Abstract

Juvenile Idiopathic Arthritis: Disease Treatment and Management from a Family Perspective

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Juvenile idiopathic arthritis, JIA, is a chronic disease that impacts many children worldwide. JIA is marked by joint pain and inflammation, and includes several categories of disease depending on the patient's symptoms. As there is no cure for JIA, successful treatment plans are vital to managing symptoms and maintaining a high quality of life. Treatments vary and can include medications and/or more conservative alternative therapies. Although only the patient carries the JIA diagnosis, the disease impacts the patient, other family members, and the family system. Despite the fact that JIA impacts the family physically, psychologically, and emotionally, many resources exist to provide information about the disease and aid in coping. This thesis details the resources available to children and families impacted by this chronic inflammatory disorder.

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JUVENILE IDIOPATHIC ARTHRITIS: DISEASE TREATMENT AND MANAGEMENT FROM A FAMILY PERSPECTIVE

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CHAPTER ONE

Introduction

Juvenile idiopathic arthritis, or JIA, is a term used to describe the various forms of childhood chronic arthritis (Abramson, 2012, 1). The term arthritis can be broken down into "arth" which means joint and "itis" which means inflammation (Tucker, 2011, 7). Arthritis in general is described as joint inflammation, or pain, swelling, redness, and stiffness in the affected area. Inflammation is caused by a malfunction in the body's immune system that leads the body's immune cells (antibodies) to attack their own joints (Tucker, 2011, 7). Inflamed joints are painful and warm to the touch because antibodies attack joint linings, such as the synovium, causing the lining to become thicker than normal and increasing the pressure within the joints (Tucker, 2011, 7). The cellular changes in the synovial fluid eventually damage joint cartilage and bones (Tucker, 2011, 7). To be diagnosed with JIA, a patient under the age of sixteen must have constant inflammation in at least one joint for a minimum of six weeks (Tucker, 2011, 7).

JIA is referred to as being "idiopathic" because the cause of the disease is unknown (Tucker, 2011, 5). Although the cause is unknown, researchers have found that the disease is not caused by previous infections or diseases in the parents of children with JIA (Kelly & Beresford, 2012, 117-118). Furthermore, researchers have found that most types of JIA are not genetically passed (Kelly & Beresford, 2012, 117-118). JIA is not contagious. As JIA is an autoimmune disease, patients can sometimes experience arthritic symptoms after developing an ordinary infection (Tucker, 2011, 9). In those cases, JIA is not caused by the infection, rather researchers believe the infection triggers

an alteration in the immune system response which leads to continuous inflammation (Tucker, 2011, 9). As the etiology of JIA remains a mystery, there is no cure for the disease (Tucker, 2011, 5). JIA is the most common childhood rheumatic disease (Gowdie & Tse, 2012, 302). Exact statistics vary by country, but one in one thousand American and Canadian children suffer from JIA (Stanley & Ward-Smith, 2011, 191).

Depending on the type of JIA and the medication used to manage symptoms, children with JIA experience a higher risk for bone diseases such as osteopenia, a lower than normal bone density, and osteoporosis, bone loss (Gowdie & Tse, 2012, 312). These bone diseases are more prevalent in children with JIA because active arthritis, constant or repeated episodes of inflammation, and the use of certain arthritis medications such as corticosteriods impact normal bone development. (Gowdie & Tse, 2012, 312). Osteopenia and osteoporosis can also occur in JIA patients due to decreased levels of physical activity and shorter periods of daily sunlight exposure (Gowdie & Tse, 2012, 312). Inflammation associated with JIA also leads to certain eye disorders such as uveitis, iritis, iridocyclitis, anterior uveitis, and nongranulomatous iritis, depending on which part of the eye is inflamed. The incidence of eye disease in children with JIA ranges from 2% to 34% (Tucker, 2011, 11). Often eye disease is asymptomatic, although in some cases blurred vision may be an early sign, and can lead to blindness if untreated. Temporomandibular joint (TMJ) involvement is prevalent in 17%-87% of children (Weiss, Arabshahi, Johnson, Bilaniuk, Zarnow, Cahill, Feudtner, & Cron, 2008). Chronic inflammation affects growth plate of the mandible and leads to deformities of the jaw, leading to jaw pain, headaches and difficulties with chewing. Finally, JIA can impact a child's growth. Growth can be expedited or slowed in certain inflamed joints,

however growth patterns typically return to normal if the disease is controlled by successful treatment plans (Tucker, 2011, 11).

The disease course in children with JIA is highly variable. Children may experience disease flares, or periods of disease exacerbation, and disease remission, or periods of time in which the disease seems to be nonexistent (Tucker, 2011, 13). Disease flares and remission periods are generally random and unpredictable, however mild infections like the flu may cause a flare (Tucker, 2011, 13). Given the variable and unpredictable disease course, it is difficult to manage the disease with medications and other treatments.

Types of Arthritis

There are several different types of juvenile arthritis. The main forms of arthritis commonly diagnosed include systemic onset JIA, oligoarticular JIA, polyarticular JIA, enthesitis-related arthritis, and psoriatic arthritis (Abramson, 2012, 2).

Systemic Onset JIA

Systemic onset JIA is a form of JIA marked by repeating fevers higher than 102°F and pink, typically salmon-colored, skin rashes (Abramson, 2012, 2). It is common for the fevers of children with systemic JIA to become very high once or twice a day, quickly returning to a somewhat normal temperature in between episodes (Gowdie & Tse, 2012, 306). Rashes associated with systemic JIA are macular and found on the patient's trunk and extremities (Gowdie & Tse, 2012, 306). Systemic JIA usually occurs in five or more joints, but impacts both large and small joints (Gowdie & Tse, 2012, 306). Systemic JIA occurs at equal rates in both girls and boys (Tucker, 2011, 17). Children with systemic

onset JIA experience joint inflammation as well as internal organ inflammation, anemia, and abnormally high levels of white blood cells (Abramson, 2012, 2). Cardiac disease and myocarditis also has been found in children with systemic JIA, but less commonly (Gowdie & Tse, 2012, 306). Finally, patients with systemic JIA can also suffer from Macrophage Activation Syndrome, or MAS, which is caused by T cells and macrophages creating life-threatening inflammation (Gowdie & Tse, 2012, 307). The majority of patients suffering from systemic JIA will experience chronic and persistent disease, however about 40% will only have a monophasic illness, consisting of only a single episode (Gowdie & Tse, 2012, 306).

Oligoarticular JIA

Oligoarticular JIA is a type of arthritis effecting fewer than five joints. This form of JIA is more common in girls than boys, and typically occurs before age four (Tucker, 2011, 15). Approximately half of all children with JIA suffer from oligoarticular JIA (Abramson, 2012, 2). Oligoarticular JIA is also called pauciarticular JIA and is the mildest form of JIA (Tucker, 2011, 15). In order to be diagnosed with oligoarticular JIA, patients must experience joint pain in the required number of joints within the first six months of active disease (Gowdie & Tse, 2012, 303). This form of JIA generally affects larger joints such as a patient's knees, elbows, wrists, and ankles (Gowdie & Tse, 2012, 303). Children suffering from oligoarticular JIA also typically experience eye problems such as uveitis or iritis (Abramson, 2012, 2). Uveitis is a specific type of eye problem that affects the middle portion of the eye that includes the iris, ciliary body and choroid. JIA related inflammation and its resultant damage to these structures impacts blood flow

to the retina and can result in loss of vision (Gowdie & Tse, 2012, 308). Finally, children with oligoarticular JIA typically experience periods of disease remission as well as periods of disease flares (Gowdie & Tse, 2012, 304-305). Unfortunately, roughly half of the children diagnosed with oligoarticular JIA will experience disease progression to more joints, therefore developing polyarthritis. However, some patients will have permanent remission after having the disease for a few years (Gowdie & Tse, 2012, 305). If treated correctly, oligoarticular JIA does not typically cause permanent joint damage (Tucker, 2011, 15).

Polyarticular JIA

Polyarticular JIA is a form of arthritis that involves five or more joints (Abramson, 2012, 2). Patients with polyarticular JIA are further categorized depending on whether or not they have either a positive rheumatoid factor, or RF (Gowdie & Tse, 2012, 305). The RF is used as a prognostic indicator of disease severity. Children with polyarticular JIA who have a negative RF can experience acute or insidious pain in either small or large joints (Gowdie & Tse, 2012, 305). RF negative polyarticular JIA is fairly common and impacts girls more than boys (Tucker, 2011, 17). This type of JIA also occurs most frequently in children between the ages of two and four and between six and twelve (Tucker, 2011, 15). Patients with a positive RF are typically female and develop polyarticular JIA at an older age, such as adolescence (Tucker, 2011, 15). Patients with RF positive JIA will often continue to experience active disease into adulthood (Gowdie & Tse, 2012, 305). RF positive polyarticular JIA is less common than RF negative polyarticular JIA (Tucker, 2011, 15). It is usually erosive, results in rheumatoid nodules,

and impacts joints in a symmetric pattern such as both the left and right knee joints (Gowdie & Tse, 2012, 305). Finally, RF positive polyarticular JIA can cause anemia, or a lower than normal red blood cell count, which leads to systemic fatigue (Tucker, 2011, 17).

Enthesitis-related Arthritis

Enthesitis-related arthritis, or ERA, is also known as spondyloarthropathy. ERA is most common in boys older than age ten (Tucker, 2011, 15). With this form of JIA children experience joint capsule inflammation as well as enthesitis, or inflammation in ligaments and tendon insertions (Gowdie & Tse, 2012, 308). Inflammation of the joint connective tissue results in pain with movement and weakened tendons and ligaments, increasing the chance for tendon and ligament rupture (Abramson, 2012, 2). Children with ERA most commonly experience pain in the joints of the lower limbs, such as the hip, intertarsal joints, and sacroiliac joint (Gowdie & Tse, 2012, 308). The Achilles and patella tendons are the most common sites of enthesitis. Sacroiliac joint involvement in the presence of an extended period of JIA, usually between ten and fifteen years, places these children at a high risk for developing ankylosing spondylitis (Gowdie & Tse, 2012, 308). Anklyosing spondylitis eventually leads to spine fusion and loss of trunk and hop range of motion.

Psoriatic Arthritis

Children with psoriatic arthritis suffer from both arthritis and the skin disease psoriasis, which presents as red skin with flaky, white patches of scales (Abramson, 2012, 2). This form of JIA is frequently diagnosed in children between the ages of two

and four and between the ages of nine and eleven (Tucker, 2011, 15). Patients with psoriatic arthritis can also experience dactylitis, or swelling in the patient's digits, which impacts their ability to grasp and manipulate objects. Nail changes such as pitting or onycholysis may also be present (Gowdie & Tse, 2012, 308). Juvenile psoriatic arthritis can be classified as two distinct types, one similar to oligoarticular JIA and one comparable to ERA (Gowdie & Tse, 2012, 308). Children with oligoarticular-like psoriatic arthritis are typically female, have a positive anti nuclear antibody test (ANA+), and suffer from eye problems (Gowdie & Tse, 2012, 308). Children with ERA-like psoriatic arthritis are generally older males who have a greater chance of also having spondyloarthritis (Gowdie & Tse, 2012, 308).

Causes of JIA

Although the exact cause of JIA remains unknown, current research suggests JIA is caused by a combination of environmental stimuli and genetic susceptibility (Gowdie & Tse, 2012, 302). As there are many forms of JIA, the potential pathogenesis may differ depending on the type of JIA (Gowdie & Tse, 2012, 302). Researchers believe that oligoarticular and polyarticular JIA typically involve positive antinuclear antibodies, or ANA, and are associated with HLA-related genes and T cells (Gowdie & Tse, 2012, 302). Oligoarticular and polyarticular JIA are therefore hypothesized to be autoimmune diseases related to a patient's adaptive immune system (Gowdie & Tse, 2012, 302). Systemic JIA is thought to be autoinflammatory and therefore related to a patient's innate immune system (Gowdie & Tse, 2012, 303). Data indicates that phagocytes and

inflammatory cytokines such as interleukins play a role in systemic JIA, not HLA genes and other autoantibodies (Gowdie & Tse, 2012, 303).

CHAPTER TWO

Disease Treatment

JIA treatment is multifaceted and individually tailored to each patient (Reiter-Purtill, Gerhardt, Vannatta, Passo, & Noll, 2003, 17). Medications, physical therapy, complementary and alternative medical therapies (CAMs), and surgery are commonly used treatments to manage the symptoms of JIA. Typical JIA treatment also focuses on the psychosocial and educational impacts of the disease (Hashkes & Laxer, 2005, 1671). Treatments are most effective when a combination of individuals including the patient, family members, and appropriate specialists such as pediatric rheumatologists, nurses, physical therapists, occupational therapists, social workers, psychologists, ophthalmologists, orthopedists, orthotists, dietitians, and cardiologists, are involved (Rhodes, 1991, 912). The goals of all JIA treatments include managing the disease by decreasing joint inflammation, alleviating pain, and helping the patient reach their highest level of physical, psychological and social functioning (Rhodes, 1991, 912).

Medications

Medications are vitally important to symptom management in JIA. Aside from alleviating symptoms such as pain and inflammation, medications also attempt to prevent permanent bone and joint damage by changing the process of JIA (Ringold, Burke, & Glass, 2005, 1722). There are several types of medications available for children with JIA including non-steroidal anti-inflammatory drugs (NSAIDs), corticosteroids, disease-

modifying antirheumatic drugs (DMARDs), and biologic modifying medications. Additional drugs such as interleukin 1 receptor antagonist, intravenous immunoglobulin (IVIg), type II collagen, and autologous stem cell transplantation (ASCT) may also be used. Due to the heterogeneous nature of JIA, certain medications may be more successful for different patients, however, combinations of medications typically lead to optimum results. As some medications are more aggressive than others, rheumatologists rely on predictors of poor disease outcomes to determine whether or not they should prescribe harsh treatments. Predictors of poorer outcomes include the diagnosis of polyarthritis and a positive rheumatoid factor, small joint involvement that is both systemic and early onset, the presence of cyclic citrullinated peptide antibodies, a particular cell surface receptor HLA-DR4, or rheumatic nodules (Hashkes & Laxer, 2005, 1672).

NSAIDs

Non-steroidal anti-inflammatory drugs (NSAIDs) target the body's inflammatory response by limiting the synthesis of prostaglandins (Rhodes, 1991, 912). NSAIDs successfully manage JIA symptoms such as pain, swelling, stiffness, and fever (Hashkes & Laxer, 2005, 1675). Examples of NSAIDs include salicylates such as aspirin, ibuprofen, naproxen, and tolmetin (Hashkes & Laxer, 2005, 1675-1676). NSAIDs are a commonly used category of medications for JIA patients, especially in conjunction with other medications (Anthony & Schanberg, 2003, 275). While NSAIDs can effectively manage symptoms, they do not modify the disease process. Negative side effects of NSAIDs include gastrointestinal symptoms such as gastritis, central nervous system

symptoms such as headaches, pseudoporphyria, and occasionally renal abnormalities such as papillary necrosis (Hashkes & Laxer, 2005, 1676).

Corticosteroids

Corticosteroids are type of steroid prescribed by pediatric rheumatologists during especially painful JIA flares. Steroid medication is fast acting and can be administered to patients directly into the joint space as intra-articular steroids, orally, or intravenously (Hashkes & Laxer, 2005, 1676). Rheumatologists typically try to avoid using corticosteroids due to adverse effects on patient's bones and growth. Steroid injections are associated with increased risk of periarticular subcutaneous atrophy, or loss of muscle mass in the affected area (Hashkes & Laxer, 2005, 1676). Additional side effects of steroids include renal damage, hypertension, cataracts, increased risk of infection and thinning of the skin.

DMARDs

Disease-modifying antirheumatic drugs (DMARDs), also known as immunosuppressive drugs or slow-acting antirheumatic drugs (SAARDs), work by slowing down the process of JIA by altering the body's autoimmune system (Rhodes, 1991, 912). Thus, this class of medications can prevent joint damage and disease progression. Examples of DMARDs include chlorambucil, gold salts, hydroxychloroquine, D-penicillarnine, sulfasalazine, methotrexate and etanercept (Anthony & Schanberg, 2003, 275). Methotrexate is the most commonly used and most effective DMARD. Methotrexate is usually given orally in low doses or more typically

by subcutaneous or intramuscular injection in higher doses (Hashkes & Laxer, 2005, 1677). Negative side effects of DMARDs include rashes, gastrointestinal symptoms and more severe diseases such as leukopenia (Hashkes & Laxer, 2005, 1677). Due to the side effects of this particular category of medications, it is recommended that rheumatologists closely monitor patients' blood cell counts, liver enzymes, and renal function via blood tests (Hashkes & Laxer, 2005, 1677).

Biologic-modifying Medications

Biologic-modifying medications are a group of treatments made from human genes that prevent components of the body's immune system from causing inflammation. Examples of biologic-modifying medications include etanercept, a soluble tumor necrosis factor (TNF) receptor, remicade, and rituxan. Biologic-modifying medications are usually given in combination therapy as injections. These medications result in side effects such as headaches, skin reactions at an injection site, severe allergic reaction, and severe upper respiratory tract infections. They can also trigger latent diseases such as tuberculosis (TB) and should be avoided if the patient has a history of TB (Hashkes & Laxer, 2005, 1678).

Additional Medications

Interleukin (IL) 1 receptor antagonists, such as anakinra, are given as daily injections and are useful in treating symptoms in children with JIA whose disease is non responsive to anti-TNF medications (Hashkes & Laxer, 2005, 1679). Intravenous immunoglobulins (IVIg) are newer medications that target systemic aspects of JIA,

particularly when used within the first year of diagnosis (Hashkes & Laxer, 2005, 1680). Oral chicken type II collagen is another newer form of JIA treatment. Type II collagen treatments were successful in reducing mild disease activity in children with JIA (Hashkes & Laxer, 2005, 1680). Finally, autologous stem cell transplantation (ASCT) is an additional treatment that is still in an experimental phase. Outcomes of ASCT treatments in children with JIA range from drug-free remission for some patients, no disease improvement, or death in a few cases. ASCT has only been tested on patients with severe JIA (Hashkes & Laxer, 2005, 1680).

CAMs

Complementary and alternative medical therapies (CAMs) are used to treat JIA patients. CAMs are usually used as an adjunct to medications and can include a variety of treatments (Rouster-Stevens, Nageswaran, Arcury, & Kemper, 2008). Examples of CAMs are stress management programs, religious activities such as prayer, homeopathy, acupuncture, dietary changes such as additional vitamins, heat, extra rest or sleep, and massage (Rouster-Stevens, Nageswaran, Arcury, & Kemper, 2008). Researchers have found that CAMs such as meditation and progressive muscle relaxation can be helpful to patients trying to overcome medication limitations (Field, Hernandez-Reif, Seligman, Krasnegor, Sunshine, Rivas-Chacon, Schanberg, & Kuhn, 1997, 608). Many children with JIA take vitamin supplements, particularly vitamin C and D on a daily basis in conjunction with prescribed medications (Rouster-Stevens, Nageswaran, Arcury, & Kemper, 2008). The supplements help to address anemia-related fatigue and boost the immune system. Massage therapy is one of the most commonly used CAMs. Several

studies have shown positive effects of massage therapy such as decreased anxiety, lower levels of the stress hormone cortisol, less joint pain, and shorter periods of morning stiffness (Field, Hernandez-Reif, Seligman, Krasnegor, Sunshine, Rivas-Chacon, Schanberg, & Kuhn, 1997, 608). Massage therapy can be provided by a professional or by the parents of children with JIA. Engaging parents in massage therapy for their children can result in lower parental anxiety levels because they feel more empowered in their child's disease management (Field, Hernandez-Reif, Seligman, Krasnegor, Sunshine, Rivas-Chacon, Schanberg, & Kuhn, 1997, 617).

Physical Activity

Remaining physically active with JIA is difficult but vital. The pain, physical limitation of movement and fatigue associated with JIA can cause children to become less active than their peers, which cyclically leads to less overall flexibility, strength, and physical ability (Anthony & Schanberg, 2003, 276). Patients with JIA are encouraged to participate in sports and group exercise because peer association is related to higher levels of motivation to continue the activity (Schoenstadt, 2008). Pediatric rheumatologists in general recommend that parents allow their children to engage in sports or other activities of their choice as long as they understand that they must take breaks when necessary and tell an adult if they begin to experience JIA symptoms (Lee & Marcellin, 2010). The most highly recommended forms of physical activity for JIA patients are low impact activities such as biking, elliptical machines or swimming because these activities do not put additional strain on the joints (Schoenstadt, 2008).

Physical Therapy

Physical therapy is an important aspect of JIA symptom management. Physical therapy is a multifaceted treatment that includes exercises to maintain an appropriate range of motion in the joints, maximize muscle strength, correct irregularities in posture, enhance aerobic conditioning, gait, and functional mobility (Rhodes, 1991, 918). Physical therapists also aid rheumatologists and other specialists in disease treatment by providing evaluations of the patient's baseline functional level and progress over time (Rhodes, 1991, 918). Physical therapy is adapted to meet the needs of the patient and is typically performed by a physical therapist in a clinic, at school or at home (Rhodes, 1991, 918). The therapist conducts an initial physical examination and history with the child and parent to develop an appropriate treatment plan. The therapist then uses different manual techniques and tools to assess the patient's pain, swelling, range of motion, muscle strength, and mobility (Rhodes, 1991, 913). Physical therapists provide children with JIA and their family members with helpful devices, important information, and useful techniques to help patients reach a higher quality of life.

Modalities

A variety of techniques and devices are used by physical therapists during treatment. Examples commonly used for children with JIA include heat in the form of heat packs or paraffin baths and moist heat from warm baths or pools to combat stiffness (Rhodes, 1991, 915). Although most patients prefer heat, physical therapists use ice or cold compresses to decrease joint and tendon pain (Rhodes, 1991, 915). Physical therapists also use devices such as transcutaneous electrical nerve stimulation (TENS) to

reduce pain and enable children to perform exercises (Rhodes, 1991, 915). Other devices such as splints are commonly recommended by physical therapists to support weak and swollen joints and vary depending on the patient's symptoms (Rhodes, 1991, 914). Finally, physical therapists are able to provide these children with adaptive equipment such as wheelchairs, bathtub transfer seats, special toilet seats, and walking aids, if necessary (Rhodes, 1991, 914).

Surgery

Surgery is a controversial JIA treatment, as some specialists prefer more conservative treatment methods such as physical therapy. Orthopedic joint manifestations typically occur in children with JIA because hip involvement is common, but surgical interventions are not always recommended (Rhodes, 1991, 915). Surgeries used to manage symptoms in children with JIA include synovectomies (removal of the synovium), soft-tissue release, epiphysiodeses (removal of the growth plate), adductor and psoas muscle tenotomies (cutting of tendons), and arthoplasty (joint replacement) (Anthony & Schanberg, 2003, 275). Some patients have noted successful pain reduction after surgery, particularly after receiving adductor and psoas muscle tenotomies (Rhodes, 1991, 916). In general, children receiving surgical interventions experience high levels of functional impairment, severe disabling pain, as well as physical deformity (Anthony & Schanberg, 2003, 275). Research suggests that specialists avoid surgery as a treatment for JIA patients until the patient's growth plates have closed (Anthony & Schanberg, 2003, 275). Finally, researchers are hopeful that continuing advances in medications and

alternative JIA treatments will further reduce the need for juvenile surgeries (Anthony & Schanberg, 2003, 275).

Cognitive-Behavioral Therapy

Cognitive-behavioral therapy (CBT) is a psychological therapeutic approach used to manage pain and promote well-being in children with JIA. CBT approaches in general help patients discover useful techniques to control behavior and cognitions. Therapists can use CBT techniques to provide JIA patients with methods for coping with the pain associated with their disease (Anthony & Schanberg, 2003, 275-276). Patients and their parents are given more information about the body's pain system and ideas for how to control JIA pain. Lastly, patients receiving CBT therapy work with a therapist to anticipate events that may cause more JIA symptoms and apply newly acquired skills to modify their lifestyle (Anthony & Schanberg, 2003, 275-276). Data indicate that CBT approaches are effective in helping children with JIA manage pain and remain physically active. CBT can be conducted in either an individual or group setting. Therapy treatment for JIA patients in a CBT approach is typically performed in six to fourteen sessions, and is led by a psychologist or other specialist (Anthony & Schanberg, 2003, 275-276).

CHAPTER THREE

Disease Impact

A diagnosis of juvenile idiopathic arthritis, or JIA, in a child has a multitude of effects. JIA impacts the patient physically, psychologically, and emotionally. Having a family member with JIA affects all other members of the family, each in a unique way. There are many negative experiences related to having JIA and having a family member with JIA.

Impact on Patient

JIA impacts a patient in many ways. Patients experience physical, psychological, and social issues related to their JIA. Although physical symptoms such as pain are commonly emphasized in the literature, the psychological and social impact of JIA is equally, if not more important.

Physical

JIA negatively impacts patients physically. Patients commonly suffer from joint pain, stiffness, swelling, limited mobility, joint deformity, fevers, rashes, and even trouble sleeping. JIA can also cause long-term disability in patients (Gerhardt, Vannatta, McKellop, Zeller, Taylor, Passo, & Noll, 2003, 13). Some children may be lucky enough to experience a period of remission, or even total disease remission, but as many as two-thirds of children with JIA will experience a recurrence of the disease later in life

(Gerhardt, Vannatta, McKellop, Zeller, Taylor, Passo, & Noll, 2003, 13). Although each case of JIA is unique to the patient, all children carrying the diagnosis experience pain.

Pain

Pain is a universal physical effect of JIA. Most children with JIA experience pain on a daily basis. Typical pain is described as mild to moderate in severity, unless the patient is in a period of high disease activity (Anthony & Schanberg, 2003, 273). Interestingly, cognitive factors contribute to the pain felt by a child with JIA (Anthony & Schanberg, 2003, 273). As a child's cognitive ability develops, the child is able to connect terms and meaning to what they feel (Anthony & Schanberg, 2003, 273). Understanding pain experiences and being able to connect how they are feeling to their disease impacts the patient's overall pain perception (Anthony & Schanberg, 2003, 273). Therefore, older children may begin to feel distressed by pain from an inflamed joint as they begin to fully understand the pathology of their disease (Anthony & Schanberg, 2003, 273). Older children may also begin to add judgment to what they are feeling, such as including associating negative feelings with joint pain (Anthony & Schanberg, 2003, 273). Comparatively, younger children may describe what they feel, such as an aching joint, without adding a positive or negative judgment to the description (Anthony & Schanberg, 2003, 273). Although JIA related pain is better understood with age, all children with JIA are able to characterize their pain using a few common terms. Pain is usually characterized as achy, sharp, burning, and uncomfortable feelings in the effected joints (Anthony & Schanberg, 2003, 273).

Despite the fact that pain is felt by all children with JIA, it is often under recognized, and therefore, under treated by health professionals (Anthony & Schanberg, 2003, 277). Thus, it is important for physical symptoms such as pain to be evaluated regularly, both by the patient and medical professionals. When assessing the impact of pain on a child with JIA it is important for health professionals to consider the patient's age, sex, coping strategies, stress, and overall mood, as all of these factors impact pain measurement (Anthony & Schanberg, 2003, 277). Among the physical impacts of JIA such as join stiffness, fatigue, and disability, pain is the most common and most limiting factor.

Psychological

JIA is responsible for causing many psychological problems. Children suffering from JIA struggle to perform everyday activities. They are constantly feeling pain in their joints, aches, and systemic fatigue. Children with JIA also have to attend regular doctor's appointments, receive special medical procedures, and maintain a regular treatment regimen. The main aspect involved in treatment is medication. Although medication is vital to helping a child combat the negative effects of their illness, medications commonly cause a number of unwanted side effects. The physical implications of JIA commonly result in psychological problems such as anxiety, behavior problems, and depression (Anthony & Schanberg, 2003, 277). The most common psychological issues seen in children with JIA are depression and anxiety (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 40). JIA may cause a child to feel anxious and depressed for multiple reasons. Children may be anxious due to worries

about how their disease may progress in the future, or if they will become crippled. Feelings of sadness may also occur because the physical limitations of JIA restrict them from acting like or being able to do the same activities as other people. Children are at a high risk for anxiety and depression from their JIA if they believe that their disease defines them as a person.

Severe Disease

Overall, more psychological issues exist among children with severe JIA, and both depression and anxiety are more prevalent in children with severe disease (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 40). Disease severity is related to psychological issues because patients with severe disease generally experience the effects of their disease in almost all aspects of their life (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 40). In severe JIA cases, children have many episodes of high disease activity and few episodes of disease remission. Severe disease may also be characterized by many serious necessary medical procedures, strong medications, and therapy. Patients with mild or moderate disease may experience more episodes of disease remission and fewer episodes of high disease activity. Therefore, JIA may not be as prominent in the child's life in a child with mild disease, leading to a lower risk of psychological impairment (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 40).

Recent Diagnosis

In addition to children with severe JIA, recently diagnosed teens are at a high risk of poor psychological adjustment, depression, and anxiety (Daltroy, Larson, Eaton, Partridge, Pless, Rogers, & Liang, 1992). A recent diagnosis can lead to a higher risk for psychological impairments because children are experiencing a period of adjustment (Daltroy, Larson, Eaton, Partridge, Pless, Rogers, & Liang, 1992). A new diagnosis generally causes feelings of uncertainty, frustration, confusion, and anger, among other emotions. Difficulty or failure to adjust to the new diagnosis can cause episodes of anxiety and depression in JIA patients (Daltroy, Larson, Eaton, Partridge, Pless, Rogers, & Liang, 1992).

Age

Age is also a factor in psychological impairment risk. Younger children and adolescents are psychologically impacted differently by JIA. Children with JIA commonly internalize, as opposed to externalize, their concerns and disease symptoms (LeBovidge, Lavigne, Donenberg, & Miller, 2003, 34). Researchers hypothesize that younger children may internalize their disease because they are unable to act out in a way that is normal for their age, such as getting into fights with peers (LeBovidge, Lavigne, Donenberg, & Miller, 2003, 34). Adolescents, who are more mature than younger children tend to externalize their symptoms, possibly because they are able to express the impact of their disease in different ways to others (LeBovidge, Lavigne, Donenberg, & Miller, 2003, 34).

Gender

Finally, gender also plays a role in the psychological impact of JIA. Although both males and females can experience the negative psychological effects of JIA, females suffer more often (LeBovidge, Lavigne, Donenberg, & Miller, 2003, 34). This difference is particularly noticeable with depression (LeBovidge, Lavigne, Donenberg, & Miller, 2003, 34). In fact, females are twice as likely to become depressed than males (LeBovidge, Lavigne, Donenberg, & Miller, 2003, 34). Overall, children diagnosed with JIA are at a high risk for psychological issues. Anxiety and depression are among the most common psychological impairments for patients with JIA. Factors such as disease severity, time of diagnosis, age, and gender impact the patient's risk.

Social

Similar to the psychological effects of JIA, many of the social issues experienced by patients are caused by the physical impacts of the disease and the necessary treatments, although psychological problems can also lead to social problems (Reiter-Purtill, Gerhardt, Vannatta, Passo, & Noll, 2003, 17). Patients with JIA are typically at a higher risk of experiencing problems adjusting, specifically with respect to social competency, creating peer relationships, and self-concept (Degotardi, Revenson, & Ilowite, 1999, 315). The physical limitations from JIA, such as limited mobility, prevent the child from participating in activities with their peers (Degotardi, Revenson, & Ilowite, 1999, 315). Even everyday classroom experiences such as carrying heavy textbooks to class or writing for long periods of time are difficult when a patient has JIA (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 44-45). The apparent differences

between what the child is able to do compared with typical peer behavior can create social isolation for the patient.

Another reason why children with JIA may suffer socially is because the disease and its treatments may cause negative changes in their physical appearance (Degotardi, Revenson, & Ilowite, 1999, 315). Physical changes such as weight gain, skin problems, and swollen or deformed joints and limbs can occur due to the disease and medications used to treat JIA (Degotardi, Revenson, & Ilowite, 1999, 315). Negative changes in appearance cause some children to become self-conscious and develop a low self-esteem. An inferior attitude can cause children to withdraw, limiting interactions with others (Degotardi, Revenson, & Ilowite, 1999, 315). Disease treatments also lead to social isolation because medications commonly produce side effects such as vomiting, nausea, and fatigue, which can sometimes cause a child to feel unwell and unable to participate in activities (Reiter-Purtill, Gerhardt, Vannatta, Passo, & Noll, 2003, 17). In addition to medications, JIA patients also have to attend regular doctor's appointments and therefore, are typically absent from school and other activities that commonly allow children to bond with their peers (Reiter-Purtill, Gerhardt, Vannatta, Passo, & Noll, 2003, 17).

Overall children with JIA participate in fewer activities than their peers due to disease limitations (Reiter-Purtill, Gerhardt, Vannatta, Passo, & Noll, 2003, 18). This lack of involvement leads to social isolation and feelings of being unpopular or disliked by others (Reiter-Purtill, Gerhardt, Vannatta, Passo, & Noll, 2003, 18). Social isolation and withdrawn behaviors increase over time as the child's disease progresses (Reiter-Purtill, Gerhardt, Vannatta, Passo, & Noll, 2003, 24). JIA leads to a fewer number of friends, especially in children with severe disease (Reiter-Purtill, Gerhardt, Vannatta,

Passo, & Noll, 2003, 25). Lack of friend relationships is incredibly detrimental to a child's social and overall development (Reiter-Purtill, Gerhardt, Vannatta, Passo, & Noll, 2003, 25). Children diagnosed with JIA at a young age are especially affected by a lack of friends because habitually engaging in few peer activities and therefore interacting with very few people continues over time, causing severe isolation (Reiter-Purtill, Gerhardt, Vannatta, Passo, & Noll, 2003, 25).

Finally, adolescents are at the highest risk for adjustment problems because developmentally adolescence is a vulnerable period of life (Degotardi, Revenson, & Ilowite, 1999, 315). Traits that characterize poor social adjustment include JIA patients' concern with body image, dependency on others due to their disease, and low self-esteem (Degotardi, Revenson, & Ilowite, 1999, 315). Adolescents are more likely to suffer socially due to their JIA because adolescence is characterized by changes in hormones, mood, and body, and they are already experiencing a developmentally normal struggle to adjust. In conclusion, patients with JIA can experience social isolation, fewer friends, and poor social skills due to many factors such as the physical effects of JIA and treatment regimens that produce negative side effects.

Impact on Family

The whole family is affected by a JIA diagnosis. Healthy siblings experience unique difficulties related to their sibling's struggle with JIA. The parental unit is impacted by their child's disease. Furthermore, both parents may be affected differently. Finally, the total family system receives positive and negative experiences due to a child's JIA.

Siblings

A child's JIA diagnosis impacts their siblings. Siblings are emotionally affected and commonly feel empathy for their sibling and act accordingly (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 45). For example, healthy siblings may be protective of their sibling, or avoid playing with them in ways that might exceed their ability or cause them pain (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 45).

Feelings of anger and jealousy may also be present in the sibling relationship. Healthy siblings may experience periods of time in which they are jealous of their ill sibling. For example, if the healthy sibling feels that they are not receiving an adequate amount of attention from parents, they may become jealous (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 44-45). Healthy siblings may also feel angry. For example, a healthy sibling may feel like their sibling does not get in trouble as often or even is spoiled by parents (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 44-45).

The sibling relationship is also impacted if the healthy sibling is not appropriately educated about the sibling's JIA. For example, healthy siblings may worry that their sibling will die, age faster, or even have stunted growth (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 46). Although JIA causes negative symptoms and experiences for the patient, it is important for siblings to have a correct understanding of the disease and how it is and will impact their sibling (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 46). Finally, healthy siblings are emotionally impacted

by their sibling's JIA. Healthy siblings commonly express feelings such as empathy, jealousy, and anger. Appropriate disease education is important to alleviate unnecessary anxiety from healthy sibling worrying about their sibling's disease.

Parents

Parents who have a child with JIA are especially impacted by the child's disease. Parents often struggle to deal with financial, social, and emotional problems related to their child's disease (Gerhardt, Vannatta, McKellop, Zeller, Taylor, Passo, & Noll, 2003, 6). Parents can feel depressed, exhausted, and overwhelmed (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 43). Parents may also feel like they are more emotional, more protective, nervous, and worried (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 44-45).

Stress

All parents, particularly parents of children who have been newly diagnosed with JIA, experience stress (Gerhardt, Vannatta, McKellop, Zeller, Taylor, Passo, & Noll, 2003, 13). Parents feel stress due to many reasons. For example, parents may be stressed because they have many additional responsibilities to care for a child with JIA (Gerhardt, Vannatta, McKellop, Zeller, Taylor, Passo, & Noll, 2003, 5). Some stress-inducing aspects of raising a child with JIA include dealing with daily medications for their child, and taking their child to routine and unexpected hospital visits (Gerhardt, Vannatta, McKellop, Zeller, Taylor, Passo, & Noll, 2003, 6).

Worry

Parents of children with JIA typically worry often. Worrying can result from feelings of uncertainty and feeling as if they have no control (Gerhardt, Vannatta, McKellop, Zeller, Taylor, Passo, & Noll, 2003, 5). A lack of control can occur because parents feel as if their child's disease runs their life. Parents may also worry about their child's physical limitations, whether or not their child will be permanently handicapped, if the child will be able to have children, the impact of JIA on the child's romantic relationships, the child's financial security, and potential job discrimination (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 46).

Although both parents are affected by their child's JIA, mothers typically are at a higher risk of psychological distress than fathers (Gerhardt, Vannatta, McKellop, Zeller, Taylor, Passo, & Noll, 2003, 6). This is hypothesized to occur because mothers typically are responsible for more of the child's daily care (Noll et al., 1995; Silver et al., 1995, 5). Mothers also take their children to medical appointments more often than fathers (Noll et al., 1995; Silver et al., 1995, 5). Because mothers are more likely to experience the full impact of having a child with JIA, mothers have a higher risk for distress. Depression is a common condition felt by mothers of children with JIA (Gerhardt, Vannatta, McKellop, Zeller, Taylor, Passo, & Noll, 2003, 6). Fathers of children with JIA do not typically express the same level of distress and depression as found in mothers (Gerhardt, Vannatta, McKellop, Zeller, Taylor, Passo, & Noll, 2003, 11-12).

In addition to each parent experiencing the impact of raising a child with JIA, the parental relationship is also affected by a child's disease (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 45). The parents' relationship may experience a period

of instability, especially during the time of diagnosis (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 45). Partners may have trouble adjusting to the new change in their family, causing them to be hard to live with or experience a change in their spouses' personality (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 45). The parents' relationship may also become strained because one or both persons may need to work longer hours to cover the additional costs of having a child with JIA (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 45). Although there are many negative experiences a couple could potentially face, there are also positive aspects that can be experienced by the parents of a child with JIA. Positive effects that may result include parents feel closer with their child and with one another as they work through the emotional issues and this can create a solid and unified relationship (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 46).

Whole Family System

Having a child with JIA impacts the entire family (Degotardi, Revenson, & Ilowite, 1999, 314). One of the main challenges faced by families is adjusting to life with a child with JIA. Because families function as a system of interconnected parts, all family members are affected by the health and well being of one another. Therefore families are particularly challenged by the poor health of a child with JIA (Degotardi, Revenson, & Ilowite, 1999, 314). JIA impacts the patient's everyday activities and creates special needs for the child. The entire family must adjust to meet the specific needs of the child. Adjusting to these needs may include making changes in the family structure such as creating new roles, routines, and rituals (Degotardi, Revenson, &

Ilowite, 1999, 314-315). For example, new roles and routines in terms of household work are commonly established in families with children who have JIA because the ill child may not be able to perform tasks such as raking leaves in the backyard due to their disease. New rituals may include spending quality family time together at a town park or beach, as family vacations and activities may be limited by JIA because medications and medical procedures can create financial trouble for the family (LeBovidge, Lavigne, Donenberg, & Miller, 2003, 30).

Although the whole family is impacted by one member's disease, family members are affected differently. Parents tend to focus on the personal and relationship stress caused by having a child with JIA. Children with JIA focus on the physical symptoms of the disease and limitations in the school environment. Children with JIA also express concern about whether or not their disease is limiting family members or negatively impacting family members. Siblings focus on their lack of understanding about their sibling's disease and experience with their disease (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 48).

The experiences of the family can be described as an empathy-resentment-guilt cycle (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 48). This cycle occurs because parents and siblings feel bad for the child with JIA, but also may feel resentment for having to provide the child with extra help, treatment, and care. Siblings may resent the child because the child receives more attention and may have an easier workload in the household. Parents and siblings may then feel guilty for resenting the child, as the child has had no control over their diagnosis (Konkol, Lineberry, Gottlieb, Shelby, Miller III, & Lorig, 1989, 48). In conclusion, the family system as a whole is

impacted by one member's JIA. Although adjusting to family life often results in negative experiences, the family may feel as if JIA is a part of the family's identity, and is a tool for organizing and centralizing the family (Degotardi, Revenson, & Ilowite, 1999, 314).

CHAPTER FOUR

Helpful Resources for JIA Patients and Families

There are several helpful resources available for children suffering from JIA and their families. Large arthritis organizations exist nationally and globally and provide helpful services for patients and families. Literature such as books, pamphlets, and newsletters are additional sources of information available to patients and families. Support groups such as online groups and in person focus groups are helpful ways for patients and families to connect with one another and share coping strategies with one another. Finally, patients and families can become informed by researching JIA on popular medical search engines on the Internet.

Organizations

Arthritis organizations are excellent resources for JIA patients and their families.

Arthritis Foundation

The Arthritis Foundation, or AF, is a well-known patient-centered arthritis organization. The AF has an easily navigable online website that provides viewers with online arthritis education, therapeutic tips, and links to additional resources (Stanley & Ward-Smith, 2011, 194). As the AF is a national organization, there are many local chapters of the AF throughout the United States. The AF is a particularly interesting arthritis organization because of its advocacy efforts. By volunteering or working with the AF, patients and families have the opportunity to become involved in arthritis

advocacy, even serving as patient and family lobbyists in Washington, D. C. The AF also hosts a variety of different events, such as the Bone Bash, conferences, dinners, and Arthritis Walks. This organization not only provides patients and families with information about JIA and hosts events for patients and families, the AF funds arthritis research.

American College of Rheumatology

The American College of Rheumatology, or ACR, is an organization for scientists, physicians, and other health professionals. The ACR holds annual scientific meetings in the fall where rheumatologists and arthritis specialists share the most current research about arthritis. Research and knowledge gained through conferences are published in the ACR's scientific journals called *Arthritis & Rheumatism* and *Arthritis Care & Research* and made available to patients and families on the organization's national website. The ACR is a great resource for families and patients to obtain the most up to date information found in recent JIA research.

Childhood Arthritis & Rheumatology Research Alliance

CARRA, or the Childhood Arthritis & Rheumatology Research Alliance, is an organization comprised of rheumatologists and arthritis researchers who work to prevent and treat childhood rheumatic diseases such as JIA. CARRA provides information about JIA and offers patients and families the opportunity to become involved in research studies. Patients and families can access the organization's online website and easily find the CARRA centers nearest to them if they wish to participate. Aside from research

studies, CARRA offers patients and families the chance to become involved in several additional organizations, such as Friends of CARRA, which is a non-profit organization that raises money for JIA through fundraisers.

National Institute of Arthritis and Musculoskeletal and Skin Diseases

NIAMS, or the National Institute of Arthritis and Musculoskeletal and Skin Diseases, is an organization created by the National Institute of Health. This organization also provides patients and families with easily accessible information about JIA. The organization is unique because in addition to focusing on JIA research, NIAMS also works to improve training for arthritis specialists. Recently, NIAMS has also been featuring links to bilingual publications about arthritis on their online website.

Literature

A wide variety of literature exists for JIA patients and their families. Some of the most easily accessible literature can be found on the online websites of arthritis organizations, such as the AF, ACR, CARRA, and NIAMS. These organizations will also send patients and families helpful and complimentary newsletters and pamphlets about JIA. In addition to pamphlets and newsletters, books are wonderful resources to help families cope with JIA.

Books

Many books exist to help patients and families handle living with JIA. One helpful book is *Taking Arthritis to School* by Dee Dee Miller, Tom Dineen, and Karen

Schader. This series of books is great to read to younger children with JIA as well as siblings or peers of patients. The books include illustrations and focus on normalizing life with JIA and the interaction between JIA patients and their peers. *Keeping a Secret: A Story About Juvenile Rheumatoid Arthritis,* by Elizabeth Murphy-Melas is a book about a young girl named Jennifer who has JIA. This book is a helpful resource for patients and families because the reader is able to learn how Jennifer copes with her disease and how she handles informing others about her JIA. *Raising a Child With Arthritis: A Parent's Guide: From Infancy to Young Adulthood,* by Charlotte Huff and Richard Vehe is a helpful resource for families, as it provides medical facts about JIA. This book contains information about treatments and coping and is particularly helpful because the authors include real JIA stories of patients and families. *A Parent's Guide to Rheumatic Disease in Children,* by Thomas Lehman, is more specifically targeted for parents of children with JIA. The book is written by the leader of a well-known pediatric rheumatology program and is incredibly informative. Another book that would be useful for parents is called *Relieve Your Child's Chronic Pain: A Doctor's Program for Easing Headaches, Abdominal Pain, Fibromyalgia, Juvenile Rheumatoid Arthritis, and More* by Elliot Krane and Deborah Mitchell. This book is unique because it focuses on ways for parents to learn more about their child's JIA pain. For example, this book provides information about how to measure and evaluate a JIA patient's pain, which can be difficult for families. Finally, a highly recommended and widely used book is *The Arthritis Helpbook: A Tested Self-management Program for Coping* by James Fries and Kate Lorig. This book has been published for over twenty years and still remains one of the best sources of information about coping with JIA. Although this book is a longer

read, it is broken up into easy to navigate chapters for readers with information ranging from arthritis medications to exercise programs for JIA patients.

Support Groups

Support groups are useful for children with JIA and their families because they provide a way for people to connect with one another, share experiences, trade helpful tips with each other, and develop friendships. As the Internet has become a commonplace medium, support groups exist both online and in person.

Online Groups

A website called MD Junction has a JIA support group. The group is for parents of children with JIA and is free to join. This group offers an open discussion forum, group diaries, videos, and relevant articles. Another online website called Daily Strength offers free support groups for juvenile arthritis. This group can be for JIA patients or parents and includes many discussion boards, blogs, answers to members' questions from JIA experts, and information about treatments. Finally, the website MySpace offers JIA forums. These forums are typically aimed for adolescent children with JIA not parents. Patients wishing to join a MySpace forum must have a MySpace account, which is free to create.

In Person Groups

If JIA patients or parents wish to meet with one another, a website called JRA allows patients and families to begin their own JIA groups, or join existing Juvenile

Rheumatoid Arthritis Meetup Groups. The website lists the current groups and includes information about the topics covered in group meetings so patients and families can choose a group that matches their needs. Focus groups also exist throughout the United States. These groups are local and generally related to research studies. Patients and parents of children with JIA should speak with their rheumatologist and/or their rheumatology health professionals to learn more about focus groups in their area.

Search Engines

If children with JIA or their families wish to conduct their own research searches to learn more about the disease, specific search engines are very helpful. One of the most useful Internet search engines is PubMed. PubMed is easy to use and allows users to conduct advanced searches. This search engine provides abstracts of research studies as well as full publications and can be used to research almost any JIA-related topic.

Conclusion

JIA is a group of chronic autoimmune diseases that impact a child's physical, social, and psychological well-being. The consequences of JIA impact the patient and all family members in mostly negative ways. Overall disease impact on the child with JIA and the entire family unit depends on many factors such as how well educated family members are about the disease, how to manage JIA symptoms, and how to best help the child remain actively engaged in daily activities. Many resources exist to support those suffering from JIA and their families, and most of these resources are easily accessible online. Additionally, many organizations provide opportunities for children and families

to meet others experiencing similar situations, share stories and make connections with each other. The ability to develop interpersonal relationships with others who either have JIA, or have a family member with JIA, can help children and families cope with the disease in many ways, such as aiding in the development of a new perspective on life. Additionally, organizations such as CARRA, ACR and the AF provide funding for research, providing hope for a cure. Advances in pharmacologic management such as the biologic therapies provide hope for children with JIA and their families. These new drugs provide symptom relief and interact with the immune system to alter disease progression. However, they come with a price. These potent medications have serious side effects and children need to be closely monitored while taking these medications. Thus, the importance of non-pharmacologic interventions such as counseling, exercise and physical activities and CAMS should not be underestimated. Regardless of the advances in medications, receiving a chronic disease diagnosis has significant psychological and social impacts on the child and his/her family. To provide social support, arthritis researchers are evaluating video gaming and other social media activities as possible venues for promoting social and psychological well-being. The promise of such interventions is the possibility of reducing social isolation and building connections with children who have the same health condition.

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