

CARE, HEALTH, ARTHRITIC MANAGEMENT

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EDITOR'S MESSAGE

In this issue, we are going to read about the management and treatment of juvenile idiopathic arthritis (JIA). Our invited paediatricians will introduce various treatment options including conventional and biologic disease modifying anti-rheumatic medications and the treat-to-target strategy on pharmacological treatment for patients with JIA. Orthopaedic surgeons have written about various Orthopaedic procedure at the early and late phase of this disease. Other than medical specialists, allied health professionals also contribute to multidisciplinary support in the management of these children and adolescents. Physiotherapist writers will walk you through the assessment and treatment they offer during the flare up and remission phases of this disease. You will also read about the important role of Occupational therapists in the provision of interventional modalities to improve functional ability and occupational lifestyle redesign program to support the growth and development of these children to become young adults with improved quality of life. Last but not the least, good nursing care with proper education for these children and their parents is also crucial on patient management. Nursing specialists will let you know how they educate patients and their parents on the medications and associated side effects. In this issue, we have also solicited the perspective from a practitioner of Traditional Chinese Medicine (TCM) on the various approaches from different TCM specialists.

It is a pity that the novel coronavirus pandemic has affected much of our daily social activities. We hope to see all of you soon at our routine yearly multidisciplinary talks when the COVID-19 situation has resolved. Meanwhile, enjoy reading and get used to a new mode of work and education from home! Stay healthy !

PHARMACOLOGICAL TREATMENT OF JUVENILE IDIOPATHIC ARTHRITIS

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Juvenile idiopathic arthritis (JIA) is the most common chronic rheumatological condition affecting children and adolescents, encompassing all forms of chronic arthritis of unknown origin, with onset before 16 years of age. In high-income countries, the prevalence ranges from 16 to 150 per 100,000 population. According to an epidemiological study in Taiwan, the prevalence of JIA is 33.8 per 100,000 population under the age of 16 years.¹ Assuming a similar epidemiology in Chinese children, we estimate the number of patients with JIA under 16 years is approximately 300 in Hong Kong.

JIA is an important cause of short-term and long-term disability. Recent therapeutic advances have made remission, or at least minimal levels of disease activity, an achievable goal for most patients. Attaining complete disease quiescence is associated with less long-term articular and extra-articular damage and physical disability, and should be regarded as the ideal therapeutic objective. This is achieved by the availability of more efficacious anti-rheumatic therapies and improved treatment strategies.²

PHARMACOLOGICAL TREATMENT OF JUVENILE IDIOPATHIC ARTHRITIS

In Hong Kong, a consensus statement on biological disease modifying anti-rheumatic drugs (DMARDs) in polyarticular course JIA, enthesitis-related arthritis and psoriatic arthritis was formulated by the JIA Work Group commissioned by The Hong Kong Society for Paediatric Rheumatology, just published earlier in 2020.³ Patients with persistently active arthritis in these disease categories despite adequate use of one or more conventional DMARDs (e.g. methotrexate, leflunomide, sulfasalazine), or those who are intolerant of these medications, treatment escalation to biological DMARDs should be considered. Readers are strongly recommended to refer to the consensus statement for detailed information. Examples of biological DMARDs, eligibility and recommended dosing regimen are summarized in Table 1.^{3,4} They are often given in association with methotrexate to patients who do not respond adequately to methotrexate alone.

The biological DMARDs that are currently used for JIA include monoclonal antibodies and recombinant proteins that block cytokine receptors, or neutralize cytokine activity, or modulate lymphocyte functioning.⁴ Tumour necrosis factor (TNF) inhibitors were the first type of biologic agents introduced for treating JIA with a polyarticular course, after adequate use of conventional DMARDs which is defined as treatment with at least one of them at adequate dose for at least 3 months unless toxicities are present. TNF inhibitors are usually the first choice of biologics to commence, except in systemic onset JIA. Five anti-TNF agents have been developed so far, including etanercept, infliximab, adalimumab, golimumab and certolizumab pegol. Of these drugs, etanercept and adalimumab have been approved for use in JIA by both FDA and EMA, while golimumab has been approved only by EMA for the treatment of paediatric patients with a body weight over 40kg. Etanercept and adalimumab have also been shown to be effective in the treatment of enthesitis-related arthritis and psoriatic arthritis.^{3,4}

Other biological agents proven effective in methotrexate-resistant polyarticular JIA include tocilizumab and abatacept, both of which are approved by FDA and EMA for use in children. Tocilizumab is a monoclonal antibody directed against the soluble receptor of IL-6. Abatacept is a fusion protein containing the extracellular domain of cytotoxic T-lymphocyte associated antigen 4 (CTLA4). Abatacept leads to homeostatic downregulation of activated T-cells and their survival by interfering with the binding of CD28 to its cell surface receptor. Abatacept is usually considered when at least one TNF inhibitor has been tried without satisfactory therapeutic response.^{3,4}

Systemic onset JIA is characterized by systemic features such as high fever and evanescent rash. IL-1 inhibitors (anakinra, canakinumab and rilonacept) and IL-6 inhibitors (tocilizumab) are effective in controlling the systemic inflammation and arthritis.^{4,5}

New therapies show promise for patients who experience resistance to the treatment options currently available.⁵ One of the novel therapeutic targets in rheumatoid arthritis is the Janus kinase (JAK) that transduces cytokine-mediated signals via the STAT pathway. Tofacitinib is an orally administered small molecule that blocks JAK3, JAK1, and JAK2 to a lesser extent. Recently, tofacitinib was shown to result in significantly fewer disease flares, improved time to flare, improvements in disease signs and symptoms and physical functioning, and a sustained clinically meaningful improvement in disease activity compared with placebo in a phase 3, randomized, double-blind placebo-controlled withdrawal study in patients aged 2 to < 18 years with polyarticular course JIA, with a safety profile consistent with that in adult rheumatoid arthritis.⁶

Treat-to-target strategy for managing JIA

Early diagnosis, prompt initiation of DMARDs, close monitoring of disease activity, and treatment adjustments aiming at the target of clinical remission or at least low disease activity are the standard of care in the management of rheumatoid arthritis. In patients with JIA, early DMARD treatment is associated with better disease control and outcome, especially when there is an early response to treatment.⁷ This suggests a window of opportunity for JIA exists, that long-term disease process can be altered by early successful disease control, which can be achieved by setting targets to monitor disease activity and treatment response, prompting escalation of treatment if the pre-determined targets are not reached.^{2.7}

The Juvenile Arthritis Disease Activity Score (JADAS) is a composite tool for scoring disease activity in JIA. JADAS includes the following four measures: 1) physician's global assessment of disease activity (measured on a 0-10 visual analog scale (VAS) where 0 = no activity and 10 = maximum activity); 2) parent global assessment of well-being (measured on a 0-10 VAS where 0 = very well and 10 = very poor; 3) the erythrocyte sedimentation rate (ESR, normalized to a 0 to 10 scale); and 4) a count of joints with active disease. The clinical JADAS (cJADAS) is a reduced version that lacks the acute phase reactant.⁸ JADAS and cJADAS aim to quantify the absolute level of disease activity by providing a number on a continuous scale, and cut-offs that correspond to clinical remission and low disease activity have been determined. In a study on polyarticular JIA adopting a treat-to-target strategy (recognizable JADAS improvement after 3 months, acceptable disease at 6 months, minimal disease activity (MDA) at 9 months and primary endpoint remission after 12 months), patients in the treat-to-target cohort were more likely to reach JADAS remission (48% vs 32%) and JADAS MDA (76% vs 59%) after 12 months compared with those on unguided therapy. Significantly more patients were treated with biologics to reach the targets of JADAS remission or MDA compared with those on unguided therapy (50% vs 9%), but notably over half of the patients in treat-to-target cohort were able to reach JADAS MDA on methotrexate monotherapy. Results from this study demonstrated that a guided treat-to-target strategy with early escalation of therapy is superior to unguided treatment in JIA, and is feasible to implement in clinical routine care.9 The ultimate treatment goals are achieving symptom control, preventing structural damage, avoiding comorbid conditions and drug toxicities, and optimizing function, growth and development, quality of life and social participation.

PHARMACOLOGICAL TREATMENT OF JUVENILE IDIOPATHIC ARTHRITIS

It should be recognized that JIA is a heterogeneous group of diseases with varying clinical phenotype, disease mechanisms, genetic background, disease course and outcome that requires distinct treatment approaches. Therapeutic targets should be individualized, and the options and strategies to achieve these targets should be based on shared decisions between parents / patient and the physicians.^{2,9}

	Mode of Action	Eligibility	Route	Recommended dosing
Etanercept	Chimeric fusion protein binding to circulating TNF- α	Polyarticular course JIA aged ≥ 2 years Enthesitis related JIA and psoriatic arthropathy aged ≥ 12 years	Subcutaneous	0.4mg/kg (maximum 25mg) twice weekly or 0.8mg/kg (maximum 50mg) once weekly
Adalimumab	A fully humanised monoclonal anti-TNF antibody binding to soluble and membrane-bound TNF- α	Polyarticular course JIA aged ≥ 2 years Enthesitis related JIA aged ≥ 6 years	Subcutaneous	10 to < 15kg: 10mg once every 2 weeks 15 to < 30kg: 20mg once every 2 weeks ≥ 30kg: 40mg once every 2 weeks
Golimumab	Recombinant human monoclonal antibody against TNF binding to soluble and membrane-bound TNF- α	Polyarticular course JIA aged ≥ 2 years	Subcutaneous	< 40kg: 30mg/m ² ≥ 40kg: 50mg Dosing interval: every 4 weeks
Abatacept	Inhibits co-stimulatory signal by binding to CD80/CD86 ligands of antigen-presenting cells and interferes with its interaction with T cells	Moderate to severe active polyarticular course JIA aged ≥ 2 years who are unresponsive to ≥ 1 conventional DMARDs and ≥ 1 TNF-inhibitor	Intravenous or Subcutaneous	Route of administration and dosage Intravenous: ≥ 6 years < 75kg: 10mg/kg > 75 to < 100kg: 750mg ≥ 100kg: 1,000mg Dosing interval: 0, 2 weeks and 4 weeks then every 4 weeks Subcutaneous: ≥ 2 years 10 to < 25kg: 50mg / 0.4ml syringe 25 to < 50kg: 87.5mg / 0.7ml syringe ≥ 50kg: 125mg / 1ml syringe Dosing interval: once weekly
Tocilizumab	A humanized anti-IL6 monoclonal antibody	Systemic JIA aged ≥ 2 years Polyarticular course JIA aged ≥ 2 years	Intravenous or Subcutaneous	Systemic JIA Intravenous: < 30kg: 12mg/kg every 2 weeks ≥ 30kg: 8mg/kg every 2 weeks Subcutaneous: < 30kg: 162mg every 2 weeks ≥ 30kg: 162mg every week Polyarticular course JIA Intravenous: < 30kg: 10mg/kg every 4 weeks ≥ 30kg: 8mg/kg every 4 weeks Subcutaneous: < 30kg: 162mg every 3 weeks ≥ 30kg: 162mg every 2 weeks
Anakinra	Recombinant IL-1 receptor antagonist	Systemic JIA aged ≥ 8 months and ≥ 10 kg	Subcutaneous	< 50kg: 1-2mg/kg daily ≥ 50kg: 100mg daily Route of administration: subcutaneous
Anakinra	Human monoclonal antibody against IL-1 β	Systemic JIA aged ≥ 2 years	Subcutaneous	4mg/kg (up to a maximum of 300mg) Dosing interval: every 4 weeks

Table 1 Biologic DMARDs for JIA. Information summarized from references 3 and 4, and package inserts available from manufacturers, meant for reference only. Readers are advised to refer to drug insert for more detailed information before prescribing.

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MANAGEMENT OF JUVENILE IDIOPATHIC ARTHRITIS -AN ORTHOPAEDIC PERSPECTIVE

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Overview

While surgery may appear to be an "overkill" for diseases caused by inflammation from juvenile idiopathic arthritis (JIA), certain patients may benefit from orthopaedic operative management with appropriate indications.

Orthopaedic surgical management can be broadly divided into 2 categories - surgeries targeting conditions arising from JIA itself, and surgeries addressing secondary effects due to pharmacological interventions (e.g. steroids) used to manage JIA.

Options of Orthopaedic Procedure in Juvenile Idiopathic Arthritis

Tender, swollen joints are frequently accompanied by synovitis. Synovectomy involves surgically excising inflamed synovium of affected joints¹, such as the knee, which could be performed by conventional "open" surgical approaches or through arthroscopic "key-hole" techniques. However, this is not commonly performed because recurrence is frequent², and evidence is lacking on its impact on long term outcomes. Therefore, synovectomy remains a second-line treatment and should only be considered upon failure of medical treatment. It provides symptomatic relief only and there is no evidence that it alters the natural history of JIA patients.

Joint contractures affecting lower limb weight bearing joints, such as the knee and the hip, could result in gait disturbances. Soft tissue releases³ have been reported, coupled with post-operative splintage to maintain gains in range of motion, with hopes of improving function and ambulatory ability. Limb deformities in the growing skeleton, a result of peri-physeal articular inflammatory activity or otherwise, could be surgically corrected by epiphysiodesis or guided growth⁴ - a process where the anatomical area responsible for longitudinal growth (i.e. physis) is surgically manipulated with the aim of achieving satisfactory limb alignment. The degree of correction depends on the timing of surgery (surgery at younger age results in corrections of greater magnitude), which may be challenging to accurately predict in some JIA patients.

All the aforementioned measures are unfortunately not disease-modifying and do not alter the natural history of JIA patients.

Avascular necrosis of the hip, a result of long-term steroid use, could cause debilitating hip pain and impair function. While downright replacing the diseased joint with orthopaedic prosthesis (i.e. arthroplasty) may be convenient solution, it is rarely the first-line treatment. Joint arthroplasty is particularly contraindicated in young patients whose bones have not yet reached its final size at skeletal maturity. Arthroplasty is also a poor choice in these patients due to the potential of long-term complications among young patients with extended life expectancies, and revision surgery is often difficult. Initial attempts, therefore, usually involve preservation of the native joint.

Core decompression⁵ (multiple drilling of the necrotic segment of the femoral head) to relieve intraosseous pressure, remove necrotic bone, stimulate the release of growth factors is an option for early stage avascular necrosis when subchondral collapse has not yet taken place. In slightly more advanced cases where larger amounts of necrotic bone have to be evacuated but femoral head collapse has not yet occurred, vascularised fibula bone graft⁶ (healthy bone from the fibula is "auto-transplanted" to the hip) is performed to further increase blood supply and provide a scaffold for creeping substitution. This surgery is technically demanding, requiring the expertise of microvascular surgeons, and is only performed in specialist centres.

If all such fails, joint replacement remains the last resort.

Role of Joint Replacement Surgery in Juvenile Idiopathic Arthritis

In patients with JIA, joint destruction may occur either directly due to significant inflammatory arthritis or avascular necrosis secondary to medications for management of the disease. Progression to end-stage joint destruction is an indication for joint replacement surgery in this population of patients, usually performed after they have reached skeletal maturity. Knee and hip joint replacement are the commonest joint replacement surgeries performed in this group of patients. Occasionally, upper limb joint replacement surgery may be necessary for sake of rehabilitation and improvement of activities of daily living.⁷

MANAGEMENT OF JUVENILE IDIOPATHIC ARTHRITIS -AN ORTHOPAEDIC PERSPECTIVE

Hip and Knee Replacement Surgery

Hip replacement surgery in JIA often come secondary to joint destruction from disease progression or avascular necrosis of the femoral head. Replacement surgery can be performed with cemented or cementless implants. Survivorship of these implants are promising, with cementless implants having a better survivorship of around 80% at 10 years, and cemented implants having a survivorship of around 70% at 10 years.⁸

Knee replacement surgery in JIA is more common than hip replacement surgery. These surgeries are often necessitated by the significant joint destruction arising from the underlying inflammatory disease progression. Cemented implants are used in this group of patients. For significant deformities in both knees, bilateral same-session knee replacements can be performed. The survivorship of these knee replacements is reported at 90% at 10 years, and 80% at 20 years.⁹

With adequate post-operative physiotherapy and training, often patients can regain satisfactory range of motion and function to cope with activities of daily living. This also helps to reduce pain and deformity, which allows them to go back to usual academic and social activities without hinderance.

It is worth noting however, that with advent of new agents and management strategies in controlling JIA, fewer patients with JIA will develop end-stage joint destruction which necessitate joint replacement surgery.

Difficulties and Challenges of Joint Replacement Surgery in Juvenile Idiopathic Arthritis

Joint replacement surgery in this population poses specific challenges and risks, calling for experienced joint replacement surgeons who are more familiar with the difficulties of surgery. Patients in this disease group often are younger in age, which may make pre-operative and post-operative management more challenging. Patient education is particularly important in this group of patients to ascertain better outcome in the long run. As this disease occurs in a growing child, often surgery has to wait until skeletal maturity for sake of preserving limb length and physeal growth. Because of this, soft tissue contractures or premature physeal closure with limb deformities may set in, leading to unique pathological changes in the joints, making surgery more complicated for these patients.

Moreover, the inflammatory nature of the disease poses additional challenges in surgery. Inflammatory joint diseases are notoriously known for their detrimental effect on bone quality, which not only makes surgery more difficult, but also leads to increased risk of intra-operative complications such as fractures and bone loss. On the other hand, medications used for management of JIA affect many aspects of perioperative and intraoperative management of these patients undergoing joint replacement surgery. Immunomodulatory agents may lead to delayed wound healing, and often treating clinician would need to balance the risks and benefits of withholding these medications before and after surgery. These patients often have use of corticosteroids which affects wound healing, perioperative glycaemic control, as well as intra-operative bony density. Given that these patients often require continued rheumatological treatment after operation, they are also at a higher risk of post-operative complications, including aseptic loosening and periprosthetic joint infections which may necessitate revision of the joint replacement.

Because of these factors, perioperative management of these patients requires comprehensive pre-operative planning, detailed discussion between patient, parents and surgeon and more often needs combined input from a multidisciplinary team of rheumatologists and experienced orthopaedic surgeons. Their peri-operative medication regimen should be well discussed and optimized, and their post-operative physical therapy should be maximized with planned from physiotherapist to optimize the replaced joint's range of motion and function.

Conclusion

Orthopaedic surgeons play a key role in the management of JIA. In the early stage of disease, surgery can help to address the pathology itself or it is secondary effect by means of synovectomy, correction of deformity and joint contracture, and prevention of avascular necrosis. For patients who suffer from end-stage joint destruction, joint replacement surgery aims to improve their pain, range of motion, and most importantly function. This is particularly important in the paediatric patient group where they have higher demand in terms of active lifestyle and academic participation.

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PHYSIOTHERAPY MANAGEMENT FOR CHILDREN WITH JUVENILE IDIOPATHIC ARTHRITIS (JIA)

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Introduction

Physiotherapy is part of the multidisciplinary management team and the mainstay of JIA interventional management.^{1,2} The common manifestation is pain, stiffness, swelling, muscle weakness and reduced mobility part from physical limitations, patients with JIA also face a decline in their quality of life. Their activities are often limited by pain, which would therefore deprive them of their opportunities to play and participate in activities such as physical education classes, high impact sports like basketball, and outdoor activities.³ Our purpose in this sharing is to adopt the International Classification of Function, Disability and Health (ICF) framework from the World Health Organization to identify areas of management strategy in physio-therapy for children with JIA. The second purpose of this sharing is to provide better understanding of the clinical issues common to the JIA population.

The International Classification of Function, Disability and Health (ICF)

The ICF provides a framework for identifying problems of a condition based on the Body Function and Structure, Activity and Participation level. Therapists can then set out the goals of therapy and the intervention directions accordingly. Figure 1 below illustrates the application of the ICF framework on the functioning in children with JIA.⁴



Figure 1. ICF model for children with JIA

Body Functions and Structure *Flare-up Phase*

Most of the JIA patient referred to physiotherapy were at their Flare-up phase. Physiotherapist carry out thorough assessment on pain manifestation and complaints, active and passive joint range, muscle power measurement, functional level limitation and balance assessment to evaluate their body function and structure impairment. Resting pain, movement-induced pain, pain-limited mobility, stiffness, swelling and increase in temperature at involved joints are the main manifestations of this phase. Pain relief therapies are either stand-alone treatments or adjunct to pharmacological input, with the aim of minimizing resting pain and pain after activity.⁵ Common electrophysical modalities for pain relief used include the followings---transcutaneous electric nerve stimulation (TENS) therapy, TENS on acupuncture points, interferential therapy, microcurrent therapy, therapeutic ultrasound. Other than electrophysical therapy, physiotherapists also provide patients with cryotherapy, which makes use of ice for a combined effect of pain reduction, swelling control and local inflammation control. Mobility is then preserved and improved with manual mobility facilitation while avoiding flare-ups. Hydrotherapy, which relies on water properties, helps physiotherapists achieve specific treatment goals for individual needs.⁶ For example, while buoyancy of water reduces mechanical stress to joints, it is also a challenging medium for balance and coordination training. For patient taking biologics, physiotherapist will record Disease Activity Score-28 (DAS28) to monitor the progress.⁷

Muscle activity at flare-up phase is preserved by a combination of different joint protection manoeuvers. At the active phase, targeted programme is focused on meeting individual needs. We therefore treasure rapport building with the family, as it plays an important role in good compliance of home care plan.

PHYSIOTHERAPY MANAGEMENT FOR CHILDREN WITH JUVENILE IDIOPATHIC ARTHRITIS (JIA)



Remission Phase

It is important for the child to remain active and involve in sports and activities with their peers. It is common for a child in remission phase to report subtle discomfort over previously affected joints, reduction in active range of motion, minor sprains or strains, joint stiffness and reduced endurance. They also report limited school activities, social activities and the opportunity to play. During the remission phase, we pay careful attention to post-flare-up joints and the ergonomics of their daily activities. Physiotherapists often apply myofascial release, a manual soft tissue technique, to mobilize soft tissues and improve the fluency of movement.⁸ Kinesiology knowledge is also applied to decide the level of assistance or resistance in training, such that the joint mechanics and movement ergonomics are optimized. Balance, coordination and synergy training is another arm of therapeutic goal in this phase. Where the child has developed interstitial lung disease, cardiopulmonary training in forms of aerobic exercise and inspiratory muscle training are also needed to improve overall exercise capacity. Physiotherapists will carry out intervals of 6-minute-walk-test and Spirometry to follow their aerobic and respiratory performance. With a comprehensive management, mobility efficacy in term of strength, endurance, and balance and co-ordination can then be achieved.

Activity and Participation

Impairments in body function and structure could result in changes at both activity and participation levels. Physiotherapist will carry out the Child Health Assessment Questionnaire (CHAQ) for disability index and discomfort index to keep track of the progress.⁹ A generalized physical activity programme aims to improve muscle strength, endurance and cardiovascular fitness with low-impact to moderate strengthening exercise.¹⁰ Long term self-care plan and exercise engagement are the keys to an active and enjoyable lifestyle. Family and peer support in the engagement of lifelong participation is crucial for the adherence to the treatment plans.



Summary

While pain may limit the amount of activity a child can handle, it is important to encourage involvement during flare-up period or remission and allow rest and symptom-reducing therapies during periods of flare-ups. Regular activity and exercise programmes help to reduce symptoms, maintain range of motion in affected joints, and also to build and maintain strength. Physiotherapy therefore plays a vital role in helping patients maintain an active lifestyle.

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OCCUPATIONAL THERAPY PERSPECTIVE IN JUVENILE IDIOPATHIC ARTHRITIS

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Prevalence of JIA

Juvenile idiopathic arthritis (JIA) describes a clinically heterogeneous group of arthritides of unknown cause, which begin before 16 years of age. This is a chronic disease characterized by prolonged synovial inflammation that may cause structural joint damage.^{1,2} Prevalence varied from 16 to 150 per 100,000. A local inter-hospital retrospective surveillance in 2000 showed that there were 125 patients with JIA receiving biologic treatment at 12 Departments of Paediatrics at the Hospital Authority.³

	Pauciarticular	Polyarticular	Systemic-Onset
Frequency of cases	60%	30%	10%
No. of joints involved (in first 6 mth)	≤4	≥5	variable
Age perdominance	Type I: preschool age Type II: 9-11 yr	2-5 yr and 10-18yr	None
Gender ratio (F/M)	Туре I: 4:1 Туре II: 1:20	3:1	1:1
Involved joints	Knees and ankles	Larger joints, symmetric involvement	Any, including hips
Chronic uveitis	20% (higher with [+] ANA)	5%	Rare
Extra-articular manifestations	uveitis	Mild fever, hepatosplenomegaly, lyrmphadenopathy, subcutaneous nodu	Once- to twice daily high-spiking fevers, hepatosplenomegaly,
Seropositivity			lymphadenopathy, polyserositis, pericarditis, and characteristic macular rash
Antinuclear antibody	75%-85%	40%-50%	10%
Rheumatoid factor	10% (increased w age)	75%-85%	
Destructive arthritis	Rare	>50%	>50%
Major morbidities	Uveitis, leg length discrepancy		Pericarditis, pleuro-pericarditis, secondary amyloidosis, macrophage activation syndrome
prognosis	Excellent apart from eyesight	Poorer prognosis with RF seropositivity and later onset	Moderate to poor

JIA may persist into adulthood in up to 50-60% of cases.⁴ Non-reversible abnormalities may also occur in extra-articular organs such as the eyes or the kidneys or result from adverse effects of medications. 80% of adult patients with JIA require various forms of pain relief; 50% suffer from functional disorders of different severity degrees; 50% require joint replacement and 22% have eye problems due to uveitis. The long-term outcome of JIA depends on its clinical variant, disease activity, target organs involvement, as well as response to therapy.

Disability and pain were the most important determinants of physical and mental health. Dzhus's research concluded that young adults with JIA had worse quality of life (QoL) with impaired physical well-being including Physical Functioning, Role Functioning & Bodily Pain than healthy individuals of the same age and gender.⁵ The risk factors were prolonged morning stiffness as a manifestation of disease activity and polyarticular variant of joint damage.

Objectives of JIA management and treat-to-target strategy

There may be times when symptoms get worse and better known as flares and remission respectively. Signs and symptoms include: joint pain, swelling, fever, stiffness, rash, fatigue, loss of appetite, inflammation of the eye, difficulty with daily activities such as walking, dressing, and playing. Pain is common despite adequate disease control and is associated with functional disability and can cause absenteeism in school and extracurricular activities. The negative experience living with JIA from physical limitations and pain might result in altered social functioning and emotional difficulties such as depression and anxiety.⁶

Recent development of new therapeutic agents including methotrexate and biologics and combination treatment strategies have radically changed the management of JIA patients and improved the long-term outcome. Constant monitoring of disease courses and child health status that facilitate normal growth is important in JIA. Multiple forms of damage may develop over time such as micrognathia, height retardation, localized growth disturbances, pubertal delay, visceral organ failure.

OCCUPATIONAL THERAPY PERSPECTIVE IN JUVENILE IDIOPATHIC ARTHRITIS

"Treat-to-target strategy" leads to more effective treatment with the following objectives:

- 1. Ameliorate patient symptoms
- 2. To improve inflammatory manifestations for improving health-related QoL
- 3. Prevent irreversible damage

The clinical targets include inactive disease and clinical remission. Inactive disease is defined by absence of joints with active disease, systemic manifestations, uveitis and disease activity by physician global assessment and normal values of acute phase reactants for ≥ 6 consecutive months when the patient is receiving anti-rheumatic medications; whereas clinical remission without medication is achieved when the criteria for inactive disease are met for ≥ 12 consecutive months after the patient has discontinued all anti-rheumatic medications.

Role of Occupational Therapy in JIA

Early diagnosis and treatment by a team of rheumatology professionals can help avoid joint damage.⁷ Occupational Therapists (OTs) are committed to empowering individuals with JIA to live life to their fullest. OTs engage clients in programs that increase their knowledge about the disease process, show them how to manage pain and related manifestations and promote their ability to participate in meaningful activities through special skills to create or modify home and work environments.

1. Assessment

include joint range of motion, muscle strength, pain and sensation and activity endurance. We will also evaluate the needs of a client for protective/ functional splints, adaptive equipment/ device, and offer advice on home and work environmental modifications. Peri-operative management may include incorporating special protocols into the evaluation process and intervention planning to improve QoL of patient and parents.

2. Intervention

strategies may include physical agent modalities to assist pain management; techniques to manage inflammation, including limb elevation, pressure garments, exercise and splinting; therapeutic activities and exercises to promote gross and fine motor control, range of motion, endurance and strength, thereby improving functional abilities with daily tasks such as self-care, home management, work and leisure activities; provision of custom or prefabricated splints to assist with controlling pain, maintaining functional positions of the hand, and enhancing function; training the use of joint protection and energy conservative techniques, including assistive devices and modify daily routines to ensure adequate rest and to avoid overuse; and ergonomic assessment and activity modification at home, work and school settings.

Occupational Lifestyle Redesign Program to enhance Self-Management

Stress management and coping strategies through exercise, relaxation techniques, and nutrition. Self-management and engagement in therapeutic activities and exercise programs to decrease pain and depression and to increase functional abilities, improve sleep, and enhance overall health. OTs collaborate with clients to find effective strategies to manage and control symptoms by addressing specific goals that target purposeful activities that are meaningful to them, helping their transition from adolescent in school to productive young adulthood.

3. Value of OT with the children/ teens growing with changes

Growing with JIA means coping with change. Programs are tailor-made to create client-centred care. With understanding of normal development, physiological and psychosocial changes that comes with growth and the challenges of managing a chronic condition might facilitate an individual to maximize performance abilities and promote independence in self-care, family, and community activities regardless of limitations. Loss of mobility as a result of arthritis is a common experience for those living with this disease. Being able to drive allows them to maintain their independence in the community. With appropriate choice of vehicle model, well-designed adaptation, and optimal strategies for raising driving concerns, young adults can live their way with even better QoL.⁸

Shaw studied the prevocational and early employment needs of adolescents with JIA and reported that this group are at higher risk of unemployment compared with peers, despite having comparable academic achievement.⁹ Academic arrangement of special educational needs (SEN) such as provision of support like use of word-processor with laptops, scribes and allowance of extra time to complete course work and examinations enables patients to produce work commensurate with their abilities. Job matching and vocational counselling offer them the scope of employment according to their physical capabilities, and appropriate attitude in the interaction with other people. There are local Patient Retraining and Vocational Resettlement Services run by Occupational Therapy Departments in Princess Margaret Hospital and Queen Elizabeth Hospital.



4. Living with JIA

Children with JIA should attend school, participate in extra-curricular and family activities, and live their life as normally as possible. To foster a healthy transition to adulthood, adolescents with JIA should be allowed to enjoy independent activities, such as taking a part-time job and learning to drive.⁷ Occupational therapy can increase joint motion, reduce pain, improve function, and increase strength and endurance. Therapists may construct splints to prevent permanent joint tightening or deformities, and work with school-based therapists to address issues at school. Summer camps run by self-help group to interact with other children who have arthritis should be encouraged. There are services that provide children with JIA special accommodations at school and vocational rehabilitation. Family members can help the child by getting the best care possible, learning about the disease and its treatment, joining a support group, treating the child as normally as possible, encouraging exercise and physical therapy, working closely with school, talking with the child about their feelings and working with therapists or social workers.¹⁰

OCCUPATIONAL THERAPY PERSPECTIVE IN JUVENILE IDIOPATHIC ARTHRITIS

5. Health literacy for adolescents

A qualitative study reflected that adolescents with JIA face social challenges.4 Adolescents in the focus group shared the specified coping strategies they used worth reference in running Occupational Lifestyle Redesign Program by disclosing to others that they have JIA, using communication skills, maintaining activities with friends, trying to minimize pain and ignoring negative comments. Adolescents can benefit from online resources which deliver useful information, strategies and self-management of their symptoms, facilitates interaction with others for peer support treatments via online education. Instagram and WhatsApp are good platforms to interact with other teens with JIA socially cope with JIA, strengthens their social networks as support system and surveys of their interests.

Do not under-estimate the impact of fatigue on the activity participation of young adults with rheumatic conditions. Energy conservation strategies and skills in integrating self-management into occupational routines. During the transition phase, OTs will support them in developing an occupation-based, fatigue management intervention tailored to the specific needs and preferences of young adults with rheumatic conditions.¹¹ This is anticipated that one-stop, holistic, patient-oriented and integrated multidisciplinary service model can benefit patients with JIA.



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NURSING CARE FOR CHILDREN WITH JUVENILE IDIOPATHIC ARTHRITIS

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Introduction

Children have juvenile idiopathic arthritis (JIA) suffer from a number of presentations of chronic inflammatory diseases and their quality of life are impaired from habitual inconvenience to endurance of pain. These young patients with JIA develop a lot of symptoms such as fevers, rash, and arthritis. Recently there are more reports showing these patients may also suffer from pulmonary arterial hypertension, interstitial lung disease and alveolar proteinosis. For reducing their agony, increasing attention should be directed to their caring and awareness of other complications in the treatment.

JIA patients present with common symptoms of inflammatory arthritis with persistent joint swelling for more than 6 weeks before 16 years old and require proper healthcare management. The management of JIA has dramatically changed in the last decade with improvement in medical therapy.¹ Current medical management includes non-steroidal anti-inflammatory drugs (NSAIDs) and analgesics, intra-articular and systemic corticosteroids, and the use of cytokine modulators ('biologics'). Long-term corticosteroids for children have major side effects. Therefore, there is a need for treatment towards disease remission and establishment of a good nursing care plan to improve quality of life of these children with JIA.

Nursing Care

To conduct nursing care to children with JIA, it is imperative to understand this disease and the various medical treatments. Early prevention and treatment of joint inflammation can avoid severity and deterioration. Inflamed joints sometimes present with morning stiffness. Daily activities may be limited, especially in physical exercises. As proper relief measure, patients are advised to use big joints instead of small joints to prevent burden to the small joints. Swimming is also good for muscle strengthening and improving movement of the joints. Good sitting posture and body weight control also help to reduce pressure on the joints.

NSAIDS help to relieve symptoms. Physiotherapy program, movement or stretching exercises may be introduced and warm compact can be applied in the early morning or a few times a day to reduce stiffness of joints. Nurses should provide special care in administering drugs to patients on NSAIDS and steroid. The side effects of corticosteroids such as increase appetites and puffy faces are minimized as the dosage is decreased. It is necessary to ensure that the children would follow the medication regimes and not stop corticosteroids without discussion with the practitioners. Parents should be advised that they need to follow the children medication regime to ensure no missed dose or disruption of the medication. Children vaccination program should be followed and not be withheld unless with permission from doctors. It will be good for nurses to explain to the children with JIA about the alteration in the body image to mitigate the impact of poor self-esteem.

NURSING CARE FOR CHILDREN WITH JUVENILE IDIOPATHIC ARTHRITIS

Uveitis is common diagnosed in association with JIA. Frequent visits to the ophthalmologist for checking to prevent complications including glaucoma, cataract or retinal detachment are necessary. Appropriate eyes drop is needed to suppress inflammation when uveitis develops.

Treatment of JIA has dramatically changed with the use of biologics which have less side effects. Administration of biologics can be easily managed at home and by means of intradermal injection with observation at the injection site for any sign of complications, such as rashes, etc. Nurses could educate parents and children who are capable of taking care of themselves on various key things of the treatment including the need to follow the frequency of the dosage. If there is missing dose longer than one day, patients should consult their doctor or nurse to decide on the next dosage or reschedule the injection plan. They should also be advised to take precaution of drug storage. Accurate dosage should be taken out from the fridge 15 to 30 minutes before administration.

Both parents and children are facing a lot of stress when diagnosed with the disease. Ensuring their understanding of condition, prognosis and treatment are important. Nurses could engage them in the discussion on the health care and planning needed, and provide feedback to their questions to facilitate their understanding on a clear treatment plan.

Support from the school is important. Nurse could assist in liaising with the school for provision of care such as extra time allowed for examination due to pain in the joints and problem of joint movement in physical exercise lessons. Nurses play a vital role to provide the school with information on the medical conditions of the children with JIA to facilitate better understanding by the school on the needs of these children.

Pulmonary diseases in JIA are increasingly detected in systemic juvenile idiopathic arthritis (sJIA).^{2,3} Clinical features of pulmonary hypertension or other potentially fatal pulmonary complications are typically subtle so that close observation and follow-up are needed, as well as screening for these complications in systemic JIA patients with persistent diseases.

The recent introduction of biological disease-modifying antirheumatic drugs is highly effective, with less joint deformity, growth retardation and other complications of corticosteroids. There has been significant growth of knowledge on caring for children especially in the transitional care to adult. A well collaborated effort and support by the medical team including doctors, nurses and allied health professionals can enhance the healthcare management for children with JIA and their families to achieve better quality of life.

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幼年特發性關節炎的中醫治驗舉隅

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幼年特發性關節炎 (Juvenile idiopathic arthritis, JIA) 是特指在兒童及青少年中發生的關節炎,其定義在發病年齡 小於16歲,排除其他自身免疫性疾病,出現持續6週或以上的單或多關節炎,以慢性關節炎為主,並可伴有全身性 多系統損害,常見症狀為發熱、皮疹、關節對稱性腫脹、壓痛和晨僵等。現代醫學認為,其發病與免疫有關。中醫 學角度認為,本病屬於中醫學「痹證」「頑痹」的範疇。本病的病理過程屬本虛標實,小兒體質純陽,臟腑嬌嫩, 形氣未充,故易感受風寒濕邪;外邪雜至,臟腑經絡鬱遏陽氣,化而為熱,濕熱互結,傷及血絡、經絡、關節、臟 腑等,故此出現鮮紅皮疹、關節腫痛、肢體腫脹、臟腑氣血痹阻等症狀。

近年中醫醫家開始對幼年特發性關節炎的診治作出論述,筆者綜合不同文獻稍作整合,供各位參考如下:

孫素平教授¹認為,JIA發作分急性期與緩解期,治療原則為"急則治標,緩則治本"。急性期表現為"濕聚熱蒸", 故治法上重在清熱解毒利濕;緩解期重在固本,根據患兒臟腑偏衰而補益臟腑之氣,而由於患兒處於生長發育的黃 金時期,脾腎作為後天及先天之本的調護更應視為重點。而此病病程較長,久病成瘀,故應全程活血化瘀。教授會 選用四妙丸加減、白虎湯合五味消毒飲加減作為急性期的主方;緩解期則在上述方劑的基礎上,加入熟地黃、杜仲、 黨參、太子參、丹參等一類補腎健脾、益氣活血的藥物隨證使用。

朱良春教授²提出以"益腎壯督"治其本,"蠲痺通絡"治其標為主要原則,根據發作期或緩解期配合健脾清利通絡 等方法進行治療。教授選以蠲痹湯貫串整個療程,輔以清熱解毒、清化濕熱作為發作期的兼治,在主方上配伍青風 藤、忍冬藤、金剛骨、桂枝等藥擬方治療,其中教授指出藤類藥善於攀越纏繞,質地堅韌,既能祛風除濕、行氣活 血亦可通絡引經,當中以青風藤和忍冬藤合用,寒熱各異,組成藥對,相互制其寒熱之性,療效更住,適應證亦更 廣;緩解期則著重益腎培本,會加入補骨脂、骨碎補、熟地黃、黨參等一類補腎健脾益氣藥物輔以主方治療;如需 涼血活血則會加入赤芍、丹皮、生地黃等藥物。

幼年特發性關節炎的中醫治驗舉隅

教授亦提出由於小兒與成年人機體上的不同,臨床上用藥亦需要多加注意的細節如:一)注意慎用毒性、藥性峻猛 之藥,如川草烏、馬錢子等;二)注意顧護脾胃,小兒脾胃嬌嫩,又因用西藥消炎止痛藥和免疫抑製劑等都可傷及 脾胃,故治療宜護脾胃,酌加茯苓、白朮、薏苡仁等顧護脾胃;三)要注意用藥劑量,不宜過大,或可將一劑藥分 多次服用,避免藥性過急過猛

么遠³則認為,幼年特發性風濕病大致可分為毒熱內蘊、濕熱合邪、風寒濕痺、久病肝腎虧虛四類,故此清熱利濕, 祛瘀散寒、活血通絡是治療的重心,根據出現全身症狀為主使用清營湯、白虎湯等以清熱解毒,涼血通絡;或關節 症狀為主的患者則選用二妙散、宣痺湯等祛濕散寒,活血通絡;久病體虛者則會選用獨活寄生湯以滋補肝腎,益氣 養心。在整個治療過程中,始終以清熱利濕作為主要方向,然而亦應參考舌象、脈象的表現,斟酌化濕、清熱及溫 經通絡藥的比例與輕重。

熊越華⁴提出除了使用中藥湯方內服以外,亦可選擇加入外洗方緩解患兒關節疼痛腫脹等相關症狀,其一以四黃水蜜 外敷,以四黃粉用蜂蜜和溫開水各半調成糊狀,然後將其敷在患兒的關節處,具有清熱解毒、止痛的作用,可有效 緩解患兒關節痛的症狀;在肢體腫脹,局部疼痛方面,則可選用四子散藥熨,使用紫蘇子、萊菔子、白芥子和吳茱 萸各60g製成溫熨藥包,溫熨患處,有袪風散寒除濕、溫經通絡、消除炎症的作用。

總結

綜合上述各醫家的論述,針對幼年特發性關節炎患者本虛標實的重點而作出相應治療均取得不錯的療效,當中應時 刻照顧幼兒生長發育的情況,顧護好脾腎兩臟,並按臨床上患者的症狀以清熱利濕、溫經散寒為原則,標本兼治, 應能做到控制病情,減輕患者不適的效果,而且亦能內外用藥並舉,應更能減輕患兒在發作期的不適。如能在以上 的基礎考慮中西藥並用,相信療效會進一步提高。

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