardized fitness tests is significantly poorer than what is necessary for optimal health and significantly less than what is age appropriate (Klepper, 2003; Klepper, 1999).

1.8 Potential Psychosocial Benefits of Physical Activity for Juvenile Arthritis

While the physical and physiological benefits of physical activity are slowly emerging in the literature, only Takken and colleagues have examined the potential psychological benefits, in the form of quality of life, of physical activity for youth with JA (Takken et al., 2001; Takken et al., 2003a; Takken et al., 2003b). The initial investigation undertaken by Takken's research team saw 10 children aged 5-12 years old participate in a 15-week aerobic conditioning program in the water (Takken et al., 2001). They examined the impact this training program has on joint status and mobility, functional ability, aerobic endurance, health-related quality of life, and reports of

pain. Takken's pilot was not entirely successful. He found that general symptoms significantly improved ($p < 0.05$) and there was a trend towards improvements in quality of life scores as well as a positive trend with regard to disability. However, the measure of aerobic capacity did not change significantly ($p > 0.05$), nor did reports of pain ($p > 0.05$). The authors suggested a number of reasons for these findings, including such factors as a small sample size ($N = 10$) and measures that were insensitive or not entirely appropriate.

In 2003 Takken, Van der Net, Kuis, and Helders once again investigated the role aquatic fitness training has on children with JA, including health-related quality of life. With a slightly larger sample of 54 participants were randomly assigned to an assessment-only control group or to the treatment group (Takken et al., 2003a). Children in the treatment group received a program facilitated by a physical therapist that included swimming, aquarobics, play, as well as flexibility and ball games once a week for 20 weeks. The researchers assessed functional ability, health-related quality of life, joint status, and an aerobic maximal physical fitness. No significant results were found. The authors again questioned whether the instruments used were sufficiently sensitive to detect training effects, a rather different purpose than to use as discriminative instruments for disability. The intensity of the program was designed as a minimum level exercise that may be adequate for health promotion, but it may have been inadequate to see exercise training effects over a relatively short period of time.

1.9 Theories of Physical Activity

A successful physical activity investigation for children with JA does not necessarily have to be guided by theory. Yet there are a number of positive potential benefits to utilizing a theoretical framework in research. Specifically, a theory provides a framework on which to base a research program, establish guidelines, and a rationale for

the choice of variables under investigation. Several theories of motivation and adherence to physical activity for adults have been forwarded over the last thirty years (Ajzen, 1991; Bandura, 1986; Ajzen & Fishbein, 1980; Prochaska & DiClemente, 1984). However, only in the last decade has the application of these theories to the understanding of physical activity behaviour in children and adolescents truly become a research focus (Pender, 1998). A brief discussion of three relevant theories that have been applied to understanding physical activity behavior in children and adolescents follows.

1.9.1 Theory of Planned Behaviour

Ajzen and Fishbein (1980) developed the theory of reasoned action (TRA) in the mid-seventies, with the premise that one's behaviour is immediately and directly influenced by a person's intention towards the behaviour. Intention, in turn, is controlled by one's attitudes and by the subjective norms surrounding the individual's enactment of the behaviour (see Appendix D for a diagram of the TRA/TPB). This was the foundation upon which Ajzen derived the theory of planned behaviour (TPB; 1991).

To overcome the volitional limitation problem of the TRA, Ajzen extended the model to include behaviours not completely under an individual's control (1991). The result, the TPB, is identical to TRA with the addition of a single factor, perceived behavioural control. This variable represents the degree of effort required to perform the behaviour. It encompasses an individual's evaluation of his or her skills, willpower, knowledge, as well as external factors such as time and support (Trost et al., 2002). Under the TPB, perceived behavioural control is recognized not only as an indirect influencing agent of behaviour, like that of attitudes and subjective norms, but also as a

direct predictor of behaviour. While the TPB is a better predictor of physical activity in children than the TRA, it too remains limited.

Trost and colleagues (2002) investigated whether the TPB and the TRA could be used to predict and explain the exercise intentions of White and African-American girls in the United States. The authors discovered that regardless of race, the addition of perceived behavioural control and self-efficacy led to significant increases in the prediction of physical activity intention and to subsequent behaviour in adolescent girls. However, not all the results of this study were statistically significant ($p < 0.05$). Indeed intention was found to be significantly related to physical activity in White girls ($p < 0.0001$) and accounted for 8% of the variance but the addition of perceived behavioural control did not contribute a meaningful difference to the variance explained ($p = 0.05$). Furthermore, the TPB as a framework for understanding African-American girls' physical activity behaviour was extremely restricted. Intention to be physically active was significant related to physical activity ($p < 0.0001$) but it accounted for only 3% of the variance. Perceived behavioural control was also significantly associated with physical activity ($p < 0.04$) and explained 1% of the variance. Apart from the ethno-cultural affiliation calling into question the practical significance of the TPB, there was an unsatisfactory correlation between intention to be physically active and actual physical activity.

Other researchers report perceived behavioural control to be the biggest contributor to physical activity intention, suggesting the superiority of the TPB to the TRA (Mummery, Spence& Hudec, 2000). Children from thirty schools across Canada were surveyed to assess their physical activity behaviour. Mummery and colleagues

(2000) discovered attitudes and social norms contributed significantly to the child's intention to exercise, but the addition of perceived behavioural control statistically improved the predictive ability of the framework. Together the three factors, perceived behavioural control, attitudes, and subjective norms accounted for 47% of the variance in exercise intention. Interestingly, Mummery and colleagues reported the relative importance of the three factors depended on the age of the individual. Specifically, the subjective norm was significantly more important to the intention to exercise in younger children compared to older children ($p < 0.05$), whereas the contribution of perceived behavioural control was significantly greater in older children as compared to younger children ($p < 0.05$). Overall, the addition of the perceived behavioural control factor led to the enhancement of the model and strong support for its utility over the TRA.

However, other researchers have not found all three components of the TPB to be statistically related to intention. Hagger, Chatzisarantis, Biddle, and Orbell (2001) surveyed British children (N = 431) in an effort to describe the relationship between physical activity and intention. The authors found statistically significant relationships between attitude and intention ($p < 0.01$), between perceived behavioural control and intention ($p < 0.01$), but they did not find a statistically significant relationship between subjective norm and intention ($p > 0.01$). As this is a fundamental component in the TPB, without empirical support for the subjective norm component one must be cautious in using this framework with children.

Finally, a substantial problem inherent to the literature investigating both the TRA and the TPB in children is that few studies exist and even fewer use a measure of the actual behaviour of interest - physical activity. A number of studies simply measure the

intention to be physically active without also measuring the true physical activity behaviour of the children, or if the study evaluates physical activity, the method used is self-report or another non-objective measure (Godin & Shephard, 1986; Hagger et al., 2001; Hagger, Chatzisarantis, & Biddle, 2002; Mummery et al., 1999). Without sizable research demonstrating its application and the concrete relationship between a child's intention to be physically active and actual physical activity, there is only limited usefulness of the TPB.

1.9.2 Transtheoretical Model

The history of the transtheoretical model (TTM) is rooted in psychopathology. It began as a means of treating addictive behaviours, but was advanced as a method for understanding exercise behaviour in the early nineties (Prochaska, DiClemente, & Norcross, 1992; Sonstroem, 1988 as cited in Marshall and Biddle, 2001). The TTM is a five-stage model of behavioural change. Each level is distinct and individuals pass through the levels according to their individual intentions and behaviours (Prochaska et al., 1992) (See Appendix E for stages and characterization of each stage).

The primary advantage of this model is its treatment of behaviour as a dynamic process. Individuals move in and out of the stages and the movement is not restricted to a linear direction. Movement between stages reflects the individual's alterations in the process of change, self-efficacy, and decisional balance. Processes of change are activities used to adjust experiences and environments in an effort to change a particular behaviour. There are ten such processes of change that are classified as either experiential or environmental. The first is where information is accumulated as a result of the individual's own actions and experiences. The latter is where information is the result of

environmental events. Decisional balance is the weighing of the pros and cons of each behaviour. As one moves through the stages of the transtheoretical model, the pros increase and the cons decrease. Self-efficacy is also purported to increase with movement into subsequent stages.

Marshall and Biddle's meta-analysis of empirical applications of the TTM found support for the fact that adults do transition through these five distinct stages (2001). After reviewing 91 published reports of the TTM, the authors concluded that the level of an individual's physical activity increases with every incremental level gained. The confidence an individual has in being physically active and the individual's perceived benefits of being active also increases with each stage.

Nigg and Courneya (1998) used the TTM to investigate whether this framework could be used to adequately understand adolescent physical activity. A questionnaire including stages of change, processes of change, self-efficacy, and decisional balance was given to over fourteen hundred high school students. The researchers found general support for this model. Specifically, every component of the core constructs was able to significantly discriminate between a minimum of one stage of change. Another study by Lee, Nigg, DiClemente, and Courneya (2001) using a set of questionnaires administered to a cross-sectional sample of Canadian high school students, also found support for the validity of the TTM in appraising motivational readiness of adolescents. Adolescents reported less exercise in Precontemplation stage versus the Action or Maintenance stages. In addition, the model was a sensitive measure in the prediction of strenuous exercise behaviour of adolescents.

Although the TTM appears competent as a means of predicting an individual's level of physical activity, no research exists demonstrating that this knowledge is sufficient for the production of a successful intervention program with children. The ability to identify the stage a child is in does not intuitively lead to an understanding of how this knowledge will assist in motivating him or her to be physically active. While the strong support for the prediction of an individual's physical activity based on the stage he or she is in is interesting, what causes a child to move from stage to stage is unclear. This question has yet to be answered in the literature and thus restricts the value of this model for the present investigation or future PA interventions.

1.9.3 Self-Efficacy Theory

Bandura developed the notion of self-efficacy to describe an individual's belief in his or her own abilities to perform a specific action to elicit a specific outcome (Bandura, 1997). According to Bandura, self-efficacy governs an individual's actions and behaviours in life. An individual with high self-efficacy has the confidence in his or her ability to surmount obstacles and to achieve desired goals and thus to direct his or her behaviour accordingly (Bandura, 1997). The antithesis, an individual with low self-efficacy, does not believe in his or her ability to achieve the desired outcome, thus limiting his or her activities. Either scenario creates a self-fulfilling prophecy best voiced by Henry Ford, "Whether you believe you can't do something or you believe you can, you're probably right" (as cited in Passer & Smith, 2001, p. 568). Bandura's self-efficacy theory (SET) has been adopted extensively within the literature as a framework for understanding physical activity behaviour.

A variety of information sources can influence an individual's self-efficacy. Reported to be the most important is previous mastery, or experience of success or failure at a task (Feltz, 1984). Belief in one's capability is enhanced if an individual has been successful in the past; conversely if one experiences failure; one is less confident in one's ability to succeed in the future. A second information source, that of social comparison, known also as observational learning, acts as a gauge of one's probable success or failure based on attending to who succeeds and who fails. Third is the influence of verbal and social persuasion by others. It is the message one receives about his or her ability from the people around him or her. For example, being picked last in gym class conveys the message that he or she is not a good athlete. Last is a person's appraisal of his or her physiological states/emotional arousal. The level of physiological arousal and its interpretation may indicate to the individual his or her ability. For example, if one feels extremely anxious at the thought of participating in a volleyball game, it may be interpreted by the person that he or she is not good at this sport, thereby lowering his or her self-efficacy belief. All four sources of information combine to create a self-efficacy belief (see Appendix F for a diagram of SET).

Evidence suggests that self-efficacy is associated with physical activity in children (Trost et al., 2002). As discussed earlier, Trost et al. (2002) found that for both Caucasian and African American girls, self-efficacy perceptions were strongly correlated ($r = 0.40$) and ($r = 0.28$) with one's intention to be physically active.

Furthermore, Strauss and team (2001) reported that greater levels of high intensity activity are associated with larger self-efficacy scores. These researchers surveyed students aged 10-16 years to characterize the social and cognitive correlates of physical

activity in children. After administering a variety of questionnaires to the children and their parents, the children were asked to wear a biaxial accelerometer on their wrists for one week. Children completed a questionnaire that included items such as "I think I: can be physically active no matter how tired I feel" (Strauss et al., 2001, p. 899). Strauss and colleagues concluded that individuals with higher self-efficacy were more likely to perform high intensity physical activity. Therefore, programs to enhance children's beliefs in their ability to exercise may hold the key to motivating children to be more physically active.

In addition, a survey of randomly selected American students in grades nine and ten demonstrated a correlation between self-reported physical activity and self-efficacy (Allison, Dwyer, & Makin, 1999). Self-efficacy was assessed in connection to conquering perceived barriers. Physical activity was measured as a self-report of the number of days in one week the individual participated in vigorous physical activity in three different environments: physical education classes, other school activities, and outside of school. Results indicated that self-efficacy or confidence in one's ability to cope with external barriers (lack of time, cost) is a statistically significant predictor of physical activity in the 'other school activities' and 'outside school' categories. With regards to internal barriers (lack of energy, not in the mood), self-efficacy was not a predictor for any environment. The authors noted that most studies of self-efficacy do not dichotomize barriers into internal and external barriers, and thus it is impossible to know whether this is a sample-specific result or a stable relationship.

In the context of health and exercise psychology, Sonstroem and Morgan (1989) elaborated on Bandura's idea of self-efficacy, proposing an exercise and self-esteem

model whereby self-perceptions of physical ability are related to global self-esteem (see Appendix F). Central to this hierarchical model, where one's physical self-efficacy is an influencing agent on self-esteem, is the tenet that there exists a reciprocal relationship between behavioural outcomes and self-efficacy. Specifically, the behavioural outcome influences one's self-efficacy and self-efficacy influences one's behaviour. Together these influence one's self-esteem. Thus, it is not the physical ability that determines if the individual enjoys a high self-esteem, but rather the belief in his or her abilities. One's beliefs in one's ability dictate one's physical competence, leading not only to physical acceptance, but also to self-esteem. Given the importance of self-esteem enhancement for children as shown in previous research (Sorensen, 1991), the addition of self-esteem to SET forms a strong foundation for my proposed research.

Specifically, there are several important advantages to SET, along with the addition of self-esteem as proposed by Sonstroem and Morgan (1989), as a framework for investigating physical activity in JA. The first is the core belief that motivation and confidence are interlinked. It makes intuitive sense that a person with greater confidence in his or her abilities to be physically active will be more motivated to be physically active. The second advantage directly related to this is the notion that there exists a reciprocal relationship between efficacy perceptions and behaviour. Rather than restricting change to be the result of unidirectional forces, SET allows for the possibility that not only do efficacy beliefs change behaviour as well as self-esteem, but behaviour in turn changes efficacy and therefore self-esteem. This is reciprocal determination, a central element within SET (Bandura, 1997). The third strength lies in the conceptualization of self-efficacy not as a personality trait but as a situation specific

construct (Maddux, 1993). If self-efficacy is not inherent to the individual's personality, but instead context specific, it should be relatively easy to modify. Last, the simplicity of the model permits a comparatively uncomplicated physical activity intervention.

1.10 Conclusion

Juvenile arthritis is a painful, physically limiting chronic illness. However, a great deal is still unknown about how the disease affects the children psychologically, and importantly, the best means of enhancing their current and future quality of life. Physical activity as an intervention to increase physical functioning and psychological well-being shows enormous promise (Klepper, 2003; Klepper, 1999; Takken et al., 2003b; Takken et al., 2002; Takken et al., 2001).

In Akikusa and Allen's overview, "Reducing the impact of rheumatic diseases in childhood" (2002), the authors commented that investigating the relationship between physical fitness and quality of life of children with juvenile arthritis is an important research goal. The ability to enhance a child's quality of life and decrease disease activity and disability through aerobic fitness and strength training justifies further research attention. They authors contend if the goal of treatment of children suffering from JA is the production of non-disabled adults, than we must begin to work towards improving the quality of life of children (Akikusa & Allen, 2002). Science must reconstruct the idea of studying these children solely to improve their joint range of motion or to assess the implications of the latest pharmaceutical invention. Rather, focusing on improving the quality of life for children who must endure a life with JA should be a priority.

Evidence exists in non-ill populations of children that physical activity and exercise are associated with a number of psychological benefits, including elevated self-esteem, less depression, and greater self-efficacy (Boyd & Hrycaiko, 1997; Kirkcaldy et al., 2002; Trost et al., 2002). Literature on the benefits of exercise and physical activity for children with JA is limited, and even less is known about the role physical activity plays in any psychosocial variable. While Takken and colleagues touched upon the role physical activity may have on health-related quality of life, to date an in-depth exploration of any associations between these variables does not exist. While Takken's two studies included quality of life (QoL) as one of a number of variables studied, their results were inconclusive and they did not consider the impact of any other psychosocial variables.

Thus, the purpose of the present study is to determine the psychosocial correlates of physical activity in children with JA, to determine the physical activity levels of this population, and to better understand the mechanisms that play a role in physical activity's promotion of enhanced quality of life for children with JA.

The specific hypotheses are as follows:

(1) there will be a positive correlation between physical activity and self-efficacy and self-concept; children who participate in more physical activity will score higher in physical self-efficacy and physical self-concept,

(2) there will be a positive correlation between physical activity and self-esteem; children who participate in more physical activity will score higher in global self-esteem,

(3) there will be a positive correlation between physical activity and quality of life; children who participate in more physical activity will score higher on measures of quality of life,

(4) there will be a positive correlation between physical activity and social functioning; children who participate in more physical activity will score higher in social functioning, and

(5) there will be a negative correlation between level of physical activity and functional disability and pain; children reporting more physical activity will report less pain and less disability.

CHAPTER TWO: METHOD

2.1 Participants

Participants were recruited through the Alberta Children's Hospital Rheumatology Clinic's database in Calgary, Alberta. After eliciting the support from the doctors practicing in this clinic, ethical approval was granted allowing these doctors to contact their own patients with information on the study. Eligibility criteria included: 1) currently between the ages of 12 and 19; 2) a patient of a doctor currently practicing in the Rheumatology clinic; and 3) having been diagnosed with juvenile arthritis. Additionally, a notice detailing the study and requesting participants was also posted on the national website of the Canadian Arthritis Society. However, no participants were obtained via this recruitment strategy. In total 74 questionnaires were mailed and 42 returned, for a response rate of 56.7%.

2.2 Design

This one time cross-sectional self-report survey was comprised of demographic questions, Godin's Leisure Time Exercise Questionnaire, the Physical Self-Description Questionnaire, Confidence to Engage in Physical Activity Scale, the PedsQL Core Questionnaire and the PedsQL Juvenile Arthritis Module the Child Health Questionnaire, a Visual Analogue Scale for pain perception, the Child Health Assessment Questionnaire, and a researcher created qualitative physical activity behaviour measure.

The questionnaire package may be viewed in Appendix G.

2.2.1 Demographics

Age (years), school grade, time since diagnosis (years/mos), height (feet/cm), and weight (lbs/kg) were requested.

2.2.2 Godin Leisure Time Exercise Questionnaire.

Past physical activity behaviour was assessed utilizing the leisure score index (LSI) of the Godin Leisure Time Exercise Questionnaire (GLTEQ; Godin, Jobin, & Bouillon, 1986; Godin, & Shepard, 1985) 'before the diagnosis' of JA and 'over past week/post-diagnosis' of JA. The LSI contains three questions and is designed to assess the frequency and duration of mild, moderate, and strenuous exercise/activity performed for at least 15 minutes over a typical week. A total LSI score is calculated by adding the frequency of exercise within the mild, moderate and strenuous categories. An independent evaluation of this measure found it to be easily administered, brief, reliable, and possess concurrent validity based on various criteria including objective activity monitors and fitness indices (Jacobs, Ainsworth, Hartman, & Leon, 1993). A test-re-test coefficient of 0.84 has been reported for healthy children and adolescents (Sallis, Buono, Roby, Micale, & Nelson, 1993). The GLTEQ has previously been used successfully with adolescent chronic illness survivors (Courneya, Friedenreich, Sela, Quinney, & Rhodes, 2002).

2.2.3 Physical Self-Description Questionnaire.

Physical self-concept as well as self-esteem was measured with the Physical Self-Description Questionnaire (Marsh, 1996). This 70-item questionnaire measures 11 dimensions of perceived physical self-concept. These dimensions are: health, co-ordination, physical ability, appearance, body fat, sports competence, global physical, strength, flexibility, endurance, and esteem. Questions are answered by checking which of the 6 response options (false, mostly false, more false than true, more true than false, mostly true, and true) most closely represent their self-perceptions. Although longer in

length, this measure's sound construct validity have led to it being recommended over other physical self-concept measures (Marsh, 1996; Marsh, Asci & Tomas, 2002). Its construct validity ranges between 0.68 and 0.84 with internal consistency estimates of reliability alpha coefficients being greater than .9 for all but one scale, which is 0.82. Test-retest reliability is a stable r = 0.83 (Marsh, 1996). The scale reliability coefficients ranged from 0.88 to 0.98 in the present study.

The scales used for subsequent analysis in the present investigation were global physical and global self-esteem scales. Scales that could be used within Sontroem's Exercise and Self-Esteem Model included the two previous scales as well as the sport competence, appearance, and body fat scales.

2.2.4 Confidence to Engage in Physical Activity Scale (CTEPA)

A scale was created to assess the participant's present confidence to engage in PA. It contained 8 items measured with a 7 point Likert scale, where a value of 1 denotes "not confident at all" and a value of 7 indicates "extremely confident". Questions included confidence to engage in PA in general one time per week, two times per week, as well as confidence to engage in mild, moderate, and strenuous levels of PA one and two times per week. Scale reliability for the present study was 0.975.

2.2.5 PedsQL.

The Pediatric Quality of Life Inventory (PedsQL) and the PedsQL Juvenile Arthritis module assess health-related quality of life of participants (Varni, 1998). The PedsQL 4.0 Generic Core Scales is comprised of 23 items assessing the physical, emotional, social, and school functioning of both healthy children and those with chronic health conditions aged 2-18 years. Unlike other health related quality of life measures

designed for assessment of children, it is quick and the PedsQL may be completed by the children, rather than the parent (Varni, Seid, & Kurtin, 2001). For the self-report data, internal consistency reliability alpha coefficients ranged from 0.68 to 0.88 with the average coefficient being 0.77. The Juvenile Arthritis Module contains twenty-two items with five subscales. The subscales include pain and hurting, daily activities, treatment, worry, and communication. In the present study, reliability coefficients ranged from 0.80 to 0.95. For the present study social functioning, overall quality of life, and disease-specific quality of life scales were used.

2.2.6 Pain Visual Analog Scale.

A 10-cm visual analog scale (VAS) determined the participant's subjective rating of pain. The VAS scale endpoints were labelled "no pain" with a corresponding picture of a happy face, and "big pain" with a picture of an unhappy face. Participants were asked to mark their level of perceived pain over the last week with an "X" on the line. Huskisson (1993) and Scott, Ansell, and Huskisson (1977) report VAS scales to be a valid and reliable measure for pain perception for children over the age of five.

2.2.7 Child Health Assessment Questionnaire

Functional disability was assessed utilizing the Childhood Health Assessment Questionnaire. This tool is extensively used world wide in both research and clinical practice and was adapted from the Stanford Health Assessment Questionnaire for use with children (Singh, Athreya, Fries, et al., 1994). It is appropriate for self-report use in children greater than 8 years. There are eight disability areas: dressing and grooming, arising, eating, walking, hygiene, reach, grip, and activities (Duffy & Lovell, 2001). It contains 30 items and each item is rated on a 4-point scales. An answer of 0 indicates can

perform that activity without any difficulty, 2 indicates with some difficulty and a rating of 3 denotes unable to do. The highest score determines the score for that particular functional area. A minimum score of 2 is assigned if any aids or assistance are required for that functional area. The mean of the eight functional areas is the child's score of disability. Internal consistency of this measure is 0.94, retest reliability has been reported as 0.79 and convergent validity numbers range from 0.54-0.77 (Klepper, 2003; Singh et al., 1994). In the present study, reliability coefficients varied widely from 0.51 to 0.99. The low values obtained were corresponded with short scales, scales containing as few as two items, and thus interitem correlations were observed. The scale of most interest, and used in subsequent analysis, was the total disability score, and its reliability was 0.94.

2.2.8 **Physical Activity Behaviour and Interests**

This series of questions was designed to ascertain the activities that children with JA participate in living in Calgary. As requested by the pediatric rheumatologist most closely connected with the project, questions assessing whether the children were currently taking medication, what medication they were taking, and their reasons for medical compliance were elicited. It also contained a qualitative open-ended question component seeking their perceptions of the advantages and disadvantages of physical activity, what they believe the biggest problems that prevent youth from being physically active are, and what can be done to encourage more physical activity. Finally, space was left for the participants to express anything else they wished.

Data from the open-ended questions were transcribed, coded, and categorized. A trained research associate then verified coding and categorization was correct. If there

was disagreement on a particular item, discussion was held between the parties until agreement was reached.

2.3 Procedure

After ensuring the support and co-operation of the rheumatologists with child and adolescent patients, ethical approval from the Child Review Board Conjoint Health Research Ethics Board was obtained. As children in the database at the Rheumatology Clinic at Alberta Children's Hospital did not give their permission to be contacted by researchers directly, ethical approval was granted for the doctors to contact their own patients about the opportunity to participate in this research study.

Seventy-three eligible participants were mailed a cover letter from their doctor, a letter from the researcher, the questionnaire package, and a self-addressed stamped envelope. In an effort to improve response rate, mail-out protocol was be based on a slightly modified version of the Total Design Method (Dillman, 1983). This consisted of (a) mailing the initial questionnaire packet, (b) mailing a post-card reminder 11-days later, and (c) mailing a second questionnaire packet 26 days later to all those who did not respond to the first mailing or post-card reminder. To improve response rates, the following features were also utilized; multiple reminders (i.e., postcard, second questionnaire package), stamped return envelopes, illustrations, assurances of confidentiality, and two personalized cover letters - one from their doctor and the other from the researcher – explaining the purpose and relevance of this research project. Each participant was asked to answer the questions on their own, and parents were specifically requested not to complete the questionnaire for their child. The survey was returned in a self-addressed, pre-stamped envelope that was enclosed with the survey package.

CHAPTER THREE: RESULTS

The purpose of the survey was to examine the relationships between physical activity and perception of pain, physical self-efficacy, health related quality of life, and functional disability in a juvenile arthritis population. Analyses included the following:

1) Descriptive statistics to describe the sample include means, ranges and standard deviations on all demographics, physical activity participation rates, and psychosocial variables.

2) Correlations examined the relationship between demographics (age, gender), physical activity participation, functional disability, pain perception, and the psychosocial variables.

3.1 Statistical Analyses

The Statistical package for the Social Sciences (SPSS) 12.0 was used for data entry and analysis. An alpha level of .05 was chosen for all statistical tests as a compromise between the probability of making Type I and Type II errors. Analyses involved descriptive statistics (means and standard deviations for all variables), as well as an examination of the relationship between variables utilizing Pearson product moment correlations. Differences between pre and post diagnosis activity levels, as well as between most and least active participants, were examined with t-tests. The small sample size precluded multivariate analyses on group differences.

3.2 Participant Characteristics

See Table 3, 4, and 5 for a detailed overview of the demographic characteristics. The sample of 42 participants included 27 females and 15 males with a mean age of 14.5

years (SD = 2.05 years). The response rate was 57%. Participants ranged from 12 to 19 years old and from grades 5 to having completed high school. Consistent with the JA literature, 81% (N = 30) of the participants had juvenile rheumatoid arthritis. Of these, 5.4% had pauciarticular display of the disease, 37.8% had polyarticular display of the disease, and 8.1% had systemic display of the disease. Of those participants who did not have juvenile rheumatoid arthritis (19%) (N = 12), 8.1% had psoriatic arthritis, and 10.8% classified their arthritis as "other". Just over 71% of the participants were diagnosed between 2000 and 2004. Treatment for their illness included medication in 93% of the participants, and only 1 indicated non-compliance with his/her medication. Reasons for compliance can be seen in Table 4.

Table 3 Demographic Characteristics of the Study Participants

Characteristic	Number [a]	Percentage [b]
Gender[c]		
Male	15	64.3
Female	27	35.7
Age[d]		
12-13	17	40.4
14-15	11	26.2
16-17	10	23.8
18-19	4	9.5
Education[e]		
Grades 5 & 6	5	11.9
Grades 7 & 8	14	33.3
Grades 9 & 10	9	21.4
Grades 11 & 12	11	28.6
Completed High School	1	2.4
Body Mass Index[f]		
> 18 (under weight)	15	45
19-25 (normal/healthy)	16	48
26-30 (overweight)	0	0
<30 (obese)	2	6
Diagnosis[g]		
Rheumatoid (JRA)	30	81.1
Pauciarticular	2	5.4
Polyarticular	14	37.8
Systemic (Still's)	3	8.1
Psoriatic arthritis	3	8.1
Other	10.8	4

Note: [a] = the number of participants who fit that descriptor; [b] = the number of response/total number of participants who made some form of response to the variable; [c] = (n = 42); [d] = (n = 42) (M = 14.52); [e] = (n = 41) (M = Grade 9); [f] = (n = 33) (M = 20.9); [g] = (n = 37).

Table 4

Reasons for Compliance with Medication Regime[a] (n = 40)

	Number[b]	%[c]
So can be physically active	17	40.5
Doctor tells me to	14	33.3
Don't want damaged joints	14	33.3
Don't take them	1	2.4
Other reasons[d]	8	19

Note: [a] = participants could agree with more than one answer; [b] = the number of participants who fit that descriptor; [c] = the number of response/total number of participants who made some form of response to the variable; [d] = responses that fit under other included such things as "it would be dumb not to", "for pain" as well as concerns about being hospitalized, and because of his or her parent.

Table 5

Demographic and Medical Characteristics of Participants (n = 42)

Variable	Number [a]	Percentage [b]
Treatment Includes Medication (n = 42)		
Yes	39	92.9
No	3	7.1
Medication Type [c] (n = 42)		
Anti-Inflammatory (inc. Non-Steroid)	30	30.9
Anti-metabolites	23	23.7
Anti- rheumatic	1	1.0
Biological Response Modifier	5	5.2
Corticosteriod & Systemic	8	8.2
Histamine H_2 Receptor Antagonist	1	1.0
H^+, K^+ - ATPase Inhibitor	3	3.1
Immunosuppressant	1	1.0
Vitamin/Mineral	15	15.5
Uncategorized	10	10.3

Note: a = the number of participants who fit that descriptor; b= the number of response/total number of participants who made some form of response to the variable, c= note all categories are from the "Compendium of Pharmaceuticals and Specialties" 2004 Repcloinsky, Welbanks., & Bisson, 2004); and if the drug was not found here, the category used was from the "21st Ed. Nursing 2001 Drug Handbook" , (Chohan, Doyle, & Nale, 2001).

3.3 Quantitative Analysis

3.3.1 Physical Activity and Psychosocial Well-being

3.3.1.1 Physical Activity

Physical activity (PA) was measured in the GLTEQ as a function of frequency of participation per week in mild, moderate, and strenuous activities, of duration longer than 15 minutes. From this, total frequency of PA was calculated as a true, unweighted measure of the frequency of physical activity, by summing over mild, moderate, and strenuous activity. This assessment of PA was used for descriptive purposes. The second means of assessing PA employed the leisure score index (LSI) of the GLTEQ. This weighted measure calculates a total exercise score based on the frequency of participation in mild, moderate and strenuous physical activity. These values are multiplied by anticipated metabolic equivalent values of 3, 5, and 9, and then summed (Godin & Shepard, 1985). Metabolic equivalent values represent estimated values of oxygen consumption for physical activities. This assessment of PA was used in subsequent analyses (correlations and t-tests). Researchers have been known to supplement this questionnaire with questions on duration of physical activity to produce a total MET score (Courneya et al., 2003). For descriptive purposes only, data on both average duration in minutes of each session for mild, moderate, and strenuous activity, and total duration of activity per session summing over mild, moderate, and strenuous activity were collected and calculated. The decision to adhere as closely as possible to the original measure (i.e., LSI) was made in an effort to keep results clear, concise and easily replicable. Pearson product-moment correlations were conducted to examine the association between physical activity and physical self-efficacy, confidence to engage in

PA (CTEPA), self-esteem, social functioning, global HRQL, disease specific HRQL, functional disability, and pain.

Descriptive statistics for pre and post diagnosis physical activity levels and activities participants engaged in are displayed in Table 6 and 7.

Table 6

Physical Activity Frequency and Duration Before and After Diagnosis

	Mild PA		Moderate PA		Strenuous PA	
	Pre	Post	Pre	Post	Pre	Post
Frequency[a]	4.76(2.71)	4.54(3.81)	3.56(2.03)	3.32(2.38)	3.44(1.64)	2.95(2.24)
Duration[b]	41.29(52.14)	41.90(95.88)	47.15(37.21)	39.22(32.19)	56.32(38.20)	38.41(40.90)

	Pre Diagnosis	Post Diagnosis
TF[c]	11.76(4.89)	10.80(6.81)
LSI[d]	63.06(25.39)	56.76(34.86)
MET[e]	57.61(45.88)	48.29(71.84)

Note: [a] = number of times per week participant engages in 15 minutes or more exercise; [b]= average number of minutes spent in activity session; [c] = total frequency (mild + moderate + strenuous); [d] = Leisure Score Index (frequency mild x 3) + (frequency moderate x 5) + (frequency strenuous x 9); [e] = Metabolic Equivalent Score (duration of mild x frequency mild x 3) + (duration of moderate x frequency moderate x 5) + (duration of strenuous x frequency strenuous x 9)

Table 7

Organized Sport Involvement Before and After Diagnosis

Activity	Number [a]		% of Response Group (n = 42) [b]		Overall % (n = 42) [c]	
	Pre	Post	Pre	Post	Pre	Post
Volleyball	9	11	21.4	26.2	23.7	27.5
Basketball	8	12	19.0	28.6	21.1	30.0
Skating/hockey	14	10	33.3	23.8	36.8	25.0
Baseball	8	6	19	14.3	21.1	15.0
Soccer	12	14	28.6	33.3	31.6	35.0
Other [d]	20	25	47.6	59.5	52.6	62.5

Note: [a] = the number of participants who responded that they participated in that activity; [b] = the number of response/total number of participants who made some form of response to the question; [c] = the number or responses/total number of study participants; [d] = mountain biking, dance, gymnastics, roller blading, bowling, ringette, curling, skiing, swimming, lacrosse, running, badminton, skateboarding, tennis, and skipping.

The physical activity measure, the Leisure Score Index (LSI), was calculated from the reported weekly frequency of PA. Individual scores on the LSI are computed as [(frequency mild physical activity x 3) + (frequency of moderate physical activity x 5) + (frequency of strenuous activity x 9)]. The mean number of times per week participants engaged in a mild, moderate, and strenuous activity greater than 15 minutes in duration pre diagnosis was 11.76, while post diagnosis it was 10.8 times per week. The mean duration of physical activity per session was 144.76 minutes pre and 119.53 post diagnosis. The mean LSI pre diagnosis was 63.06 and 56.76 post diagnosis. The mean MET pre diagnosis was 57.61 and 48.29 post diagnosis.

Paired-sample t-tests to investigate if there was a significant difference in total physical activity pre to post diagnosis revealed no significant differences. Specifically, the t-tests revealed LSI pre-diagnosis (M = 63.06, SD = 25.39) to post diagnosis (M = 59.82, SD = 35.75), t(33) = 0.525, p = 0.302. Note the differences in means and standard deviations reported with these t-tests differ slightly from those reported with the correlations above. This is a reflection on the elimination of individuals who did not report both pre (n = 41) and post data (n = 34).

3.3.2 Psychosocial Variables

Means and standard deviations for the psychosocial variables are presented in Table 8. As this questionnaire did not elicit retrospective data on the psychological states of participants pre-diagnosis, the psychosocial variables are a measure of the individuals functioning post-diagnosis/over the past week. Variables included physical self-concept (M = 4.69, SD = 1.48), confidence to engage in physical activity (CTEPA) (M = 6.12, SD

= 1.25), global self-esteem (M = 5.25, SD = 0.87), social functioning (M = 80.50, SD = 17.82), global health related quality of life (HRQL) (M = 73.51, SD = 18.36), disease specific HRQL (M = 75.00, SD = 17.88), functional disability (M = 0.30, SD = 0.40), and pain (M = 11.95, SD = 10.57).

Table 8

Pearson Correlations Between Physical Activity (LSI) and Psychosocial Variables.

	PA	Glo. HRQL	Dis. Sp. HRQL	Pain	Self-Concept	CTEPA	Self-Est.	Func. Disab	Soc. Func.	M(SD) LSI
PA	x	.17	.17	-.19	.36*	.52**	.32*	-.24	.28*	48.30 (78.84)
Global HRQL	x	x	.86**	-.76**	.76**	.68**	.78**	-.67**	.79**	73.51 (18.34)
Disease Specific HRQL	x	x	x	-.73**	.61**	.63**	.74**	-.64**	.58**	75.00 (17.89)
Pain	x	x	x	x	-.48**	-.40**	-.62**	.85**	-.63**	11.95 (10.57)
Self Concept	x	x	x	x	x	.66**	.84**	-.50**	.66**	4.69 (1.48)
CTEPA	x	x	x	x	x	x	.65**	-.38**	.65**	6.12 (1.25)
Self-Esteem	x	x	x	x	x	x	x	-.61**	.58**	5.25 (0.87)
Functional Disability	x	x	x	x	x	x	x	x	-.63**	0.30 (0.40)
Social Functioning	x	x	x	x	x	x	x	x	x	80.50 (17.82)

Note: PA = physical activity, measured in LSI, scale range from 0- unlimited; Glo.HRQL = global health-related quality of life (scale range 0-100); Ds. Sp. HRQL = disease specific health related quality of life (scale range from 0-100); Self-Effic. = physical self-efficacy (scale range from 1-6); CTEPA = confidence to engage in physical activity (scale range 1-7); Self-Est. = global self-esteem (scale range from 1-6); Func. Disab = functional disability (scale range from 0-4); Soc. Func = social functioning (scale range from 0-100). * Correlation is significant at the 0.05 level (1-tailed) ** Correlation is significant at the 0.01 level (1-tailed).

3.4 Physical Activity Level Results (Past Week)

3.4.1 Total physical activity

Significant positive correlations were observed between total frequency of physical activity (mild + moderate + strenuous) and physical self-concept (r = 0.330, p = .017), CTEPA (r = 0.500, p = 0.001) global self-esteem (r = 0.309, p = 0.025), and social functioning (r = 0.276, p = 0.042). There was no statistically significant correlations between total frequency of physical activity and global HRQL (r = 0.143, p = 0.189), disease specific HRQL (r = 0.168, p = 0.150), functional disability (r = -0.223, p = 0.083), or pain (r = -0.176, p = 0.136).

3.4.2 Strenuous physical activity

Significant positive correlations were observed between frequency of strenuous physical activity and physical self-concept (r = 0.314, p = 0.023), CTEPA (r = 0.453, p = 0.002) and global self-esteem (r = 0.267, p = 0.046). There was a trend towards a significant positive correlation between frequency of strenuous physical activity and social functioning (r = 0.258, p = 0.054) and negative correlation with functional disability (r = -0.215, p = 0.092). There was no statistically significant correlations between frequency of strenuous physical activity and global HRQL (r = 0.163, p = 0.157), disease specific HRQL (r = 0.116, p = 0.238), or pain (r = -0.173, p = 0.140).

Correlations between duration of strenuous physical activity and physical self-concept (r = 0.362, p = 0.01), CTEPA (r = .372, p = 0.009), global self-esteem (r = 0.309, p = 0.025), and global HRQL (r = 0.264, p = 0.05) were all statistically significant. There was a trend towards a significant positive correlation between duration of strenuous activity and social functioning (r = 0.211, p = 0.095) and disease specific HRQL (r =

0.238, $p = 0.07$), and a negative correlation with functional disability (r = -0.249, p = 0.061) and with pain (r = -0.244, $p = 0.062$).

3.4.3 Moderate and mild physical activity

A statistically significant correlation was found between frequency of moderate physical activity and physical self-concept (r = 0.319, $p = 0.021$) and CTEPA (r = 0.406, $p = 0.005$). There was a trend towards a significant positive correlation between duration of moderate activity and global self-esteem (r = 0.260, p = 0.051), global HRQL (r = 0.226, p = 0.080), and disease specific HRQL (r = 0.214, p = 0.092). There was no significant correlation with either social functioning (r = 0.170, $p = 0.148$) or functional disability (r = -0.195, $p = 0.114$). The only significant correlation with mild frequency of physical activity was CTEPA (r = 0.377, $p = 0.008$).

3.4.4 Correlations between psychosocial variables and leisure score index (LSI)

Significant positive correlations were observed between LSI and physical self-concept (r = 0.358, p = 0.022), CTEPA (r = 0.522, p = 0.000), global self-esteem (r = 0.319, $p = 0.021$), and social functioning (r = 0.284, $p = 0.038$). There was no statistically significant correlations between LSI and global HRQL (r = 0.177, $p = 0.138$), and disease specific HRQL (r = 0.172, $p = 0.145$) or pain (r = -0.189, $p = 0.118$). A trend towards a significant negative correlation was observed for functional disability (r = -0.240, p = 0.068).

3.5 Physical Activity Group Differences

To ascertain whether the psychosocial variables of interest differed between youth who engaged in more activity, an analysis of extreme groups was performed. This was completed by performing a tertile split on LSI post diagnosis (n = 41). Those individuals

in the top third were considered in the high physical activity group (HPAG; n=13) and those individuals in the bottom third were considered in the low activity group (LPAG; n=14). An independent groups t-test confirmed these groups were significantly different (LPAG = 22.93), (HPAG = 94.77), t(25) = -8.201, p = 0.00. The justification for this analytic technique was if scores on the psychosocial variables are indeed a function of physical activity levels, then the detection of any associations or relationships should be most evident with individuals in the extreme groups. See Table 9, 10, and 11 for review of group findings.

Table 9

Significant Correlations Between Physical Activity and Psychosocial Variables Based on Group Membership (LSI) [d]

Variable [a]	LPAG [b]	HPAG [c]
Physical Self-Concept	*NS*	*NS*
CTEPA[e]	$p = 0.002$	*NS*
Global Self-Esteem	$p = 0.014$	*NS*
Social Functioning	$p = 0.032$	*NS*
Global HRQL[f]	$p = 0.018$	*NS*
Disease Specific HRQL	$p = 0.008$	*NS*
Functional Disability	$p = 0.027$	*NS*
Perceived Pain	$p = 0.022$	*NS*

Note: *NS* = non-significant correlation; [a] = psychosocial variables; [b] = low physical activity group (bottom third of physical activity variable); [c] = high physical activity group (top third of physical activity variable); [d] = physical activity defined by leisure score index (LSI)); [e] = CTEPA = confidence to engage in physical activity); [f] =.HRQL = health related quality of life.

Table 10

T-Test of Differences Between Group Means of LPAG[c] and HPAG[d]

Relationship Tested	Significant[a]	Non-Significant[b]
Physical Self-Concept	$p = 0.001$	*NA*
CTEPA[e]	$p = 0.009$	*NA*
Global Self-Esteem	*NA*	$p = 0.129$
Social Functioning	*NA*	$p = 0.061$
Global HRQL[f]	*NA*	$p = 0.114$
Disease Specific HRQL	*NA*	$p = 0.154$
Pain Perception	*NA*	$p = 0.136$

Note: *NA* = not applicable; [a] = statistically significant relationship was found between variables ($p \leq .05$); [b] = relationship between variables failed to reach statistical significance ($p \geq .05$) [c] = low physical activity group (bottom third of physical activity variable); [d] = high physical activity group (top third of physical activity variable); [e] = CTEPA = confidence to engage in physical activity); [f] =HRQL = health related quality of life.

3.5.1 Relationship Between Physical Activity and Physical Self-Concept

A significant correlation was not observed between PA and self-concept in either the LPAG ($r = 0.413, p = 0.14$) or the HPAG ($r = 0.290, p = 0.168$). However, differences between means of the LPAG ($\underline{M} = 3.59$) and the HPAG ($\underline{M} = 5.39$) on self-concept were statistically significant, $t(18) = -3.843, p = 0.001$.

3.5.2 Relationship Between Physical Activity and Confidence to Engage in Physical Activity

There was a statistically significant positive correlation between PA and CTEPA for LPAG ($r = 0.711$, $p = 0.002$). No significant results were found between these variables in the HPAG ($r = 0.261$, $p = 0.194$). However, the differences between means on the CTEPA variable were statistically significantly different between the LPAG ($M = 5.69$) and the HPAG ($M = 6.89$), $t(13) = -2.719, p = 0.009$.

3.5.3 Relationship Between Physical Activity Participation and Self-Esteem

A significant correlation was detected between PA and global self-esteem scores for the LPAG ($r = .584, p = 0.014$). However, this did not hold true for the HPAG ($r = 0.311$, $p = .151$). Differences between global self-esteem means were in the expected direction, LPAG ($\underline{M} = 4.95$) and HPAG ($\underline{M} = 5.39$), however, the difference between groups failed to reach significance ($t(19) = -1.168, p = 0.129$).

3.5.4 Relationship Between Physical Activity Participation and Quality of Life

For the LPAG, a significant positive correlation was observed between PA and global HRQL scores ($r = .565, p = 0.018$) and disease specific HRQL ($r = 0.632$, $p = 0.008$). There was a trend towards significance for HPAG's PA and global HRQL ($r = -0.450, p = 0.062$) and disease specific HRQL ($r = -0.381, p = 0.10$). Differences between

global HRQL means of LPAG (M = 66.77) and HPAG (M = 76.09) were in the expected direction, however were not significant (t(19) = -1.246, p = 0.114). Similarly, a trend was also observed in the disease specific HRQL means (M = 70.61) and (M = 78.15), however it also failed to reach significance (t(19) = -1.046, p = 0.154).

3.5.5 Relationship Between Physical Activity Participation and Social Functioning

A significant positive correlation was observed between PA and social functioning (r = .508, p = 0.032) in the LPAG. In the HPAG, there was no significant correlation for PA and social functioning (r = -0.016, p = 0.480). Differences between social functioning means of LPAG (M = 73.21) and HPAG (M = 84.23) failed to reach significance (t(19) = -1.625, p = 0.061), but were in the expected direction.

3.5.6 Relationship Between Physical Activity Participation and Functional Disability

In the LPAG, a statistically significant negative correlation was observed between PA and functional disability (r = -0.546, p = 0.027). There was not a corresponding relationship in the HPAG (r = -0.246, p = 0.209). Furthermore, the difference between means of the LPAG (M = 0.423) and the HPAG (M = 0.279) were not significantly different t(24) = 0.853, p =0.202), although mean values were in the expected direction.

3.5.7 Relationship Between Physical Activity Participation and Perceived Pain

A significant negative correlation between PA and perceived pain was observed (r = -0.543, p = 0.022) in the LPAG. No significant correlation was evident between PA and perceived pain (r = 0.153, p = 0.309) in the HPAG. Furthermore, no significant difference between group means was obtained, LPAG (M = 23.71) and HPAG (M = 14.10) (t (17) = 1.138, p = 0.136).

Table 11

Pearson Correlations of Psychosocial Variables within High and Low Physical Activity Groups (LSI)

Variable	Hi PA (n = 13)	Low PA (n = 14)	Mean (SD)	
			Hi PA	Low PA
Glo. HRQL	-0.45 (p = .062)	0.56*(p = .018)	76.09 (12.12)	66.77 (13.05)
Ds. Sp. HRQL	-0.38 (p = .100)	0.63** (p = .008)	78.14 (12.05)	70.62 (23.84)
Pain	0.15 (p = .309)	-0.54* (p = .022)	14.10 (11.66)	23.71 (29.22)
Self-Concept.	0.29 (p = .168)	0.41 (p = .140)	5.03 (1.24)	4.06 (1.89)
CTEPA	0.26 (p = .194)	0.71** (p = .002)	6.89 (0.189)	5.69 (1.65)
Self-Est.	0.31 (p = .151)	0.59* (p = .014)	5.39 (0.64)	4.95 (1.24)
Func. Disab	-0.25 (p = .209)	-0.55* (p = .027)	0.28 (.35)	0.423 (0.499)
Soc. Func.	-0.02 (p = .480)	0.51* (p = .032)	84.23 (10.96)	73.21 (22.67)
Mean (SD)	94.77 (29.89)	22.93 (13.05)		

Note: PA = physical activity, measured in LSI, scale range from 0- unlimited; Glo.HRQL = global health-related quality of life (scale range 0-100); Ds. Sp. HRQL = disease specific health related quality of life (scale range from 0-100); Self-Effic. = physical self-concept (scale range from 1-6); Self-Est. = global self-esteem (scale range from 1-6); Func. Disab = functional disability (scale range from 0-4); Soc. Func = social functioning (scale range from 0-100). * Correlation is significant at the 0.05 level (1-tailed) ** Correlation is significant at the 0.01 level (1-tailed)

3.6 Qualitative Analysis

Using Sandelowski's framework for qualitative description using qualitative content analysis (2000), qualitative analyses examined 4 questions for descriptive and explanatory purposes. Sandelowski recommends qualitative description be focussed on obtaining the who, what, and where of experiences. In addition she recommends analysis be data-derived, whereby coding is created from the data in the study rather than by the application of a pre-set coding formula.

The first question asked, "has your arthritis been a barrier to your physical activity/sport participation", and 23/41 respondents (54.8%) answered in the affirmative. Next, three open ended questions were examined to obtain a better understanding of how children and adolescents with juvenile arthritis perceive physical activity. Responses were transcribed and grouped according to the question it answered. From this collection of responses, a tentative list of themes was compiled. Responses were then sorted according to themes, and any response categories missed were subsequently created. This process continued until all responses were appropriately matched with a corresponding theme/category. The transcribed list was once more scrutinized and each response was grouped according to the new list of themes/categories. This process resulted in all qualitative responses fitting into a theme/category.

The first question was "what do you believe are the main advantages and disadvantages of exercising or being physically active"? With respect to the advantages, twenty categories of responses emerged from 116 responses. The most frequent response category (17.2%) was 'that you stay in shape/fit/active'. This was followed by 'good for

health generally' (12.1%); 'fun/enjoyable' (10.3%); and 'meet people/be sociable' (8.6%). See Table 12 for review.

Table 12

Response Categories to the Advantages of Physical Activity (n = 116)

	Number[a]	%[b]
Stay in shape/fit/active	20	17.2
Good for you/general health	14	12.1
Fun/enjoyable	12	10.3
Social/meet new people	10	8.6
Muscle strength	6	5.2
Heart health	6	5.2
Physical appearance/body	6	5.2
Maintain/lose weight	5	4.3
Stay limber/be less stiff	5	4.3
For flexibility	3	2.6
Something to do	3	2.6
More energy	3	2.6
Feel good	3	2.6
Healthy joints	3	2.6
Improve self-esteem/self-image	2	1.7
Helps for sports	2	1.7
Endurance/stamina improvement	2	1.7
Pain reduction	2	1.7
Healthy internal organs	1	0.9
Co-ordination	1	0.9

Note: [a] = the number of participants who fit that descriptor; [b] = the number of responses fitting that descriptor/total number of responses made some form of response to the variable

To the question of disadvantages, 62 responses were elicited corresponding to 15 categories. 'Pain/soreness/hurts' was by far the most frequent category of response (35.5%). The next most common was 'tiring/fatigue/no energy' (11.2%), followed by 'time consuming' and 'negative impact on joints/damage/swelling' (9.7%). See Table 13 for complete review.

Table 13

Response Categories to the Disadvantages of Physical Activity (n = 62)

	Number[a]	%[b]
Pain/soreness/hurts	22	35.5
Tiring/fatigue/no energy	7	11.2
Time consuming	6	9.7
Negative impact on joints/damage/swelling	6	9.7
Can't do everything peers can/can't keep up	5	8.0
Could be hurt (not related to arthritis)	2	3.2
Gain weight/fat	2	3.2
Emotional reasons (fear/disappointment)	2	3.2
Can't concentrate/headaches	2	3.2
No reason not to	2	3.2
Won't improve strength/make more weak	2	3.2
Don't want to appear different	1	1.6
It's difficult	1	1.6
Make less limber	1	1.6
Less sports	1	1.6

Note: [a] = the number of participants who fit that descriptor; [b] = the number of responses fitting that descriptor/total number of responses made some form of response to the variable

The second qualitative question requested "what do you feel are the biggest problems that would prevent youth like yourself from exercising regularly? What could be done to help youth like yourself exercise regularly"? Eighteen response categories were created from the 72 answers. The most frequent problem that prevents participation in physical activity was 'pain/hurt' (20.8%) followed by 'schoolwork/homework/job' (11.1%). See Table 14 for complete overview. In response to what could encourage physical activity participation, 14 response categories were generated from 35 responses. By far the most popular category was 'make more fun/do with friends' (17.2%). This was followed by 'motivate them' (12.1%) and 'offer more appropriate activities' (10.3%).

Finally, the third question was, "did we miss anything? Is there anything that you would like to add about physical activity and you"? This section was completed by the fewest participants (n = 15), and occasionally included statements from their parents (n = 3). It elicited a variety of responses from "I love exercising!" to "I am disappointed that I can't run with my friends and do other sports I like". See Appendix H for complete transcription of participants' responses.

Table 14

Response Categories to Question "What Prevents Youth From Participating in Physical Activity (n = 72)

	Number[a]	%[b]
Pain/hurt	15	20.8
School/homework/jobs	8	11.1
Lazy/not motivated	6	8.3
Lack of support/role models	5	6.9
TV/video games/computer	4	5.6
Too busy	4	5.6
Think it's boring/no interest	4	5.6
Bad attitude/don't want to	3	4.2
Too hard	3	4.2
No energy/tired	3	4.2
Embarrassed about abilities	3	4.2
Expense	3	4.2
Inconvenient/too far away	3	4.2
Not enjoyable	2	2.8
The disease itself	2	2.8
No disease appropriate activities offered	2	2.8
Poor self-image	1	1.4
Weight	1	1.4

Note: [a] = the number of participants who fit that descriptor; [b] = the number of responses fitting that descriptor/total number of responses made some form of response to the variable

Table 15

Response Categories to Question "What Would Encourage Youth Like You To Participate in Physical Activity (n = 35)

	Number[a]	%[b]
Make Fun/do with friends	10	28.6
Motivation	5	14.3
Offer more appropriate activities	3	8.6
Learn more skills/be better at activities	3	8.6
Take away TV/video/computer	2	5.7
Sense of personal excellence	2	5.7
Other	2	5.7
Fitness centres at school/free membership	2	5.7
Rewards	1	2.9
Force	1	2.9
Educate other about disease	1	2.9
Seeing examples of bad role models	1	2.9
Weight lose	1	2.9
Pay to exercise	1	2.9

Note: [a] = the number of participants who fit that descriptor; [b] = the number of response/total number of participants who made some form of response to the variable

CHAPTER FOUR: DISCUSSION

The purpose of the present investigation was to examine the psychosocial correlates of physical activity in children with juvenile arthritis (JA), to determine the physical activity levels of youth with this chronic disease, and to gain an understanding of the influence physical activity has on the health related quality of life (HRQL) of children and adolescents living with JA.

In general, this sample of children and adolescents with JA was reflective of the expected characteristic disease display. Specifically, the majority were female (JA affects more girls than boys); and the most common form of JA reported was rheumatoid arthritis with polyarticular display (more common in girls than boys) (Laxer, 1998). With the exception of one participant, all respondents' treatment course included medication. The medication category most frequently prescribed was anti-inflammatory, but the most frequently prescribed drug was Methotrexate, an anti-metabolite. The top three reasons for their compliance with the prescribed medication regime included the following; enabled them to be physically active, directed to by their physician, and to avoid damaging their joints.

From this sample, it would appear that children being treated by a physician for JA demonstrate a high degree of physical functioning and a low degree of disability, similar to some previous studies and normative data (Shun-wai Fan et al., 1998; Takken et al., 2003a; Varni, YEAR). They report engaging in physical activity of mild, moderate, and strenuous types for duration of 15 minutes or longer approximately 11 times per week for a total of 433.8 minutes of activity per week. This does not meet the physical activity recommendations set out by Health Canada of 630 minutes of activity per week

(Public Health Agency of Canada, 2002). However, less than half of all children in Canada participate in the recommended physical activity levels.

JA youth report mild type most frequently, then moderate, and lastly strenuous. To my knowledge, no JA study has differentiated between type of activity (mild, moderate, strenuous), but these PA results are consistent with other studies utilizing the GLTEQ (Keats, Courneya, Danielsen, & Whitselt, 1999; Falk et al., 2000). While the current sample also report being involved in a variety of organized sport activities, most common being volleyball, basketball, and skating/hockey, more than half report their illness has been a barrier to their participation in physical activities. This is unique to this population and deserves further examination in future work.

Initial results, although primarily descriptive, predominantly support the hypotheses. Specifically, support was found for the hypothesis that there would be a positive correlation between physical activity and self-concept and self-efficacy, as children who participated in more physical activity scored higher on measures of both self-concept and self-efficacy. A statistically significant positive correlation was found between participation in physical activity, as defined by the leisure score index (LSI), and both physical self-concept scores and confidence to engage in physical activity (CTEPA). However, analyses examining group differences using LSI scores found a correlation only between PA and CTEPA scores in the low physical activity group (LPAG). The difference between the means of the high physical activity group (HPAG) and the LPAG were statistically significant for both physical self concept and CTEPA (self-efficacy) measures, in the expected direction. In other words, both the self-concept and self-

efficacy means were higher in the more active children than the less active children, generating support for our hypotheses.

While there is no JA literature examining PA's relationship to physical self-concept or physical self-efficacy, our results correspond with Trost and colleagues' (2002) findings that self-efficacy perceptions were correlated with intention to be active, which was in turn related to activity. In addition, other researchers have found greater amounts of activity are associated with greater self-efficacy perceptions (Allison et al., 1999; Struass et al., 2001) and that enhancing self-efficacy results in adolescents' increasing their physical activity (Dishman et al., 2004).

Support was also found for the hypothesis that there would be a positive correlation between physical activity and self-esteem, as children who engaged in more physical activity scored higher in global self-esteem. Specifically, there was a positive correlation between physical activity, as defined by LSI, and global self-esteem scores. When PA groups were examined, a significant correlation between activity level and global self-esteem was observed in the LPAG, but not with the HPAG. Although the differences between HPAG and LPAG on self-esteem were in the expected direction, it failed to reach significance. Scores for both groups were 4.95 (LPAG) and 5.39 (HPAG) on the 1-6 scale, indicating a fairly high level of self-esteem. As with self-efficacy, there is no literature specifically involving children with JA that examines the relationship between self-esteem and PA. However, the results are supported by previous research that indicates PA is positively associated with self-esteem in children and adolescents (Boyd & Hrycaiko, 1997; Brettschneider, 1999; Calfas & Taylor, 1994; Dekel et al., 1996).

There was no support for the third hypothesis that a positive correlation exists between physical activity and HRQL in children with JA, and that children participating in more physical activity would experience higher scores on HRQL. However, when groups were examined, a significant positive correlation in the LPAG between PA and global HRQL as well as disease specific HRQL was found. A trend was also evident in the HPAG between PA and both measures of HRQL. Differences between groups on HRQL (global or disease specific) failed to reach significance, even though the scores were in the expected direction. Scores for both groups were at 66.77 (LPAG) and 76.09 (HPAG) on the 1-100 scale, indicating a fairly high level of HRQL. A plausible explanation for the lack of significant differences between groups centres on the small sample size. With a larger sample and therefore more power to detect differences, the observed differences between groups might have been sufficient to reach statistical significance.

Although disappointing, findings that PA was not associated with HRQL were not entirely surprising. Takken and colleagues' PA interventions examining HRQL simply found statistical trends towards improved HRQL following completion of a controlled activity intervention. Specifically, out of two studies investigating quality of life, and a third examining functional ability, only one study by these researchers found statistically significant relationship with any dimension of HRQL (functional ability; Takken et al., 2001; Takken et al., 2003a; Takken et al., 2003b).

The present findings, however, are different from research that has found a positive correlation between PA and HRQL in the general child and youth literature

(Berger & Motl, 2001). Differences in methodology, and in particular, sample size, may be partially responsible for the discrepant findings.

Support was discovered for the fourth hypothesis that there would be a positive correlation between participating in physical activity and scores on social functioning, as children who participated in more physical activity scored higher on social functioning. There was a statistically significant positive correlation between these variables. Notably, when groups based on activity level were examined, a significant positive correlation was observed in the LPAG between PA and social functioning, while no correlation between PA and social functioning existed in the HPAG. Although differences were in the expected direction, no statistically significant differences were found between group means. To date, the relationship between social functioning and physical activity in children remains unclear in the literature (Brettschneider, 2001; Saunders et al., 2000). However, our results appear to substantiate the section of this literature that espouses a positive correlation between healthy social relationships and physical activity (Field et al., 2001).

Finally, mixed support was obtained for the last hypothesis that there would be a negative correlation between physical activity participation and scores on functional disability and pain, children who participated in more physical activity scored lower on measures of functional disability and perceived pain. While there were no statistically significant correlations between PA and either functional disability or pain, upon further group analysis, statistically significant results were demonstrated. Specifically, within the LPAG there was a negative correlation between functional disability and PA, and pain and PA. In other words, less PA was associated with greater functional disability and

perceptions of pain. These results are consistent with previous literature that has demonstrated a relationship between perception of pain and physical activity. Klepper's pilot physical activity intervention found that after the 8-week physical activity intervention, there was a statistically significant reduction in reported pain and disease severity (1999). However, other research has found no such link. Specifically, after completion of a PA intervention, Takken (2001) found no change in reports of pain. Future research must continue to examine this relationship between physical activity and pain.

4.1 The Role of PA Level and Amount

Analysis of high and low physical activity groups uncovered interesting relationships. In the LPAG (n = 14), lower PA participation was significantly associated with lower scores on physical self-concept, CTEPA, global self-esteem, social functioning, HRQL, disease specific HRQL, and higher scores on functional disability and perceived pain. However participants in the HPAG (n = 13) did not demonstrate an equivalent corresponding relationship. Specifically, higher PA participation was not associated with significantly higher scores on any of the psychosocial variables or a significant reduction in functional disability or perceived pain. Plausible explanations for these findings include: a) the possibility of a ceiling effect, or b) the statistical power, due to the small sample size, was insufficient in detecting an existing relationship.

Interestingly, the level of physical activity engaged in, be it mild, moderate, or strenuous, influenced the expression of various psychosocial variables. Specifically, there were correlations between frequency of strenuous activity engaged in per week and scores of physical self-concept, CTEPA, and global self-esteem, while the frequency of

moderate PA was positively correlated with physical self-concept and CTEPA. Additionally, a trend was observed between strenuous activity frequency and social functioning and between moderate frequency of PA and global self-esteem, global HRQL, and disease specific HRQL. A negative trend between strenuous PA and functional disability was also observed.

Perhaps most importantly, there were no significant associations with the frequency of mild activity participation, except with CTEPA. This is especially important, as mild PA was the most reported (frequency and duration in the past week) level of PA, while strenuous PA was the least reported (both frequency and duration in the past week). Yet the literature clearly illustrate less benefits associated with mild, or lower levels of PA. Specifically, moderate to vigorous physical activity has demonstrated a relationship with self-efficacy whereas mild has not (Allison et al., 1999; Ryan, & Dzewaltowski, 2002; Strauss et al., 2001; Trost et al., 2002). The relationship between level of PA and other psychosocial indices, including HRQL, deserves further examination.

4.2 Model – Utility for Future Research

Although testing the Exercise Self-Esteem Model (ESEM) model was not a focus of the present investigation, following Baranowski et al.'s (1992) suggestion that physical activity research, even if descriptive, be based on a model, the ESEM provided the framework on which to choose the variables. According to Sonstroem and Morgan's ESEM (1989), enhancing physical self-efficacy will result in increasing self-esteem. This relationship paradigm is mediated by increases in physical competence and in physical acceptance. While the ESEM is founded on the premise of a physical activity intervention, this preliminary examination of the relationship between variables suggests

that PA is associated with the expression of physical self-concept, physical self-efficacy, and global self-esteem, as predicted by the model. In this investigation, a significant positive relationship between physical self-efficacy and self-esteem was found. Furthermore physical competency, as measured with the sports competence scale of the PSDQ, was significantly related to self-efficacy, self-esteem and to physical acceptance (as measured with body fat and physical appearance scales of PSDQ). In addition, there were significant correlations between physical acceptance (body fat & physical appearance) and self-esteem.

4.3 Limitations

Several limitations of this study restrict the generalizability and confidence in its findings. The first is the small sample size of 42 children. This is an unavoidable limitation of working with a small specialized population of children. However, it is in line with, and in some cases, is larger than, previous work (Klepper, 1999; Takken et al., 2003a; Takken et al., 2003b). While the small sample size prevented the application of certain analytic techniques and diminished statistical power for detecting significant results, the fact statistically significance results were obtained lends credence to the existence of the observed relationships. For statistical significance to be observed under these study conditions implies a large degree of strength in the relationships.

Second, this is a retrospective self-report examination of PA levels that required individuals as young as 12 years to recall their frequency, duration, and activities they participated in before being diagnosed with JA. From the demographic data, we know that participants were diagnosed between 1991 and 2004, leaving room for memory problems in the recall of information and thus potentially inaccurate reports. In addition,

some participants were too young to classify themselves as engaging in mild, moderate, and strenuous activity. This was exemplified by the difference in sample size of those individuals who answered before diagnosis (n = 34) and those reporting activity in the past week (n = 41), as well as by comments provided by the participants that they were "too young to remember". Furthermore, there remains the possibility of a social desirability bias in the over-reporting of PA. However, other sources utilizing this measure with children found similar results (Keats et al., 1999).

The one-time cross-sectional nature of this survey methodology provides only a "snapshot" examination of this population. However, while correlational in design and thereby eliminating the ability to attribute causation, this study was the first attempt to investigate psychosocial variables other than HRQL with respect to PA in this understudied population of juvenile arthritis. Thus, it provides an important initial point from which further, more experimentally controlled research, may continue to examine these relationships.

Finally, there are issues with the self-efficacy measurement tools utilized. Specifically, physical self-efficacy was assessed using a researcher created measure which assessed the confidence to engage in physical activity, confidence to engage in mild, moderate, and strenuous physical activity, and confidence to engage in the different types of physical activity (mild, moderate, strenusous) for one and two times per week. Thus this was not a standardized psychometrically derived measure. However,

One note of special interest for researchers working with special clinical populations is that our response rate from patients of the doctor most closely involved in the study was 74%. However, the response rate from children under the care of the other

clinic doctors varied between 25 and 52%, for an overall participant response rate of 56%. This may be indictive of a strong social desirability bias or it may indicate the promising potential of liaising with or fostering a close research relationship with medical professionals in future academic research. No responses were obtained via the national website posting on the Arthritis Society website.

4.4 Conclusion and Future Directions

Strenuous PA emerges as essential to an individual's physical self-concept, confidence to engage in physical activity, and global self-esteem, more so than mild or moderate PA. However, one of the issues that remains to be addressed with this population is to determine the role of frequency, type, and duration of physical activity in promoting psychosocial well-being for juvenile arthritis patients. Although preliminary, it would appear that clinicians and health professionals involved in the treatment of youth with JA ought to stress the importance of participation in moderate and strenuous activities, rather than just in being 'physically active'. If fostering improved psychological well-being, in particular physical self-concept, physical self-efficacy, self-esteem, and social functioning in children and adolescents with JA is a priority, then behavioural programming to supplement current physical activity shows immense promise.

In conclusion, this study provides a strong first step for continuing to examine PA in the population of children who suffer from JA. It provides evidence of the existence of a relationship between self-concept, self-efficacy, self-esteem, and physical activity. The precise nature of this relationship remains to be decided with future prospective experimentally controlled studies. While not the central focus of the present work, future

work utilizing Sonstroem's Exercise and Self-Esteem Model (1989) in an intervention setting would add to the literature and aid in the exploration of the importance of self-efficacy and self-esteem for this population of children with JA. HRQL should continue to be studied in JA, but there is a great need to look beyond this dimension and explore other psychosocial variables such identity, intimacy, emotional isolation, stress, coping skills along with body image and so forth, which also influence these children's lives.

References

Ajzen, I. (1991). The theory of planned behaviour. *Organizational Behavior and Human Decision Processes, 50*, 179-211.

Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behaviour.* New Jersey: Prentice Hall.

Akikusa, J.D., & Allen, R.C. (2002). Reducing the impact of rheumatic diseases in childhood. *Best Practice & Research Clinical Rheumatology, 16*(3), 333-345.

Allison, K.R., Dwyer, J.J.M., & Makin, S. (1999). Self-efficacy and participation in vigorous physical activity by high school students. *Health Education and Behavior, 26*(1), 12-24.

Bacon, M.C., Nicholson, C., Binder, H., & White, P.H. (1991). Aquatic exercise and lower-extremity function. *Arthritis Care and Research, 4(*2), 102-105.

Bailey, D.A. (1997). The Saskatchewan Pediatric Bone Mineral Accrual Study: bone mineral acquisition during the growing years. *International Journal of Sports Medicine, 18* (suppl.), S191-S194.

Bailey, D.A., & Martin, A.D. (1994). Physical activity and skeletal health in adolescents. *Pediatric Exercise Science, 6*, 330-347.

Bandura, A. (1997). *Self-efficacy: The exercise of control.* New York: W.H. Freeman.

Bandura, A. (1986). *Social Foundations of thought and action.* New York: Prentice-Hall.

Baranowski, T. et al.(1992). Assessment, prevalence, and cardiovascular benefits of physical activity and fitness in youth. *Medicine and Science in Sports and Exercise, 24*, S237-S247.

Berger, B., & Motl, R. (2001). Physical activity and Quality of Life. *Handbook of Sport Psychology.* New York, NY: Wiley.

Biddle, S.J.H., & Mutrie, N. (2001). *Psychology of Physical Activity: Determinants, Well-being, and Interventions*. Routledge: London.

Biddle, S.J.H., Gorely, T., & Stensel, D.J.(2004). Health-enhancing physical activity and sedentary behaviour in children and adolescents. *Journal of Sports Sciences, 22,* 679-701.

Brace, M., Smith, M.S., McCauley, E., & Sherry, D.D. (2000). Family reinforcement of illness behavior: a comparison of adolescents with chronic fatigue syndrome, juvenile arthritis, and healthy controls. *Developmental and Behavioral Pediatrics, 21*(5), 332-339.

Boreham, C., & Riddoch, C. (2001). The physical activity, fitness and health of children. *Journal of Sports Sciences, 19*, 915-929.

Boreham, C., Twisk, J., Neville, C., et al. (2002). Associations between physical fitness and activity patterns during adolescence and cardiovascular risk factors in young adulthood: the Northern Ireland Young Hearts Project. *International Journal of Sports Medicine, 23* (suppl.), S22-S26.

Boyd, K.R., & Hrycaiko, D.W. (1997). The effect of a physical activity intervention package on the self-esteem of pre-adolescent and adolescent females. *Adolescence, 32*(127), 1-9.

Brettschneider, W.D. (1999). Psychological outcomes and social benefits of sport involvement and physical activity implications for physical education. *International Council of Sport Science and Physical Education,* 77-84.

Brosnahan, J., Steffen, L.M., Lytle, L., Patterson, J., & Boostrom, A. (2004). The relation between physical activity and mental health among Hispanic and non-Hispanic white adolescents. *Archives of Pediatric and Adolescent Medicine, 158,* 818-823.

Brostrom, E., Nordlund, M.M., & Cresswell, A.G. (2004). Plantar- and dorsiflexor strength in prepubertal girls with juvenile idiopathic arthritis. *Archives of Physical and Medical Rehabilitation, 85,* 1224-1230.

Brown, J.D. *The Self.* Boston: McGraw-Hill.

Brown, S.W., Welsh, M.C., Labbe, E.E., Vitulli, W.F., & Kulkarni, P. (1992). Aerobic exercise in the psychological treatment of adolescents. *Perceptual and Motor Skills, 74,* 555-560.

Bullinger, M., Petersen, C., Schmidt, S., Baars, R.M., & the DISABKIDS Group. (2002). *Quality of Life Newsletter, 29,* 5-6.

Calfas, K.J., & Taylor, W.C. (1994). Effects of physical activity on psychological variables in adolescents. *Pediatric Exercise Science, 6,* 406-423.

Chohan, N., Doyle, R.M., & Nale, P. (Eds.). (2001). *21st edition: nursing 2001 drug handbook.* Springhouse: PY: Springhouse Corp.

Cooper, D.M., Nemet, D., & Galassetti, P. (2004). Exercise, stress, and inflammation in the growing child: from the bench to the playground. *Current Opinion in Pediatrics, 16,* 286-292.

Cotton, D.H.G. (1990). *Stress Management: Integrated Approach.* New York: NY

Courneya, K.S., Friedenreich, C.M., Sela, R., Quinney, H.A., & Rhodes, R.E. (2002). Correlates of adherence and contamination in a randomized controlled trial of exercise in cancer survivors. *Annals of Behavioral Medicine, 24,* S049.

Covey, L.A., & Feltz, D.L. (1991). Physical activity and adolescent female psychological development. *Journal of Youth and Adolescence, 20*(4), 463-474.

Crews, D.J., & Landers, D.M. (1987). A meta-analytic review of aerobic fitness and reactivity to psychosocial stressors. *Medicine and Science in Sports and Exercise, 19,* S114-S120.

Daltroy, L.H., Larson, M.G., Eaton, H.M., Partridge, A.J., Pless, I.B., Rogers, M.P., & Liang, M.H. (1992). Psychosocial adjustment in juvenile arthritis. *Journal of Pediatric Psychology, 17*(3), 277-289.

Dekel, Y., Tenenbaum, G., & Kudar, K. (1996). An exploratory study on the relationship between postural deformities and body-image and self-esteem in adolescents: the mediating role of physical activity. *International Journal of Sport Psychology, 27*, 183-196.

Diener, E., (2000). Subjective well-being: the science of happiness, and a proposal for a national Index. American Psychologist, 55, 34-43.

DiLorenzo, T.M., Bargman, E.P., Stucky-Ropp, R., Brassington, G.S., Frensch, P.A., & LaFontaine, T. (1999). Long-term effects of aerobic exercise on psychological outcomes. *Preventive Medicine, 28*, 75-85.

Dishman, R.K., Motl, R.W., Saunders, R., Felton, G., Ward, D.S., Dowda, M., et al. (2005). Enjoyment mediates effects of a school-based physical-activity intervention. Enjoyment mediates effects of a school-based physical-activity intervention. Medicine and Science in Sports and Exercise, 37(3),478-87.

Duffy, C.M., Arsenault, L., Duffy, K., Paquin, J.D., & Strawczynski, H. (1997). The Juvenile Arthritis Quality of Life Questionnaire – development of a new responsive index for juvenile rheumatoid arthritis and juvenile spondyloarthritides. *The Journal of Rheumatology, 24*(4), 738-746.

Duffy C., & Lovell D. (2001). Assessment of Health Status, Function, and Outcome. In *Textbook of Pediatric Rheumatology* (pp. 178-187). J.T.P. Cassidy and E. Ross, (Eds.). New York: NY: W.B. Saunders Company.

Eppright, T.D., Sanfacon, J.A., Beck, N.C., & Bradley, J.S. (1997). Sport psychiatry in childhood and adolescence: an overview. *Child Psychiatry and Human Development, 28*(2), 71-88.

Falk, B., Portal, S, Tiktinsky, R, Weinstein, Y, Constantini, N, & Martinowitz, U.R.I. (2000). Anaerobic power and muscle strength in young hemophilia patients. Medicine and Science in Sports and Exercise, 32(1), 52-57.

Felz, D. (1984). Self-efficacy as a cognitive mediator of athletic performance. In *Cognitive Sport Psychology.* Straub, W.F. & Williams, J.M (Eds.). Lansing, NY: Sport Science Associates.

Ferron, C., Narring, F., Cauderay, M., & Michaud, P.A. (1999). Sport activity in adolescence: associations with health perceptions and experimental behaviours. *Health Education Research, 14*(2), 225-233.

Field, T., Diego, M., & Sanders, C. (2001). Adolescent depression and risk factors. *Adolescence, 36*(143), 491-498.

Godin, D.R., Anisworth, B.W., Hartman, T.J., & Leon, A.S. (1993). A simultaneous evaluation of 10 commonly used physical activity questionnaires. *Medicine and Science in Sports and Exercise, 25*, 81-91.

Godin, G., & Shepard, R.J. (1986). Psychosocial factors influencing intentions to exercise of young students from grades 7 to 9. *Research Quarterly, 57*(1), 41-52.

Godin, G., & Shephard, R. J. (1985). A simple method to assess exercise behavior in the community. *Canadian Journal of Applied Sport Sciences, 10,* 141–146.

Godin, G., Jobin, J., & Bouillon, J. (1986). Assessment of leisure time exercise behavior

by self-report: a concurrent validity study. *Canadian Journal of Public Health. Revue Canadienne de Sante Publique. 77(5),* 359-62.

Hagger, M.S., Chatzisarantis, L.D., & Biddle, S.J. (2002). The influence of autonomous and controlling motives on physical activity intentions within the Theory of Planned Behaviour. *British Journal of Health Psychology, 7*, 283-297.

Hagger, M.S., Chatzisarantis, L.D., Biddle, S.J., & Orbell, S. (2001). Antecedents of children's physical activity intentions and behaviour: predictive validity and longitudinal effects. *Psychology and Health, 16*, 391-407.

Harkcom, T.M., Lampman, R.M., Branwell, B.F., & Castor, C.W. (1985). The therapeutic value of graded aerobic exercise training in rheumatoid arthritis. *Arthritis and Rheumatology, 28,* 32-39.

Hartup, W.W., & Stevens, N. (1999). *Friendships and adaptation across the life span.* Blackwell Publishers: Minneapolis, MN.

Henderson, C.J., Specker, B.L., Sierra, R.I., Campaigne, B.N., & Lovell, D.J. (2000). Total-body bone mineral content in non-corticosteroid-treated postpubertal females with juvenile rheumatoid arthritis. *Arthritis & Rheumatism, 43*(3), 531-540.

Holloway, J.B., Beuter, A., & Duda, J.L. (1988). Self-efficacy and training for strength in adolescent girls. *Journal of Applied Social Psychology, 18*(8), 699-719.

House, J.S., Landis, K.R., & Umberson, D. (1988). Social relationships and health. *Science, 241*, 531-537.Huskisson, E. (1993). Visual analogue scales. In: Melzack R, editor. *Pain measurement and assessment.* New York: Raven.

Huang, M.H., Lin, Y.S., Yang, R.C., Lee, C.L. (2003). A comparison of various

therapeutic exercises on the functional status of patients with knee osteoarthritis. *Seminars in Arthritis and Rheumatism, 32*: 398-406.

Huskisson, E.C. (1983). Measurement of Pain. *Journal of Rheumatology*, 768-769.

Janssens, J. M., & Dekovic, M. (1997). Child rearing, prosocial moral reasoning, and prosocial behaviour. *International Journal of Behavioural Development, 20*, 509-527.

Janz, K.F., Dawson, J.D., & Mahoney, L.T. (2002). Increases in physical fitness during childhood improve cardiovascular health during adolescence: the Muscatine Study. *International Journal of Sports Medicine, 23(suppl.),* S534-S541.

Jacobs, D.R., Ainsworth, B.E., Hartman, T.J., & Leon, A.S. (1993). A simultaneous evaluation of 10 commonly used physical activity questionnaires. *Medicine & Science in Sports and Exercise, 25*, 81-91.

Keats, M.R., Courneya, K.S., Danielsen, S., & Whitsett, S.F. (1999). Leisure-time physical activity and psychosocial well-being in adolescents after cancer diagnosis. *Journal of Pediatric Oncology of Nursing, 16(*4):180-188.

Kirkcaldy, B.D., Shephard, R.J., & Siefen, R.G. (2002). The relationship between physical activity and self-image and problem behaviour among adolescents. *Social Psychiatry & Psychiatric Epidemiology, 37*, 544-550.

Klepper, S.E. (1999). Effects of an eight-week physical conditioning program on disease signs and symptoms in children with chronic arthritis. *Arthritis Care & Research, 12*(1), 52-40.

Klepper, S.E. (2003). Exercise and fitness in children with arthritis: evidence of benefits for exercise and physical activity. *Arthritis & Rheumatism, 49*(3), 435-443.

Klein-Platat, C., Oujaa, M., Wagner, A., Haan, M.C., Arveiler, D., Schlienger, J.L., & Simon, C.

(2005). Physical activity is inversely related to waist circumference in 12-y-old French a adolescents. *International Journal of Obesity, 29,*9-14.

Kohl III, H.W., & Hobbs, K.E. (1998). Development of physical activity behaviors among children and adolescents. *Pediatrics, 101*(3), 549-555.

Konkol, L., Lineberry, J., Gottlieb, J., Shelby, P.E., Miller III, J.J., & Lorig, K. (1989). Impact of juvenile arthritis on families: an educational assessment. *Arthritis Care & Research, 2*(2), 40-49.

Labyak, S.E., Bourguignon, C., & Docherty, S. (2003). Sleep quality in children with juvenile rheumatoid arthritis. *Holistic Nursing Practice, 17(4),* 193-200.

Laxer, R.M.(Ed.). (1998). *You, your child, and Arthritis 3rd Ed.* The Arthritis Society.

LeBovidge, J.S., Lavigne, J.V., Donenberg, G.R., & Miller, M.L. (2003). Psychological adjustment of children and adolescents with chronic arthritis: a meta-analytic review. *Journal of Pediatric Psychology, 28*, (1), 29-39

Lefevre, J., Philippaerts, R., Delvaux, K. et al. (2002). Relation between cardiovascular disease risk factors at adult age, and physical activity during youth and adulthood: the Leuven Longitudinal Study on Lifestyle, Fitness and Health. *International Journal of Sports Medicine, 23* (suppl.), S32-S38.

Lee, R.L., Nigg, G.R., DiClemente, C.C., & Courneya, K.S. (2001). Validating motivational readiness for exercise behavior with adolescents. *Research Quarterly for Exercise and Sport, 72*(4), 401-410.

Lindehammar, H., & Backman, E. (1995). Muscle function in juvenile chronic arthritis. *Journal of Rheumatology, 26*(6), 1159-1165

Maddux, J.E. (1993). Social cognitive models of health and exercise behavior: an

introduction and review of conceptual issues. *Journal of Applied Sport Psychology, 5*, 116-140.

Malina, R.M. (2001). Physical activity and fitness: pathways from childhood to adulthood. *American Journal of Human Biology, 13*, 162-172.

Marsh, H.W. (1996). Physical Self Description Questionnaire: stability and discriminant validity. *Research Quarterly for Exercise and Sport, 67*(3). 249-264.

Marshall, S.J., & Biddle, S.J.H. (2001). The Transtheoretical Model of Behavioural Change: a meta-analysis of applications to physical activity and exercise. *Annual Behavior Medicine, 23*(4), 229-246.

Matza, L., Swensen, A.R., Flood, E.M., Secnik, K., & Leidy, N.K. (2004). Assessment of health related quality of life in children: a review of conceptual, methodological, and regulatory issues. *Value in Health, 7*(1), 79-92.

McDonagh, J.E. (2001). Osteoporosis in juvenile idiopathic arthritis. *Current Opinion in Rheumatology, 13,* 399-404.

McGill, H.C., McMahan, A., Herderick, E.E. et al. (2000). Origin of arteriosclerosis in childhood and adolescence. *American Journal of Clinical Nutrition, 72* (suppl.), 1307S-1315S.

Meijer, S.A., Sinnema, G., Bijstra, J.O., Mellenbergh, G.J., & Wolters, W.H.G. (2000). Peer interaction in adolescents with a chronic illness. *Personality and Individual Differences, 29*, 799-813.

Miller, M.L, Kress, A.M., & Berry, C.A. (1999). Decreased physical functioning in juvenile rheumatoid arthritis. *Arthritis Care & Research, 12*(5), 309-313.

Mummery, W.K., Spence, J.C., & Hudec, J.C. (2000). Understanding physical activity

intention in Canadian school children and youth: an application of the Theory of Planned Behavior. *Research Quarterly for Exercise and Sport, 71*(2), 116-124.

Murray, K.J., & Lovell, D.J. (2002). Advanced therapy for juvenile arthritis. *Best Practice & Research Clinical Rheumatology, 16*(3), 361-378.

Nigg, G.R., & Courneya, K.S. (1998). Transtheoretical Model: examining adolescent exercise behaviour. *Journal of Adolescent Health, 22*, 214-224.

Nicklas, T.A., von Duvillard, S.P., & Berenson, G.S. (2002). Tracking of serum lipids and lipoproteins from childhood to dyslipidemia in adults: the Bogalusa Heart Study. *International Journal of Sports Medicine, 23*(suppl.), S39-S43.

Noll, R.B., Kozlowski, K., Gerhardt, C., Vannatta, K., Taylor, J., & Passo, M. (2000). Social, emotional, and behavioral functioning of children with juvenile rheumatoid arthritis. *Arthritis & Rheumatism, 43*(6), 1387-1396.

Norris, R., Carroll, D., & Cochrane, R. (1992). The effects of physical activity and exercise training on psychological stress and well-being in an adolescent population. *Journal of Psychosomatic Research, 36*(1), 55-65.

Oberg, T., Karsznia, B., Andersson, G., & Lagerstrand, A. (1994). Physical training of children with juvenile chronic arthritis. *Scandinavian Journal of Rheumatology, 23*, 92-95.

Ohki, Y., Kishi, M., Orimo, H., & Ohkawa, T. (2004). The factors affecting glycemic control in Japanese adolescents with type 2 diabetes mellitus. *Journal of Nippon Medical School, 71(3),* 156-159.

Page, R.M, & Tucker, L.A. (1994). Psychosocial discomfort and exercise frequency: an epidemiological study of adolescents. *Adolescence, 29*(113), 183-192.

Passer, M.W., & Smith, R.E. (2001). *Psychology: Frontiers and Applications.* New York, NY:

McGraw Hill.

Pender, N.J. (1998). Motivation for physical activity among children and adolescents. *Annual Review of Nursing Research, 16*, 139-172.

Prochaska, J.O., & DiClemente, C.C. (1984). *Changing for good.* New York: Avon.

Prochaska, J.O., DiClemente, C.C., & Norcross, J.C. (1992). In search of how people change: Applications to addictive behaviors. *American Psychologist, 47*, 1102-1114.

Reiter-Purtill, J., Gerhardt, C.A., Vannatta, K., Passo, M.H., & Noll, R.B. (2003). A controlled longitudinal study of the social functioning of children with juvenile rheumatoid arthritis. *Journal of Pediatric Psychology, 28*(1), 17-28.

Rejeski, W.J., Brawley, L.R., & Shumaker, S.A. (1996). Physical activity and health-related quality of life. *Exercise and Sport Science Reviews, 24*, 71-108.

Ribeiro, J.C., Guerra, S., Oliveira, J., Teixeira-Pinto, A., Twisk, J.W.R., Duarte, J.A., & Mota, J. (2004a). Physical activity and biological risk factors clustering in pediatric population. *Preventive Medicine, 39,* 569-601.

Ribeiro, J.C., Guerra, S., Oliveira, J., Teixeira-Pinto, A., Twisk, J.W.R., Duarte, J.A., & Mota, J. (2004b). Body fatness and clustering of cardiovascular disease risk factors in Portuguese children and adolescents. *American Journal of Human Biology, 16,* 556-562.

Riddoch, C.J. (1998). Relationships between physical activity and health in young

people. *In Young and active? Young people and health enhancing physical activity: evidence and implications.* Biddle, S., Sallis, J., & Cavill, N. (Eds.). London: Eng: London Health Education Authority.

Rodin, J., & Salovey, P. (1989). Health psychology. *Annual Review of Psychology, 40,* 533-579.

Repcloinsky, C., Welbanks, L., & Bisson, R. (Eds.). (2004). *Compendium of pharmaceuticals & specialties: the Canadian drug reference for health professionals.* Ottawa, ONT: Canadian Pharmacist's Association.

Ross, C.K., Lavigne, J.V., Hayford, J.R., Berry, S.L., Sinacore, J.M., & Pachman, L.M. (1993). Psychological Factors Affecting Reported Pain in Juvenile Rheumatoid Arthritis. *Journal of Pediatric Psychology, 18*(5), 561-573.

Ryckman, R.M., Robbins, M.A., Thornton, B., & Cantrell, P. (1982). Development and validation of a physical self-efficacy scale. *Journal of Personality and Social Psychology,* 42, 891-900.

Sallis, J.F. (1995). A North American perspective on physical activity research in children and adolescents. In C.J.R. Blimkie (Ed.), *New Horizons in Pediatric Exercise Science* (pp. 221-234). Champion, IL.

Sallis, J.F., Buono, M.J., Roby, J.J., Micale, F.G., & Nelson, J. (1993). 7-Day recall and other physical activity self-reports in children and adolescents. *Medicine and Science in Sports and Exercise, 25*(1), 99-108.

Sallis, J.F., & Patrick, K. (1994). Physical activity guidelines for adolescents: consensus statement. *Pediatric Exercise Science, 6,* 302-314.

Sallis, J.F., Patterson, T.L., Buono, M.J., & Nader, P.R. (1988). Relation of cardiovascular fitness

and physical activity to cardiovascular disease risk factors in children and adults. *American Journal of Epidemiology, 127*(5), 933-941.

Sallis, J.F., Prochaska, J.J., & Taylor, W.C. (1999). A review of correlates of physical activity of children and adolescents. *Medicine and Science in Sports and Exercise,* 963-975.

Sandelowshi, M. (2000). Focus on research methods: whatever happened to qualitative description? *Research in Nursing & Health, 23*, 334-340.

Sanders, C.E., Field, T.M., Diego, M., & Kaplan, M. (2000). Moderate involvement in sports is related to lower depression levels among adolescents. *Adolescence, 35*(140), 793-797.

Schanberg, L.E., Anthony, K.K., Gil, K.M., & Maurin, E.C. (2003). Daily pain and symptoms in children with polyarticular arthritis. *Arthritis & Rheumatism, 48*(5), 1390-1397.

Schanberg, LE., Lefebvre, J.C., Keefe, F.J., Kredich, D.W., & Gil, K.M. (1997). Pain coping and the pain experience of children with juvenile chronic arthritis. *Pain, 73,* 181-189.

Schanberg, L.E., Sandstorm, M.J., Starr, K., Gil, K.M., Lefebvre, J.C., Keefe, F.J., Affleck,G., & Tennen, H. (2000). The relationship of daily mood and stressful events to symptoms in juvenile rheumatic disease. *Arthritis Care & Research, 13*(1), 33-41.

Schwarzer, R. (1998). Stress and coping from a social-cognitive perspective. *Annals of the New York Academy of Sciences, 857*, 531-537.

Scott, P.J., Ansell, B.M., & Huskisson, E.C. (1977). Measurement of pain in juvenile chronic polyarthritis. *Annals of the Rheumatic Disease, 36*, 186-187.

Seid, M., Varni, J.W., Rode, C.A., & Katz, E.R. (1999). The pediatric cancer quality of life inventory: a modular approach to measuring health-related quality of life in children with cancer. *International Journal of Cancer. Supplement 12,* 71-76.

Shun-Wai Fan, J., Wessel, J., & Ellsworth, J. (1998). The relationship between strength

and function in females with juvenile rheumatoid arthritis. *The Journal of Rheumatology, 25,* 1399-1405.

Singh, G., Athreya, B.H., Fries, J.F., & Goldsmith, D.P. (1994). Measurement of health status in children with juvenile rheumatoid arthritis. *Arthritis & Rheumatism, 37(12),* 1761-1769.

Sonstroem, R.J., & Morgan, W.P. (1989). Exercise and self-esteem: rationale and model. *Medicine and Science in Sports and Exercise, 21(3), 329-337.*

Sorensen, E.S. (1991). Identification of stress buffers in school-age children. *Journal of Community Health Nursing, 8*(1), 15-24.

Stein, F. (2001). Occupational stress, relaxation therapies, exercise and biofeedback. *Work, 17,* 235-245.

Steinbeck, K.S. (2001). The importance of physical activity in the prevention of overweight and obesity in childhood: a review and opinion. *Obesity Reviews, 2,* 117-130.

Strauss, R.S., Rodzilsky, D., Burack, G., & Colin, M. (2001). Psychosocial correlates of physical activity in healthy children. *Achieves of Pediatric Adolescent Medicine, 155,* 876-902.

Takken, T., Van der Net, J., & Helders, P.J.M. (2003). Relationship between functional ability and physical fitness in juvenile idiopathic arthritis patients. *Scandinavian Journal of Rheumatology, 32,* 174-178.

Takken, T., Van Der Net, J., & Helders, P.J. (2001). Do juvenile idiopathic arthritis patients benefit from an exercise program? A pilot study. *Arthritis Care & Research, 45,* 81-85.

Takken, T., Van Der Net, J., Kuis, W., & Helders, P.J.M. (2003). Aquatic fitness training for children with juvenile idiopathic arthritis. *Rheumatology, 42,* 1408-1414.

Taylor, A.H. (2000). Physical activity, anxiety, and stress. In: *Physical Activity and*

Psychological well-being. S. J. H. Biddle, K. R. Fox, S. H. Boutcher (Eds.). London, UK: Routledge, 10-46.

Telma, R., Yang, X., Laakso, L., & Vukari, J. (1997). Physical activity in childhood and adolescence as predictor of physical activity in young adulthood. *American Journal of Medicine, 13*(4), 317-323.

Tolfrey, K., Jones, A.M., & Campbell, I.G. (2000). The effects of aerobic exercise training on the lipid-lipoprotein profile of children and adolescents. *Sports Medicine, 29*(2), 99-112.

Trost, S.G., Saunders, R., & Ward, D.S. (2002). Determinants of physical activity in middle school children. *American Journal of Health Behaviour, 26*(2), 95-102.

Trost, S.G., Pate, R.R.., Dowda, M., Ward, D.S., Felton, G., & Saunders, R. (2002). Psychosocial correlates of physical activity in White and African-American girls. *Journal of adolescent health, 31*, 226-233.

Trudeau, F., Laurencelle, L., & Shepard, R.J. (2004). Tracking of physical activity from childhood to adulthood. *Medicine & Science in Sports & Exercise, 36*(11), 1937-1943.

Twisk, J.W.R. (2001). Physical activity guidelines for children and adolescents. *Sports Medicine, 31(8), 617-627.*

Ungerer, J.A., Horgan, B., Chaitow, J., & Champion, G.D. (2001). Psychosocial functioning in children and young adults with juvenile arthritis. *Pediatrics, 81*(2), 195-202.

Varni, J.W., Katz, E.R., Seid, M, et al. (1998). The Pediatric Cancer Quality of Life Inventory (PCQL-32): I. Instrument development, descriptive statistics, and cross-informant variance. *Journal of Behavioral Medicine, 21*, 179-204.

Varni, J.W., Seid, M., & Kurtin, P.S. (2001). PedsQL 4.0: reliability and validity of the Pediatric

Quality of Life Inventory Version 4.0 generic core scales in healthy and patient populations. *Medical Care, 39*(8), 800-812.

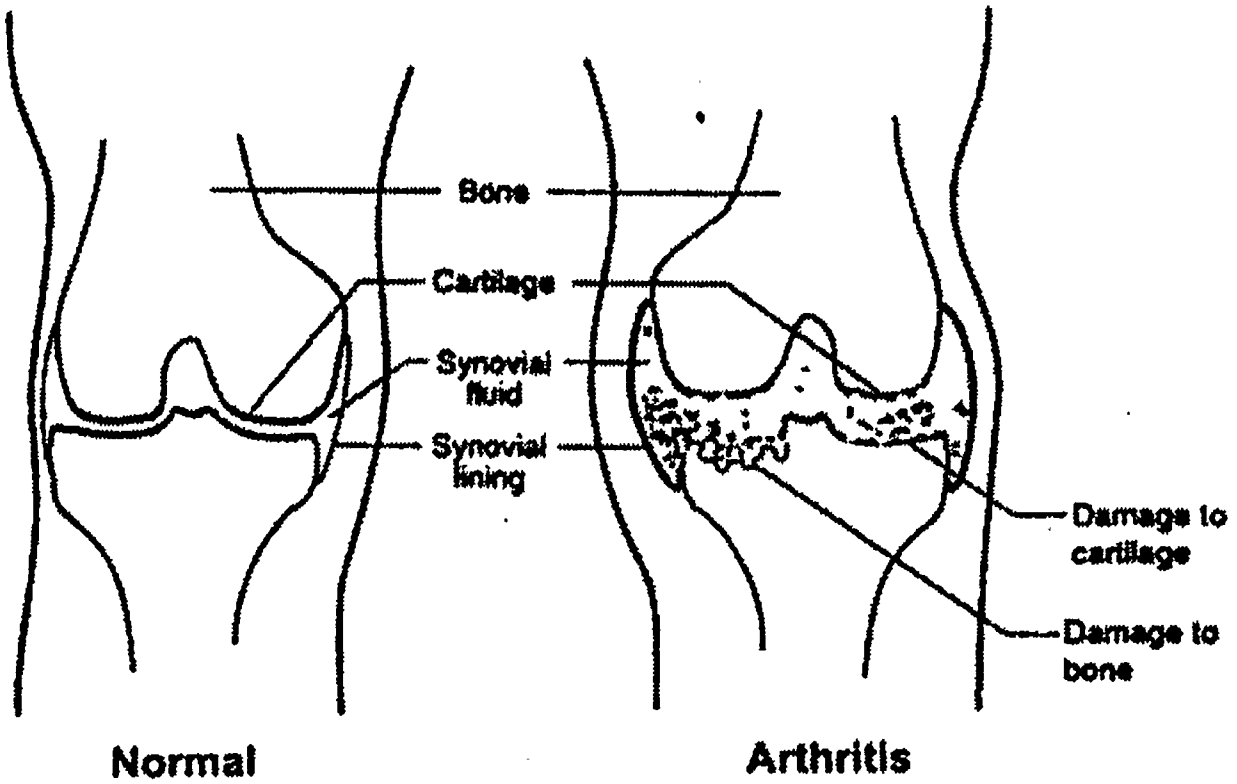
Welk, G.J. (1999). The Youth Physical Activity Promotion Model: a conceptual bridge between theory and practice. *Quest, 51*, 5-23.

Winters, E.R., Petosa, R.L., & Charlton, T.E. (2003). Using social cognitive theory to explain discretionary, "leisure time" physical exercise among high school students. *Journal of Adolescent Health, 32*, 436-442.

Zak, M., & Pedersen, F.K. (2000). Juvenile chronic arthritis into adulthood: a long-term follow up study. *Rheumatology, 39,* 198-204.

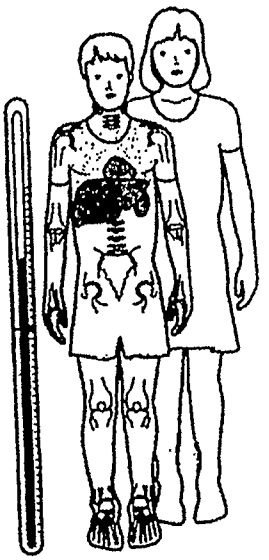
APPENDIX A

DIAGRAM OF ARTHRITIC JOINT (Laxer, 1998)

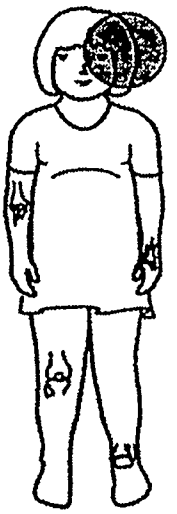


APPENDIX B

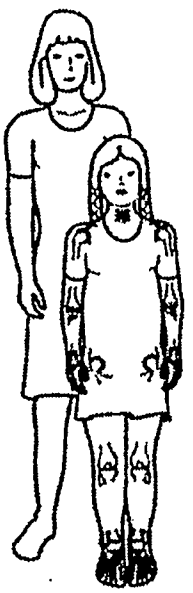
DIAGRAMS OF FORMS OF JUVENILE ARTHRITIS (Laxer, 1998)



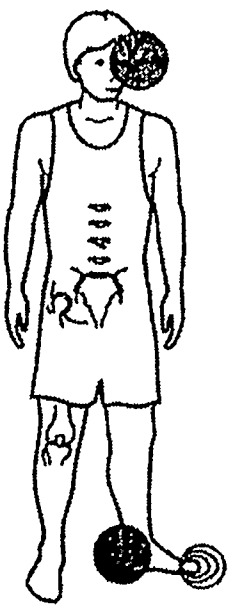
Systemic



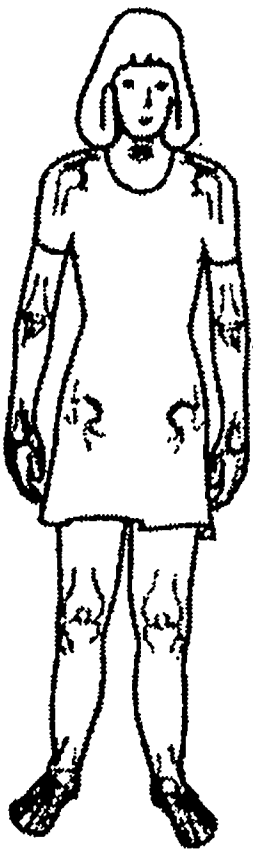
Pauciarticular



Polyarticular



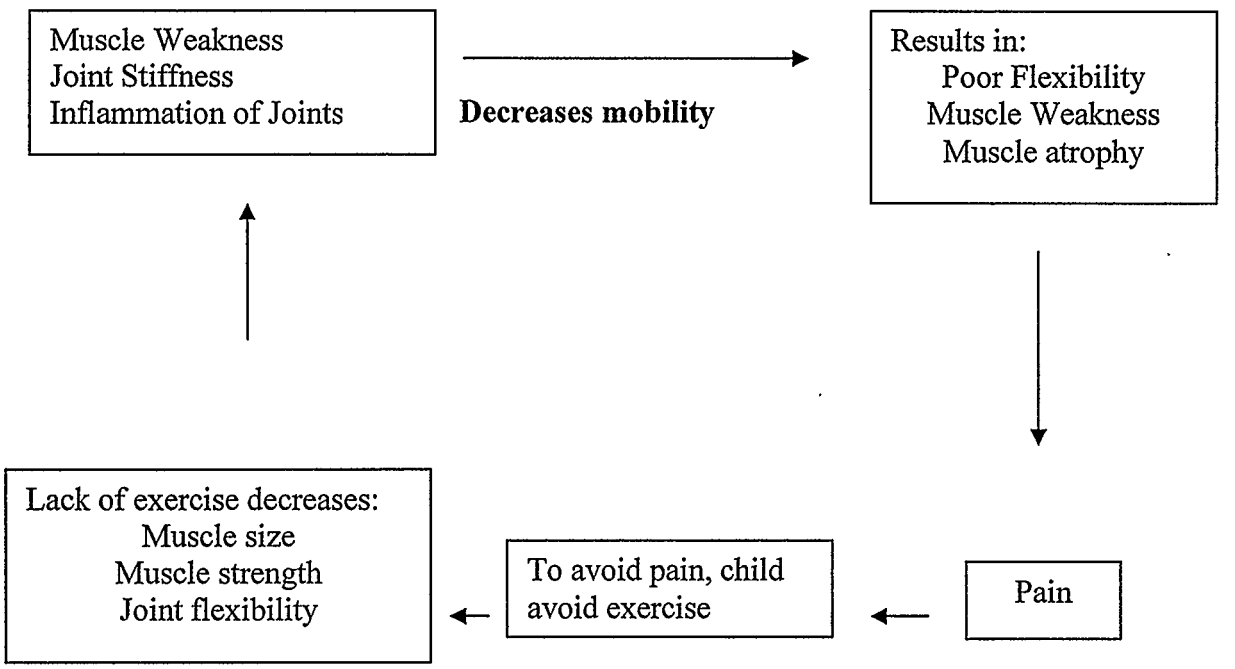
Spondylarthropathia



Adult

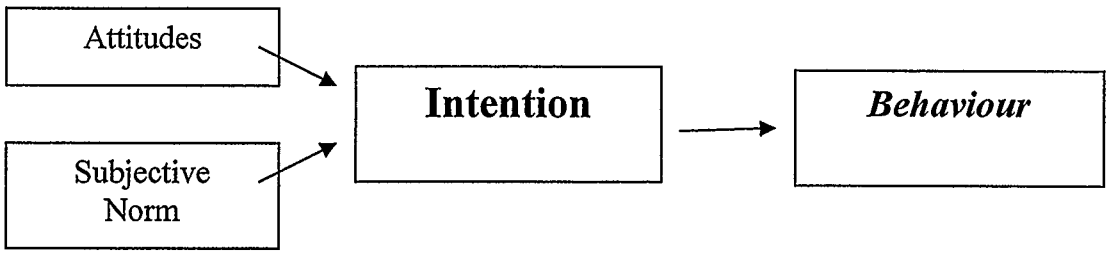
APPENDIX C

CYCLE OF DISUSE

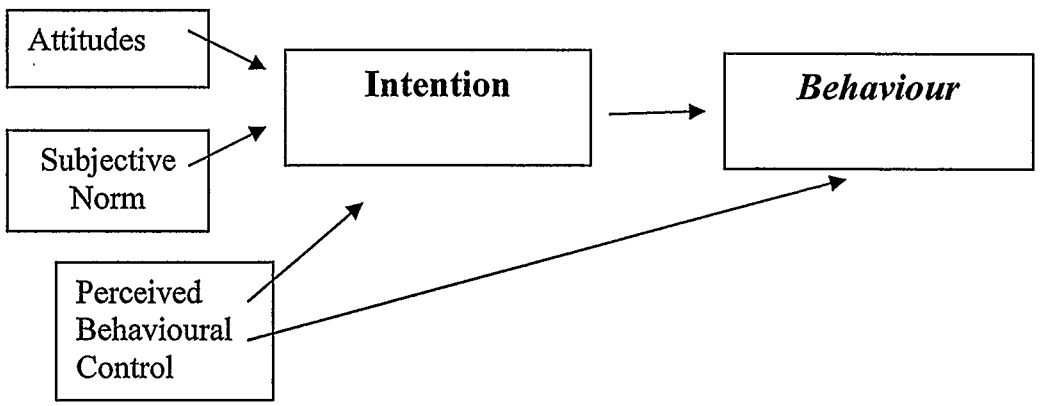


Appendix D

THEORY OF REASONED ACTION (Ajzen,& Fiscbein, 1980):

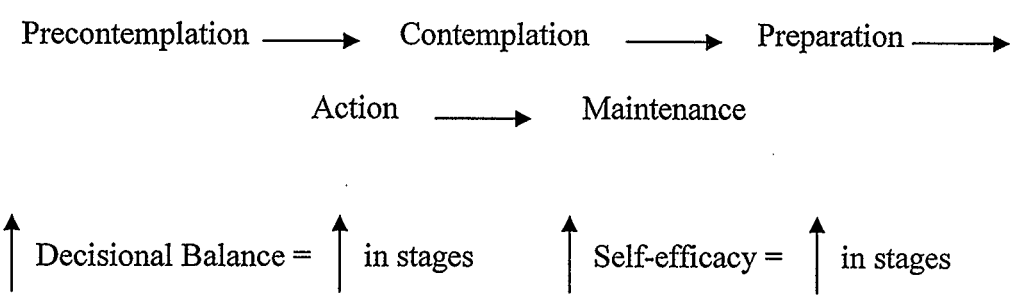


THEORY OF PLANNED BEHAVIOUR (Ajzen, 1991):



Appendix E

THE TRANSTHEORETICAL MODEL (Prochaska, DiClemente, & Norcross, 1992):



STAGES OF CHANGE:

1) *Precontemplation stage* - characterized by an individual's lack of intention to change his or her behaviour to become physically active. He or she does not believe there is any reason to change his or her behaviour and does not intend on being active in the next six months.

2) *Contemplation stage* - individual begins to think about starting to change his or her behaviour, recognizes there is a reason he or she should become physically active, but is not committed to that behaviour change. The individual is planning on becoming active in the next six months.

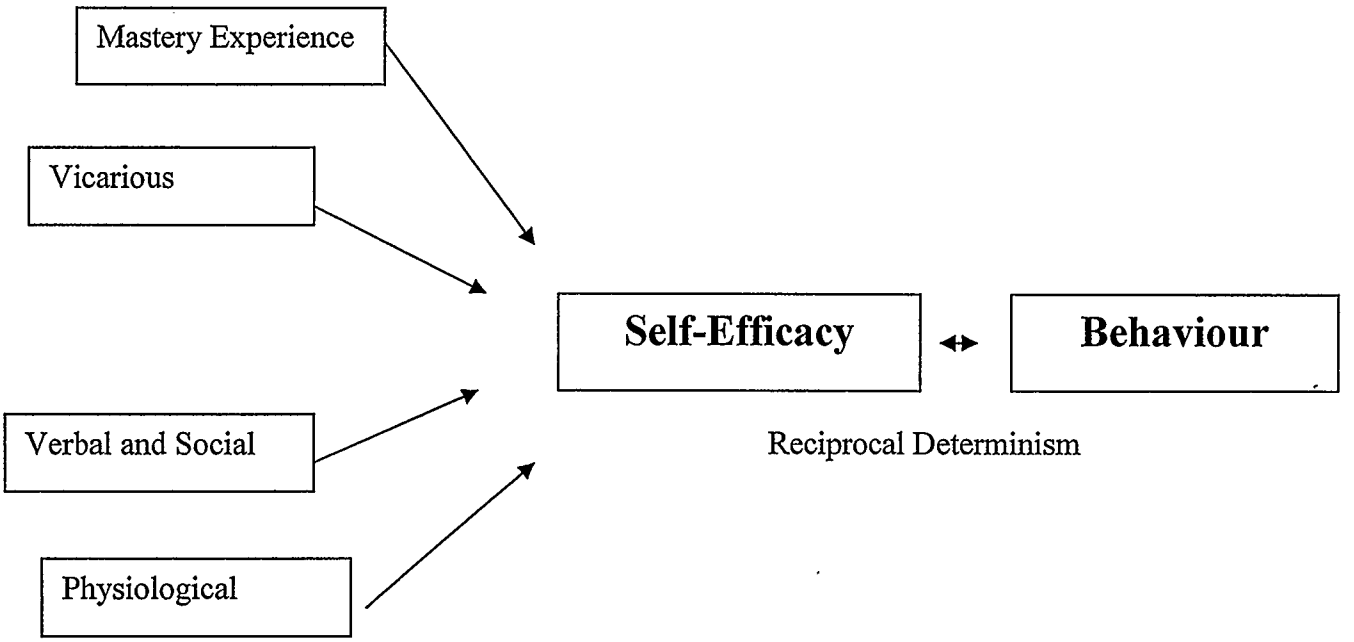
3) *Preparation stage* - one begins to make small changes and one has the intention to continue to make more changes. However, the amount of physical activity would not meet the criterion for being designated physically active, preparing to begin an activity program in the next month.

4) *Action stage* - the individual consciously attempts to alter his or her behaviour. The commitment to be physically active is high. However, has not engaged in the activity program for more than six months.

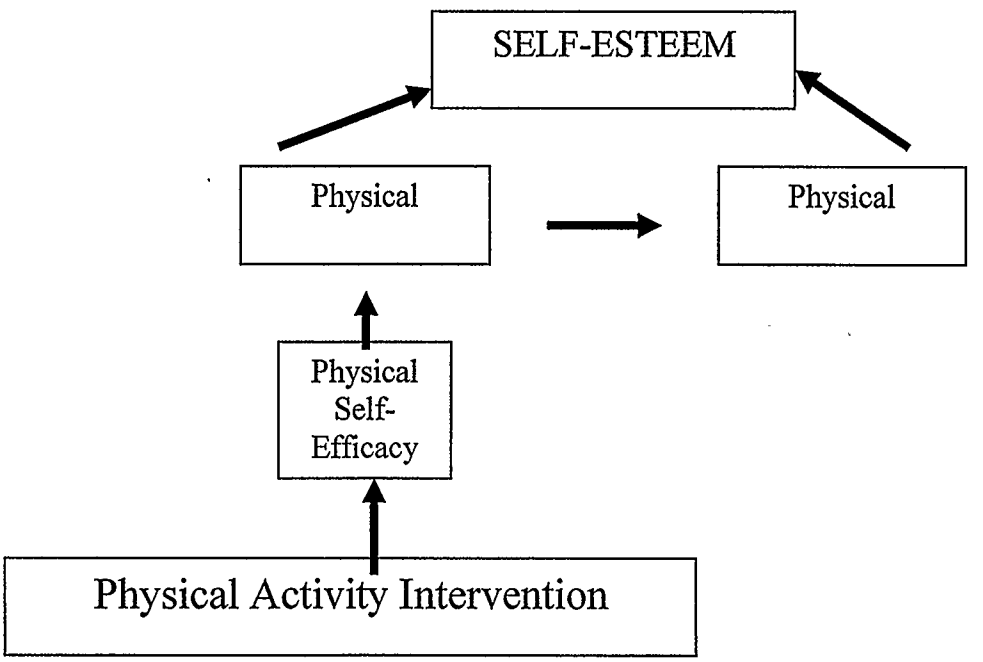
5) *Maintenance stage* - meets the criterion for being physically active for a duration longer than six months, regularly participates in physical activity and endeavors to avoid relapses of inactivity.

Appendix F

SELF-EFFICACY THEORY (SET) (Bandura, 1986):



EXERCISE AND SELF-ESTEEM MODEL (Sonstroem & Morgan, 1989):



Appendix G

Dr. Paivi Miettunen
Pediatric Rheumatology
Alberta Children's Hospital
1820 Richmond Road SW
Calgary, AB T2T 5C7

Phone: (403) 943-7771
Fax: (403) 228-6106

calgary health region

Dear [child's name],

I am sending you this letter because I am involved in a research project investigating the effects of physical activity on children and adolescents with juvenile arthritis (JA). As you are a patient of mine with JA, I wanted to offer you this unique opportunity to be involved in this study. Study participation requires you to simply complete the enclosed questionnaire. The questionnaire will take approximately 30-45 minutes. If you think you might be interested in participating, please see the enclosed letter from Kerry Coupland for more information.

Your participation is greatly appreciated! Please know that whether or not you decide to complete the questionnaire, your medical care under my supervision will not be impacted.

Thank-you for your time and assistance.

Sincerely,

Paivi Miettunen MD

UNIVERSITY OF CALGARY
KINESIOLOGY

Health and Wellness Laboratory

Telephone: (403) 210-8482
Fax: (403) 284-3553

Dear [child name]

My name is Kerry Coupland and I am currently working on my master's degree at the University of Calgary. I am very interested in both the mental and physical benefits of physical activity and exercise for children and adolescents with juvenile arthritis. Along with Dr. Nicole Culos-Reed at the University of Calgary and Dr. Paivi Miettunen, your pediatric rheumatologist, we are conducting a research study and we are seeking your voluntary participation. The study is a paper and pencil survey that should take about 30-45 minutes of your time.

If you would like to take part in the study, and if you are under 18 years of age, you will first need to get your parents permission. If your parents agree to allow you to participate, all you need to do is complete the enclosed survey and return it to us in the self-addressed, stamped envelope provided for you. **Parents, your decision to allow your child to complete and return the questionnaire will be interpreted as an indication of your agreement to allow your child to participate.** If you have any questions concerning your child's rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782 or by email at plevans@ucalgary.ca. Please keep this letter for your future reference.

We hope that you will take this opportunity to contribute to the research being conducted in the area of juvenile arthritis. It is only through voluntary participation in research that we increase our understanding of the disease, its treatment and the long-term impact that it has on individuals. If you have any questions or problems understanding a question please feel free to ask your parents for help.

If you have any questions or concerns about this study, please feel free to contact me at (403) 210-8482 or by email at krcoupla@ucalgary.ca. On behalf of the entire research team, I thank you for your time and support.

Sincerely,

Kerry Coupland, BA(hon)., MSc. Student
Faculty of Kinesiology
University of Calgary
2500 University Drive NW
Calgary, Alberta T2N 1N4
Tel: (403) 210-8482
E-mail: krcoupla@ucalgary.ca

Dr. Nicole Culos-Reed, Ph.D.
Assistant Professor, Faculty of Kinesiology
University of Calgary
2500 University Drive NW
Calgary, Alberta T2N 1N4
E-mail: nculosre@ucalgary.ca

Questionnaire: Section 1

Child Health Assessment Questionnaire

In this section we are interested in learning how your illness affects your ability to function in daily life. Please feel free to add any comments in the space provided at the end of this section.

In the following questions, please check the ONE response which best describes your usual activities (**averaged over an entire day**) **OVER THE PAST WEEK.**

ONLY NOTE THOSE DIFFICULTIES OR LIMITATIONS WHICH ARE DUE TO ILLNESS

Due to Juvenile Arthritis Illness Only

Dressing & Grooming **Are you able to:**	**Without ANY Difficulty**	**With SOME Difficulty**	**With MUCH Difficulty**	**UNABLE To Do**	**Not Applicable**
1. Dress, including tying shoelaces and doing buttons?					
2. Shampoo your own hair?					
3. Remove socks?					
4. Cut fingernails?					

Eating **Are you able to:**	**Without ANY Difficulty**	**With SOME Difficulty**	**With MUCH Difficulty**	**UNABLE To Do**	**Not Applicable**
7. Cut your own meat?					
8. Lift a cup or glass to mouth?					
9. Open a new cereal box?					

Arising **Are you able to:**	**Without ANY Difficulty**	**With SOME Difficulty**	**With MUCH Difficulty**	**UNABLE To Do**	**Not Applicable**
5. Stand up from a low chair or floor?					
6. Get in and out of bed?					

Walking Are you able to:	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE To Do	Not Applicable
10. Walk outdoors on flat ground?					
11. Climb up 5 steps?					

Please check any *AIDS or DEVICES* that you usually use for any of the above activities:

_____ Cane
_____ Walker
_____ Crutches
_____ Wheelchair
_____ Devices used for dressing (button hook, zipper pull, long-handled shoe horn)
_____ Built up pencil or special utensils
_____ Special or Built-up chair
_____ Other Specify: _____

Please check any categories for which you usually needs help from another person *BECAUSE OF ILLNESS*:

_____ Dressing and Grooming
_____ Arising
_____ Eating
_____ Walking

Due to Juvenile Arthritis Illness Only

Hygiene Are you able to:	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE To Do	Not Applicable
12. Wash and dry entire body?					
13. Take a tub bath (get in & out of tub)?					
14. Get on and off the toilet?					
15. Brush teeth?					
16. Comb/Brush hair?					

Reach Are you able to:	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE To Do	Not Applicable
17. Reach and get down a heavy object such as a large game or books from just above your head?					
18. Bend down to pick up clothing or a piece of paper from the floor?					
19. Pull on a sweater over your head?					
20. Turn neck to look over shoulder?					

Grip Are you able to:	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE To Do	Not Applicable
21. Write or scribble with a pen or pencil?					
22. Open car doors?					
23. Open jars which have been Previously opened?					
24. Turn faucets on and off?					
25. Push open a door when he/she has to turn knob?					

Errands, Chores, and Play Are you able to:	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE To Do	Not Applicable
26. Run errands and shop?					
27. Get in and out of car?					
28. Ride bike?					
29. Do household chores (e.g. wash dishes, take out trash, vacuuming, yardwork, make bed, clean room)?					
30. Run and play??					

Please check any *AIDS or DEVICES* that you usually uses for any of the above activities:

_____ Raised Toilet Seat
_____ Bathtub Seat
_____ Bathtub bar
_____ Jar Opener (for jars previously opened)
_____ Long-Handled Appliances for Reach
_____ Long Handled Appliances in Bathroom

Please check any categories for which you usually need help from another person *BECAUSE OF ILLNESS:*

_____ Hygiene
_____ Reach
_____ Gripping and Opening things
_____ Errands, Chores, and Play

We are also interested in learning whether or not you have been affected by pain because your illness. How much pain do you think you have because of your juvenile arthritis IN THE PAST WEEK?

Place mark on the line below to indicate the severity of the pain.

---

0 — 100

No Pain — Very Bad Pain

Section 2

This is a chance to look at yourself. **It is not a test.** There are no right answers and everyone will have different answers. We will keep your answers private and not show them to anyone.

The purpose of this study is to see how people describe themselves physically. In the following pages you will be asked to think about yourself physically; For example, how good looking you are, how strong you are, how good you are at sports, whether you exercise regularly, whether you are physically coordinated, whether you get sick very often and so forth. Answer each sentence quickly as you feel now. Please do not leave any sentence blank.

When you are ready to begin, please read each sentence and decide your answer. There are six possible answers for each question – "True", "False", and four answers in between. There are six boxes next to each sentence, one for each of the answers. The answers are written at the top of the boxes. Choose your answer to a sentence and put a tick in the box under the answer you choose. Before you start there are three examples below. A student named Bob has already answered the first two examples to show you how to do it. In the third example you must choose your own answer by ticking a box.

EXAMPLE QUESTIONS:

	MOSTLY FALSE	FALSE	MORE FALSE THAN TRUE	MORE TRUE THAN FALSE	TRUE	MOSTLY TRUE
1.I like to read comic books.....1	☐	☐	☐	☐	☐	☑

(Bob put a tick in the box under the answer "TRUE". This means that he really likes to read comic books. If Bob did not like to read comic books very much, he would have answered "FALSE" or "MOSTLY FALSE").

2.In general, I am neat and tidy.....2	☐	☐	☐	☑	☐	☐

(Bob answered "MORE TRUE THAN FALSE" because he is not very neat, but he is not very messy either.)

3.I like to watch T.V.....3	☐	☐	☐	☐	☐	☐

For this sentence you have to choose the answer that is best for you. First you must decide if the sentence is "TRUE" or "FALSE" or somewhere in between. If you really like to watch T.V. a lot you would answer "TRUE" by putting a tick in the last box. If you hate watching T.V. you would answer "FALSE" by putting a tick in the first box. If your answer is somewhere in between then you would choose one of the other three boxes.

If you want to change an answer you have marked you should cross out the tick and put a new tick in another box on the same line. For all the sentences be sure that your tick is on the same line as the right sentence. You should have one answer and only one answer for each sentence. **Do not leave out any of the sentences**.

Please begin

			FALSE	MOSTLY FALSE	MORE FALSE THAN TRUE	MORE TRUE THAN FALSE	MOSTLY TRUE	TRUE
1.	When I get sick I feel so bad that I cannot even get out of bed.....	1	O	O	O	O	O	O
2.	I feel confident when doing coordinated movements...	2	O	O	O	O	O	O
3.	Several times a week I exercise or play hard enough to breathe hard (to huff and puff).....	3	O	O	O	O	O	O
4.	I am too fat.....	4	O	O	O	O	O	O
5.	Other people think I am good at sports.....	5	O	O	O	O	O	O
6.	I am satisfied with the kind of person I am physically	6	O	O	O	O	O	O
7.	I am attractive for my age.....	7	O	O	O	O	O	O
8.	I am a physically strong person.....	8	O	O	O	O	O	O
9.	I am quite good at bending, twisting, and turning my body.....	9	O	O	O	O	O	O
10.	I can run a long way without stopping.....	10	O	O	O	O	O	O
11.	Overall, most things I do turn out well.....	11	O	O	O	O	O	O
12.	I usually catch whatever illness (flu, virus, cold, etc.) is going around.....	12	O	O	O	O	O	O
13.	Controlling movements of my body comes easily to me.....	13	O	O	O	O	O	O
14.	I often do exercise or activities that makes me breathe hard.....	14	O	O	O	O	O	O
15.	My waist is too large.....	15	O	O	O	O	O	O
16.	I am good at most sports	16	O	O	O	O	O	O

			FALSE	MOSTLY FALSE	MORE FALSE THAN TRUE	MORE TRUE THAN FALSE	MOSTLY TRUE	TRUE
17.	Physically, I am happy with myself.....	17	O	O	O	O	O	O
18.	I have a nice looking face.....	18	O	O	O	O	O	O
19.	I have a lot of power in my body	19	O	O	O	O	O	O
20.	My body is flexible.....	20	O	O	O	O	O	O
21.	I would do well in a test of physical endurance and stamina.....	21	O	O	O	O	O	O
22.	I don`t have much to be proud of.....	22	O	O	O	O	O	O
23.	I am sick so often that I cannot do all the things I want to do.....	23	O	O	O	O	O	O
24.	I am good at coordinated movements.....	24	O	O	O	O	O	O
25.	I get exercise or activity three or four times a week that makes me huff and puff and lasts at least 30 minutes.....	25	O	O	O	O	O	O
26.	I have too much fat on my body.....	26	O	O	O	O	O	O
27.	Most sports are easy for me.....	27	O	O	O	O	O	O
28.	I feel good about the way I look and what I can do physically.....	28	O	O	O	O	O	O
29.	I am better looking than most of my friends.....	29	O	O	O	O	O	O
30.	I am stronger than most people my age.....	30	O	O	O	O	O	O
31.	My body is stiff and inflexible.....	31	O	O	O	O	O	O
32.	I could jog 5 kilometres without stopping.....	32	O	O	O	O	O	O
33.	I feel that my life is not very useful.....	33	O	O	O	O	O	O

			FALSE	MOSTLY FALSE	MORE FALSE THAN TRUE	MORE TRUE THAN FALSE	MOSTLY TRUE	TRUE
34.	I hardly ever get sick.....	34	O	O	O	O	O	O
35.	I can perform movements smoothly in most physical activities.....	35	O	O	O	O	O	O
36.	I do physically active things (like jogging, dancing, bicycling, aerobics, gym, or swimming) at least three times a week.....	36	O	O	O	O	O	O
37.	I am overweight.....	37	O	O	O	O	O	O
38.	I have good sports skills.....	38	O	O	O	O	O	O
39.	Physically I feel good about myself.....	39	O	O	O	O	O	O
40.	I am ugly.....	40	O	O	O	O	O	O
41.	I am weak and have no muscles.....	41	O	O	O	O	O	O
42.	My body parts bend and move in most directions well	42	O	O	O	O	O	O
43.	I think I could run a long way without getting tired.....	43	O	O	O	O	O	O
44.	Overall, I am no good.....	44	O	O	O	O	O	O
45.	I get sick a lot.....	45	O	O	O	O	O	O
46.	I find my body handles coordinated movements with ease.....	46	O	O	O	O	O	O
47.	I do lots of sports, dance, gym, or other physical activities.....	47	O	O	O	O	O	O
48.	My stomach is too big	48	O	O	O	O	O	O
49.	I am better at sports than most of my friends.....	49	O	O	O	O	O	O
50.	I feel good about who I am and what I can do physically.....	50	O	O	O	O	O	O

			FALSE	MOSTLY FALSE	MORE FALSE THAN TRUE	MORE TRUE THAN FALSE	MOSTLY TRUE	TRUE
51.	I am good looking.....	51	O	O	O	O	O	O
52.	I would do well in a test of strength.....	52	O	O	O	O	O	O
53.	I think I am flexible enough for most sports.....	53	O	O	O	O	O	O
54.	I can be physically active for a long period of time without getting tired.....	54	O	O	O	O	O	O
55.	Most things I do, I do well.....	55	O	O	O	O	O	O
56.	When I get sick it takes me a long time to get better.....	56	O	O	O	O	O	O
57.	I am graceful and coordinated when I do sports and activities.....	57	O	O	O	O	O	O
58.	I do sports, exercise, dance or other physical activities almost every day.....	58	O	O	O	O	O	O
59.	Other people think that I am fat.....	59	O	O	O	O	O	O
60.	I play sports well.....	60	O	O	O	O	O	O
61.	I feel good about who I am physically.....	61	O	O	O	O	O	O
62.	Nobody thinks that I am good looking.....	62	O	O	O	O	O	O
63.	I am good at lifting heavy objects.....	63	O	O	O	O	O	O
64.	I think I would perform well on a test measuring flexibility.....	64	O	O	O	O	O	O
65.	I am good at endurance activities like distance running, aerobics, bicycling, swimming, or cross-country skiing.....	65	O	O	O	O	O	O

			FALSE	MOSTLY FALSE	MORE FALSE THAN TRUE	MORE TRUE THAN FALSE	MOSTLY TRUE	TRUE
66.	Overall, I have a lot to be proud of.....	**66**	O	O	O	O	O	O
67.	I have to go to the doctor because of illness more than most people my age.....	**67**	O	O	O	O	O	O
68.	Overall, I am a failure.....	**68**	O	O	O	O	O	O
69.	I usually stay healthy even when my friends get sick.....	**69**	O	O	O	O	O	O
70.	Nothing I do ever seems to turn out right.....	**70**	O	O	O	O	O	O

Section 3

PedsQL™

Pediatric Quality of Life Inventory

Version 4.0

TEEN REPORT (ages 13-18)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month**, how much of a **problem** has this been for you …*

About My Health and Activities *(PROBLEMS WITH...)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

About My Feelings (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

How I Get Along with Others (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. I have trouble getting along with other teens	0	1	2	3	4
2. Other teens do not want to be my friend	0	1	2	3	4
3. Other teens tease me	0	1	2	3	4
4. I cannot do things that other teens my age can do	0	1	2	3	4
5. It is hard to keep up with my peers	0	1	2	3	4

About School (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

PedsQL™

Arthritis Module

Version 3.0

TEEN REPORT (ages 13-18)

DIRECTIONS

Teens with arthritis sometimes have special problems. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month,** how much of a **problem** has this been for you ...*

Pain and Hurt (problems with...)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I ache or hurt in my joints and/or muscles	0	1	2	3	4
2. I hurt a lot	0	1	2	3	4
3. I have trouble sleeping because of pain or aching in my joints and/or muscles	0	1	2	3	4
4. I feel stiff in the morning or when I sit too long	0	1	2	3	4

Daily Activities (problems with...)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard to turn on water faucets	0	1	2	3	4
2. It is hard to turn door handles	0	1	2	3	4
3. I have trouble eating with a fork and knife	0	1	2	3	4
4. It is hard to write or draw with a pen or pencil	0	1	2	3	4
5. I have trouble carrying my school books	0	1	2	3	4

Treatment (problems with...)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. My medicines make me feel sick	0	1	2	3	4
2. My physical therapy or daily exercise hurts	0	1	2	3	4
1. It is hard to be responsible for my medicines or physical therapy	0	1	2	3	4
2. It is hard to manage my arthritis	0	1	2	3	4
3. I get scared when I have to have blood tests	0	1	2	3	4
4. I get scared about having needle sticks/shots	0	1	2	3	4
5. I get scared when I have to go the doctor	0	1	2	3	4

Worry (problems with...)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I worry about the side effects from medicines	0	1	2	3	4
2. I worry about whether or not my medicines are working	0	1	2	3	4
3. I worry about my arthritis	0	1	2	3	4

Communication (problems with...)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard for me to tell the doctors and nurses how I feel	0	1	2	3	4
2. It is hard for me to ask the doctors and nurses questions	0	1	2	3	4
3. It is hard for me to explain my illness to other people	0	1	2	3	4

Section 4

The following questions ask you to recall your levels of physical activity at two *different time periods in your life:*

1. Before you were diagnosed with juvenile arthritis.
2. Over the past week.

When answering the following *three* questions, please remember to:

a. **Only count activity/exercise sessions that lasted *15 minutes or longer.***
b. **Include all exercise/physical activity that you do *other than school physical education classes* (e.g., competitive school teams, organized/competitive sports outside of school, recreational activities).**
c. **Please also record the average duration or time that you performed each activity.**

***KEEP THIS DEFINITION IN MIND* when answering the next series of questions.**

***Physical activity* IS ANY BODY MOVEMENT THAT INCREASES YOUR ENERGY EXPENDITURE ABOVE RESTING LEVELS AND INCLUDES ANY PHYSICAL RECREATION, EXERCISE, AND SPORTING ACTIVITIES.**

In this section would like you to think back to BEFORE you were diagnosed with arthritis.

Please insert in a number in the spaces provided.

A. STRENUOUS EXERCISE (heart beats rapidly, sweating)

(e.g., running, jogging, hockey, soccer, squash, cross country skiing, judo, roller blading, vigorous swimming, vigorous long distance bicycling, vigorous aerobic classes, heavy weight training, laser tag)

Before being diagnosed with juvenile arthritis, in an average week I was involved in strenuous activities _____ times/week for an average duration of _____minutes/each session.

B. MODERATE EXERCISE (not exhausting, light perspiration)

(e.g., fast walking, baseball, tennis, easy bicycling, shooting hoops, volleyball, badminton, easy swimming, alpine skiing, popular and line dancing, leisure skating)

Before being diagnosed with juvenile arthritis, in an average week I was involved in moderate activities _____times/week for an average duration of _____minutes/each session.

C. MILD EXERCISE (minimal effort, no perspiration)

(E.g., easy walking, yoga, archery, fishing, bowling, pool, shuffleboard, horseshoes, golf, darts, frisbee)

Before being diagnosed with juvenile arthritis, in an average week I was involved in mild activities _____times/week for an average duration of _____minutes/each session.

In this section we would like you to think back over the PAST WEEK.

Please insert in a number in the spaces provided.

A. STRENUOUS EXERCISE (heart beats rapidly, sweating)

(e.g., running, jogging, hockey, soccer, squash, cross country skiing, judo, roller blading, vigorous swimming, vigorous long distance bicycling, vigorous aerobic classes, heavy weight training, laser tag)

In an average week I am involved in strenuous activities _____ times/week for an average duration of _____minutes/each session.

B. MODERATE EXERCISE (not exhausting, light perspiration)

(e.g., fast walking, baseball, tennis, easy bicycling, shooting hoops, volleyball, badminton, easy swimming, alpine skiing, popular and line dancing, leisure skating)

In an average week I am involved in moderate activities _____times/week for an average duration of _____minutes/each session.

C. MILD EXERCISE (minimal effort, no perspiration)

(e.g., easy walking, yoga, archery, fishing, bowling, pool, shuffleboard, horseshoes, golf, darts, frisbee)

In an average week I am involved in mild activities _____times/week for an average duration of _____minutes/each session.

Section 5

The following questions in this survey use a 7-point scale. Please circle the number that *best describes your opinion.*

For example, if you were asked to rate how confident you are that you could walk around a street block, the 7 points would be read as follows:

If you think that you are "Extremely Confident", then you would circle the *number 7,* as follows:
If you think that you are only "Slightly Confident" that you could walk around a

1	2	3	4	5	6	7
Not at all Confident	Quite not confident	Slightly Not confident	I don't feel one way or another	Slightly confident	Quite confident	Extremely Confident

street block then you would circle the *number 5,* as follows:

1	2	3	4	5	6	7
Not at all Confident	Quite not confident	Slightly Not confident	I don't feel one way or another	Slightly confident	Quite confident	Extremely Confident

If you are not sure whether you could or could not, that is, you really don't have an opinion "I don't feel one way or another", you would then circle the *number 4,* as follows:

1	2	3	4	5	6	7
Not at all Confident	Quite not confident	Slightly Not confident	I don't feel one way or another	Slightly confident	Quite confident	Extremely Confident

When making your ratings on the following scales, please remember the following:
Be sure to answer all of the items – DO NOT SKIP ANY
Do not circle more than one number on a single question

KEEP THIS DEFINITION IN MIND **when answering the next questions.**

Physical activity **IS ANY BODY MOVEMENT THAT INCREASES YOUR USING OF ENERGY ABOVE RESTING LEVELS AND INCLUDES ANY PHYSICAL RECREATION, EXERCISE, AND SPORTING ACTIVITIES.**

How confident are you that you can do the following behaviors right now:

1. "Engage in physical activity one time per week?"

1	2	3	4	5	6	7
Not at all Confident	Quite not confident	Slightly Not confident	I don't feel one way or another	Slightly confident	Quite confident	Extremely Confident

2. "Engage in your physical activity two times per week?"

1	2	3	4	5	6	7
Not at all Confident	Quite not confident	Slightly Not confident	I don't feel one way or another	Slightly confident	Quite confident	Extremely Confident

Keep the following definition in mind for the next 2 questions:

MILD EXERCISE (minimal effort, no perspiration)

(E.g., easy walking, yoga, archery, fishing, bowling, pool, shuffleboard, horseshoes, golf, darts, frisbee)

1. "Engage in a mild physical activity one time per week?"

1	2	3	4	5	6	7
Not at all Confident	Quite not confident	Slightly Not confident	I don't feel one way or another	Slightly confident	Quite confident	Extremely Confident

2. "Engage in mild physical activity two times per week?"

1	2	3	4	5	6	7
Not at all Confident	Quite not confident	Slightly Not confident	I don't feel one way or another	Slightly confident	Quite confident	Extremely Confident

Keep the following definition in mind for the next 2 questions:

MODERATE EXERCISE (not exhausting, light perspiration)

(e.g., fast walking, baseball, tennis, easy bicycling, shooting hoops, volleyball, badminton, easy swimming, alpine skiing, popular and line dancing, leisure skating)

How confident are you that you can do the following behaviors over the next twelve weeks:

1. "Engage in a moderate physical activity one time per week?"

1	2	3	4	5	6	7
Not at all Confident	Quite not confident	Slightly Not confident	I don't feel one way or another	Slightly confident	Quite confident	Extremely Confident

2. "Engage in moderate physical activity two times per week?"

1	2	3	4	5	6	7
Not at all Confident	Quite not confident	Slightly Not confident	I don't feel one way or another	Slightly confident	Quite confident	Extremely Confident

Keep the following definition in mind for the next 2 questions:

STRENUOUS EXERCISE (heart beats rapidly, sweating)

(e.g., running, jogging, hockey, soccer, squash, cross country skiing, judo, roller blading, vigorous swimming, vigorous long distance bicycling, vigorous aerobic classes, heavy weight training, laser tag)

How confident are you that you can do the following behaviors over the next twelve weeks

1. "Engage in a strenuous physical activity one time per week?"

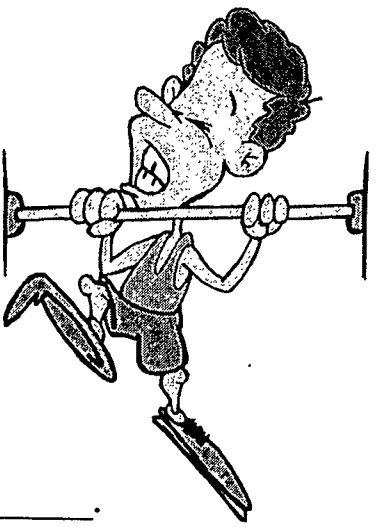
1	2	3	4	5	6	7
Not at all Confident	Quite not confident	Slightly Not confident	I don't feel one way or another	Slightly confident	Quite confident	Extremely Confident

2. "Engage in strenuous physical activity two times per week?"

1	2	3	4	5	6	7
Not at all Confident	Quite not confident	Slightly Not confident	I don't feel one way or another	Slightly confident	Quite confident	Extremely Confident

This part of the survey is needed to help us understand more about you. For this reason, it is very important information. All of the information is held in strict trust and your name will **NOT** appear on any public documents. However, if you feel uncomfortable answering any of the questions, please feel free to leave them blank. Also, you may not know the answers to some of the medical questions – if so, please indicate this by marking the "do not know" option. Please answer the following questions based on your present status.

PERSONAL HISTORY



1. Age: _____

2. Gender: ☐ Male ☐ Female

3. Grade: _____

II) MEDICAL INFORMATION

4. Height and Weight:

Weight in pounds _____or kilograms _____.

Height in feet/inches_____or metres/cm._____.

5. Month and Year of diagnosis: _____.

6. What type of juvenile arthritis did/do you have:

Rheumatoid (JRA) ☐
Pauciarticular ☐
Polyarticular ☐
Systemic (Still's) ☐
Psoriatic arthritis ☐
Spondylarthropathy ☐
Other _____ ☐

7a. Does your treatment include medication? ☐ Yes ☐ No

7b. If yes, what are you taking? _____

_____

_____.

Or If you don't Know check this box ☐

7c. If yes, what motivates you to take your medications?

I take them because my doctor tells me to ☐
I take them because I don't want to have damaged joints ☐
I take them so that I can be physically active ☐
I don't take them ☐
Other _____ ☐

8 a. What types of organized sports were you involved in before your diagnosis? (check as many as apply to you)

Volleyball ☐
Basketball ☐
Skating/hockey ☐
Baseball ☐
Soccer ☐
Other _____ ☐

8 b. How many hours per week did you participate in these activities before your diagnosis? _____ hours per week.

9a. What types of organized sports have you been involved in after your diagnosis?

Volleyball ☐
Basketball ☐
Skating/hockey ☐
Baseball ☐
Soccer ☐
Other _____ ☐

9 b. How many hours per week do you participate in these activities now? _____ hours per week.

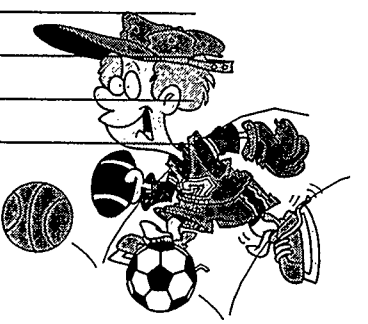
10. Has your arthritis been a barrier to your physical activity/sport participation?

Yes ☐
No ☐

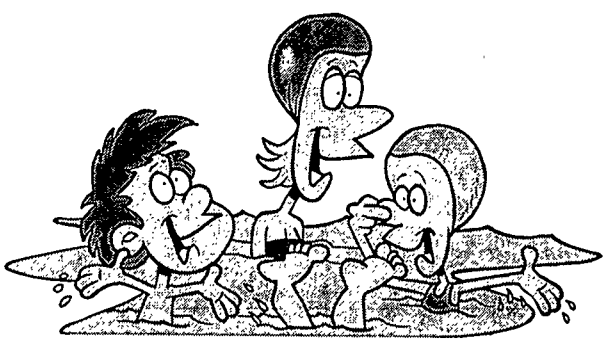
11. What do you believe are the main advantages and disadvantages of exercising or being physically active (e.g., running, swimming, cycling, volleyball, basketball) for you right now? List as many advantages and disadvantages that you think may result from you being physically active right now. (Point form is fine).

ADVANTAGES:

DISADVANTAGES:



12. There are a number of reasons why people choose not to exercise or reasons why it may be easier or more difficult for people to be physically active. What do you feel are the biggest problems that would prevent youth like yourself from exercising regularly? What could be done to help youth like yourself exercise regularly? (Point form is fine).



13. During a *normal week*, how many hours a day do you watch television or play video/computer games:

Never	☐
1 hour or less	☐
2 to 3 hours	☐
4 to 5 hours	☐
6 or more hours	☐

14. Would you be interested in participating in an organized physical activity program in Calgary that is designed for youth with juvenile arthritis?

Yes	☐
No	☐

15. I prefer to exercise at: (check one)

Home	☐
School	☐
Club/Team	☐
Fitness Facility	☐
Outdoors	☐

16. I like to exercise in the: (check one)

Morning	☐
Afternoon	☐
Late Afternoon	☐
Evening	☐

17. The best day of the week or weekend for me to participate in an organized physical activity program would be: _____

18. I participate in the following activities: (check ALL that apply)

☐ Physical Education Classes at school _____ x per week
☐ Team/Club activities (e.g. soccer, hockey)_____ x per week
☐ Physiotherapy _____ x per week
☐ Other (please indicate what) _____ x per week

Did we miss anything? Is there anything that you would like to add about physical activity and you? Please feel free to use as much space as you need.

Thank-you for your help.

End of Questionnaire

APPENDIX H

Id 1: No. I have a part time job at KFC.

Id 5: I had a lot of fun at the sailing party last summer at Chestermere!

Id 2: No.

Id 11: I would like to live as much of a carefree, normal youth as possible!

Id 15: I am disappointed that I can't run with my friends and do other sports I like.

Id 6: I LOVE exercising! I just almost never have the time to do it. ☹

Id 25: No, I don't think so.

Id 18: No more NEEDLES

Id 88: Answered by child's mother:

My child has been doing extremely well with her arthritis fro the last year but about 1.5 to 2 years ago she had a major flare up which left her in significant pain daily. She could only walk for 20 minutes and was unable to participate in school gym classes at all. We used cold packs on her ankles several times a day . We and the doctor do not if this will happen again but hopefully with all the changes in her medications it won't. Physical activity for her ws only fun and possible when there was no pain.

Id 43: I don't think that you missed anything.

Id 36: I would like to go to the gym and work out, its just that I have not energy to do this. Its also hard, low motivation, and its hard because I can't drive yet so I have to arrange all these things to be able to get out, takes too much energy.

Id 48: I have a basketball "Hoop" in the yard and I practice everyday.

Also I do gymnastics on my trampoline daily!

Id 56: I did not change my fitness habits because of my arthritis. I am more physically active now than I was before I was diagnosed, but for unrelated reasons. My disease only affects my not being able to pushups, lift free weights etc. Otherwise, I am fully functional.

Id 50: No you did not miss anything!

Note (from Mother): It took 6 months to get a diagnosis, by this time she could barely walk, sit or stand. The variety of doctors all agreed she was extremely ill and deteriorating quickly but no one knew why – until we got inot the children's hospital (Jan-June 2004).

Also have found little information to share with tearchers and coaches to help them be supportive at school.

Areas for your next questionnaire to see if all arthritis children go through the same PAIN and frustration pre-diagnosis and after.

Id 54: Note from Parent:

I think that my son has done so well with his illness because of continued physical activity either through sports or active activities – walking to school.

He has always had a positive outlook which has helped him work through his pain.

In the early days of his illness he had a lot of worries about arthritis killing him or stopping him from playing sports which are his passion. I think that Doctors and the adults in these children's lives need to acknowledge these types of thoughts and fears as real and not tell them to find something else to do, if possible. Thanks for your interest in Jr. Arthritis. There is not a lot of current info out there!