The Evolving Role for Physical Therapy for Patients with Rheumatic Diseases.

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Disclosures

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- We do not intend to discuss an unapproved or investigative use of a commercial product or device in this presentation.

Key References


Objectives

1. Identify the clinical presentation of the diagnoses presented.
2. Recognize appropriate assessments and interventions based on knowledge gained from the clinical update.
3. Describe the evolving role of the PT from interventionist to preventionist with these diagnoses.

Systemic Lupus Erythematosus (SLE)

- 10-20% have onset in childhood and adolescence
- More severe course
- Varying presentation
- Chronic multi-system inflammatory disease involving mostly skin, joints, kidneys, CNS, serous membranes and hematological system (Silva)
- Childhood onset presents < 18 years old
- Survival has increased due to earlier diagnosis and better approaches to treatment
SLE Classification System

<table>
<thead>
<tr>
<th>Malar rash</th>
<th>Pleuritis or pericarditis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discoid rash</td>
<td>Renal</td>
</tr>
<tr>
<td>Photosensitivity</td>
<td>Neurologic</td>
</tr>
<tr>
<td>Oral ulcers</td>
<td>Hematologic</td>
</tr>
<tr>
<td>Nonerosive arthritis</td>
<td>Immunologic</td>
</tr>
<tr>
<td>(+) ANA</td>
<td></td>
</tr>
</tbody>
</table>

Clinical Presentation

- Large variability in presentation
- Higher need to measure QOL due to outcome measures of health status, disease activity
- Mortality rates have decreased due to advances in management, but increase in long term co-morbidities
  - Cardiovascular disease
  - Long term corticosteroid use
  - Systemic inflammation
  - Autonomic dysfunction
  - Hypertension
- Physical inactivity induces chronic fatigue, obesity and weakness/atrophy

Rashes of SLE

- Photosensitive Rash
- Malar Rash

Assessment

- ROM
- MMT
- Cardiorespiratory exercise test
- Systemic Lupus Erythematosus Disease Activity Index (SLEDAI)
- Childhood Health Assessment Questionnaire (CHAQ)
- Pediatric Quality of Life Inventory Rheumatology module
- Simple Measure of the Impact of LE in Youngsters (Silva, 11)

Management Considerations for Childhood Onset Systemic Lupus Erythematosus Patients and Implications on Therapy

(Silva 2015)

Methods:
- Review of effect of exercise on individuals with SLE

Results:
- Reduces inflammatory markers
- Improves physical function and strength
- Increases overall QOL

Exercise Training in Childhood-onset Systemic Lupus Erythematosus: A Controlled Randomized Trial

(Prado 2013)

Methods:
- Disease activity was assessed using the SLE disease activity index: validated disease activity measure that contains 24 descriptors in 9 organ systems
- Accumulated damage was measured with Systemic Lupus International Collaborating clinics/ACR Damage Index: physician rated index

Results:
- Patients with JSLE have poorer HRQOL as compared to healthy controls in both physical and psychosocial domains.
  - This indicates parents are concerned with their child’s overall health, susceptibility to sickness, and are distressed about their child’s functioning on many levels.
Scleroderma

- Incidence of 0.3-2.8 cases per 100,000/year (European countries)
- Most common between 30-50 yo
- Affects females (80%)
- Characterized by excessive collagen deposition and vascular changes in different organs and body systems

Clinical Presentation

- Insidious course, aggressive
- Repercussions on integumentary, musculoskeletal, GI, kidneys, and cardiopulmonary system
- 80% of cases have myositis, myopathy, calcification, and arthritis
- Involvement of vascular system causes insufficiency
- Hand deformities are the most observable and common MS impairment

Clinical Presentations

<table>
<thead>
<tr>
<th>Skin changes on the face</th>
<th>Linear Scleroderma</th>
</tr>
</thead>
</table>
Linear Scleroderma of the Face

Assessment

- ROM
- MMT
- Joint count
- Functional assessment
- QOL

Authors

<table>
<thead>
<tr>
<th>Authors</th>
<th>Subjects</th>
<th>Exercise Intervention</th>
<th>Outcome Measures/Results</th>
<th>Discussion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pils et al</td>
<td>n=16</td>
<td>12 paraffin wax</td>
<td>Improvement in joint</td>
<td>Improvement maintained &gt;3 months in ROM group also improved in</td>
</tr>
<tr>
<td>Mugui et al</td>
<td>n=42</td>
<td>treatments</td>
<td>motion and skin</td>
<td></td>
</tr>
<tr>
<td>Maddali, Bongi</td>
<td>n=40</td>
<td>Randomized into no</td>
<td>stiffness</td>
<td></td>
</tr>
<tr>
<td>Seeger and Furst</td>
<td>n=19</td>
<td>wax vs wax x 3 months</td>
<td>significantly improved</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(mean age 48.6)</td>
<td>Self administered</td>
<td>total passive joint</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>stretching</td>
<td>motion in all fingers</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3-10 reps x 10</td>
<td>No change in HAQ</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>seconds each</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Connective tissue</td>
<td>Significant improvemen</td>
<td>ROM in PIP</td>
</tr>
<tr>
<td></td>
<td></td>
<td>massage</td>
<td>t for fist closure, joint</td>
<td>joint did not</td>
</tr>
<tr>
<td></td>
<td></td>
<td>McMennell joint</td>
<td>motion, hand</td>
<td>change</td>
</tr>
<tr>
<td></td>
<td></td>
<td>manipulation</td>
<td>function and QOL</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>ROM HEP</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dynamic splints worn</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>8 hrs/day x 2 months</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Juvenile Dermatomyositis

- Inflammatory disease of the muscle (myositis), skin (derm) and blood vessels
- Affects about 1.9-4.1 million children each year
Clinical Presentations

- Muscle weakness
- Limited range of motion (ROM)
- Difficulty with functional activities
- Decreased endurance
- Calcinosis
- Skin rashes

Skin Rashes

| Heliotrope | Gottron’s Papules |

Assessment

Physical Therapy Evaluation

- Range of Motion (ROM)
- Manual Muscle Test (MMT)
- Childhood Health Assessment Questionnaire (CHAQ)
- 6 Minute Walk Test (6MWT)
- Childhood Myositis Assessment Scale (CMAS)

CMAS Scoring Sheet
CMAS Activities

1. Head lift
2. Leg raise/touch object
3. Straight leg lift/duration
4. Supine to prone
5. Sit-ups
6. Supine to sit
7. Arm raise/straighten
8. Arm raise/duration
9. Floor sit
10. All fours maneuver
11. Floor rise
12. Chair rise
13. Stool step
14. Pick up

Interpreting the CMAS score (Huber 2004)

<table>
<thead>
<tr>
<th>Physical Disability</th>
<th>CMAS score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moderate</td>
<td>30 to 38</td>
</tr>
<tr>
<td>Mild to Moderate</td>
<td>39 to 44</td>
</tr>
<tr>
<td>Mild</td>
<td>45 to 47</td>
</tr>
<tr>
<td>None</td>
<td>&gt;48</td>
</tr>
</tbody>
</table>

CMAS >48
- Does not need active PT
- Consider community activities or sports

CMAS 45-47
- Mild to no ROM issues
- Consider PT consult 1x/month - 3x/year

CMAS 39 to 44
- and/or decreased ROM
- No ROM issues - consider 1x/week, to every other week
- Decreased ROM - consider 1x/week

CMAS *12-38
- Consider rehab stay with 3 hrs/day of therapy

CMAS <10
- Requires Acute care

Exercise and Treatment Approaches

<table>
<thead>
<tr>
<th>Author and Year</th>
<th>Study Design</th>
<th>Level</th>
<th>Disease Stage</th>
<th>Age of Patients (yrs)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Omori 2012</td>
<td>Quasiexperimetal</td>
<td>II</td>
<td>Active, remission and chronic</td>
<td>7 to 13</td>
</tr>
<tr>
<td>Takken 2008</td>
<td>Quasiexperimetal</td>
<td>II</td>
<td>Active vs remission</td>
<td>11.2 ± 2.6</td>
</tr>
<tr>
<td>Hicks 2002</td>
<td>Quasiexperimetal</td>
<td>II</td>
<td>Remission to moderately active</td>
<td>11.2 ± 3.0</td>
</tr>
<tr>
<td>Maillard 2005</td>
<td>Quasiexperimetal</td>
<td>II</td>
<td>Active, remission, controls</td>
<td>Age of onset 6</td>
</tr>
<tr>
<td>Rissager 2013</td>
<td>Quasiexperimetal</td>
<td>II</td>
<td>Remission</td>
<td>16 to 42</td>
</tr>
<tr>
<td>Omori 2010</td>
<td>Case study</td>
<td>V</td>
<td>Active vs control</td>
<td>7</td>
</tr>
</tbody>
</table>

Things to consider with the CMAS

- Healthy younger children ages 4 to 9 do not receive the full score (Rennebohm 2004, Quinoes 2013)
- Younger children may have a hard time following directions or cooperating
- Must perform on the right lower extremity (LE)
- May have a ceiling affect or may not be sensitive to slight weakness (Rider 2011)
**Interventions**

Exercise programs: 1 session up to 12 weeks
- Cycle ergometer (Hicks 2002, Riisager 2013, Takken 2008)
- Open chain-concentric and eccentric LE (Maillard 2005)
- SLR, sitting MAQ, sidelying hip add/abd, prone hamstring curls, back extensor, sit ups and heel raises (Omari 2010)
- Treadmill
- Resistance training: bench-press, leg press, lat pull down, leg extension and seated row exercises (Omari 2010)
- Stretches

**Outcome Measures**

<table>
<thead>
<tr>
<th>OUTCOME MEASURES</th>
<th>TREATMENT EFFECT</th>
<th>AUTHORS</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMAS</td>
<td>Improved</td>
<td>Omori 2010</td>
</tr>
<tr>
<td></td>
<td>No Change</td>
<td>Riisanger 2013</td>
</tr>
<tr>
<td>VO_{2} peak</td>
<td>Improved</td>
<td>Takken 2008, Omari 2010, Riisanger 2013</td>
</tr>
<tr>
<td>Timed up and go/Stand</td>
<td>Improved</td>
<td>Omari 2010</td>
</tr>
<tr>
<td>Peds QL</td>
<td>Improved</td>
<td>Omari 2010</td>
</tr>
<tr>
<td>Disease Activity Score</td>
<td>Improved</td>
<td>Omari 2010</td>
</tr>
<tr>
<td>Blood Serum Levels (CK and LDH)</td>
<td>No Change</td>
<td>Maillard 2005</td>
</tr>
</tbody>
</table>

**Factors Limiting Exercise**

- Pain → inflammation, calcinosis, change in muscle architecture
- Weakness → pathological changes to muscle tissue
- Decreased VO_{2} peak 30 to 40% decrease
- Pulmonary issues → chest muscle weakness
- Calcinosis → pain, skin ulcerations, nerve entrapment, joint contractures
- Skin rash

**Treatment Guidelines**

- **ACUTE**
  - ROM: AAROM, PROM, Splinting
  - Strengthening: Strength to tolerance, Isometric, Light weights, Isotonic
  - Endurance: Consult with Respiratory Therapist, Stationary bike, Treadmill
  - Functional Activities: Bed mobility, Transitions, Bed mobility
  - Wound Care: Yes

- **REHAB**
  - ROM: AROM, Stretching
  - Strengthening: Isometric, Light resistance bands
  - Endurance: Stationary bike, Treadmill
  - Functional Activities: Transitions, Ambulation
  - Wound Care: Yes

- **OUTPATIENT**
  - ROM: Stretching
  - Strengthening: Isometric, Concentric/eccentric, Isotonic, Resistance bands
  - Endurance: Stationary bike, Treadmill
  - Functional Activities: Community distance for ambulation
  - Wound Care: Yes

**Juvenile Idiopathic Arthritis (JIA)**
**JIA Classification**

(Petty 2004)

**Polyarticular**
- Affecting 5 or more joints
- Can be RF+ or RF -

**Oligoarthritis**
- Affecting 1-4 joints
- Persistent and extended

**Systemic**
- Arthritis in 1 or joint with characteristic fever and at least one of the following:
  - Enanthema rash, generalized lymphadenopathy, liver or spleen enlargement, spleenitis

**Psoriatic**
- Arthritis or psoriasis or arthritis and 2 of the following:
  - dactylosis, nail pitting, onycholysis, psoriasis in a 1st degree relative

**Enthesitis Related**
- Arthritis and Enthesitis or Arthritis or enthesitis and 2 of the following: SI joint tenderness or spinal inflammatory pain, +HLA-B27, family history of confirmed HLA-B27

**Clinical Presentations**

- Joint swelling and stiffness
- Limited joint motion with morning stiffness
- Fatigue and limited endurance
- Muscle atrophy
  - reduced isometric quad strength
- Secondary osteopenia related to long term oral steroid use
- Uveitis

**Assessment**

Physical Therapy Evaluation

- Large focus on participation and activity restrictions
- Pain - VAS
- ROM/MMT
- Joint count and structure
- Gait and functional movement analysis
- Childhood Health Assessment Questionnaire (CHAQ)
- 6 minute walk (6MWT)
CHAQ Scoring Sheet

- Agges 1-19
- Assesses the health status and function in children with JIA, JDMS, SLE, children with chronic musculoskeletal pain, spina bifida
- Includes the International Classification of Functioning, Disability and Health
  - Body function
  - Activities and participation
  - Overall health status

Interpreting the CHAQ (Dempster 2001)

<table>
<thead>
<tr>
<th>Physical Function</th>
<th>CHAQ Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moderate</td>
<td>1.53</td>
</tr>
<tr>
<td>Mild to moderate</td>
<td>0.71</td>
</tr>
<tr>
<td>Mild disability</td>
<td>0.24</td>
</tr>
<tr>
<td>No disability</td>
<td>0</td>
</tr>
</tbody>
</table>

Exercise and Treatment Approaches

- Takes about 10 minutes to complete
- Easy to use in clinic or for research
- There is a ceiling effect in children with mild disease (Klepper 2011)
- There is another version that may reduce ceiling effect (Groen 2010)

CHAQ38CAT

Things to consider with the CHAQ

- Takes about 10 minutes to complete
- Easy to use in clinic or for research
- There is a ceiling effect in children with mild disease (Klepper 2011)
- There is another version that may reduce ceiling effect (Groen 2010)
Exercise and Treatment Approaches  (Klepper 2007)

1) Early referral to rehabilitation services
   *baseline measurements
   *recommendations for maintaining active lifestyle
2) Assessment of exercise capacity or performance
   *reassess periodically during periods of active and inactive disease
3) Identify goals that are important for child and parent
4) Provide information on importance of exercise

Authors  
Tarakci (2012)  
Singh-Grewal (2008)  
Apti (2014)  

Subjects  
- 81 children with JIA ages 5-17 y/o  
- 80 children with JIA ages 8-16 y/o  
- 47 children with JIA 8-16 y/o  

Exercise Intervention  
- 12 week land-based HEP (1x/wk at hospital as well)
- Individually based
- Compared to controls
- Moderate intense aerobic exercise vs. qigong program
- 12 weeks, 1x supervised, 2x at home
- Aerobic walking 4x/week for 8 weeks
- Active and passive ROM to involved joints
- Compared to controls

Outcome Measures/Results  
- Improvement shown in 6MWT, CHAQ, pain, PedsQL
- VO2max and peak power showed no changed
- Improved CHAQ
- Improved exercise parameters
- Improved CHAQ
- Improved ROM

Discussion  
- Home based, supervised program proved beneficial
- Qigong group more compliant
- No exacerbation of disease
- ROM and aerobic exercise proved beneficial

Staging Exercise  
(table adapted from Klepper 2008)

<table>
<thead>
<tr>
<th>Phase</th>
<th>ROM and Flexibility</th>
<th>Aerobic Activity</th>
<th>Neuromuscular Training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute Disease</td>
<td>AROM or AAROM</td>
<td>Balance rest with low intensity PA</td>
<td>Submaximal isometric pain free ROM</td>
</tr>
<tr>
<td>Subacute and Chronic</td>
<td>1-2 reps</td>
<td>Reduce load on inflamed joints - aquatic - bike</td>
<td>1 set of 1-6 reps</td>
</tr>
<tr>
<td>Inactive and Remission</td>
<td>1-2 reps 1x/day</td>
<td>Active flexibility exercises</td>
<td>8-10 reps against gravity (no pain and good form)</td>
</tr>
<tr>
<td></td>
<td>Modified Yoga poses</td>
<td></td>
<td>Use light weights</td>
</tr>
<tr>
<td></td>
<td>1-2x/day</td>
<td></td>
<td>Increase muscle endurance by adding 15-20 reps</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Resistance exercise</td>
</tr>
<tr>
<td></td>
<td>20sec rest between reps</td>
<td></td>
<td>Determined starting weight based on 6-10 reps</td>
</tr>
</tbody>
</table>

Neuromuscular control - proprioception - postural control - coordination
- agility - speed

- Coordination, speed and agility

Common foot issues with JIA  
(Hendry 2012)

- Synovitis
- Tenosynovitis
- Enthesitis
- Pain
- Stiffness
- Deformity

Orthotics

Staging Exercise  
(table adapted from Klepper 2008)
### Splinting for ROM

| Knee Extension Splint | Wrist Cock-up Splint |

### Considerations for Sports and Physical Activity (Rice 2008)

<table>
<thead>
<tr>
<th>Consideration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systemic or polyarticular JIA who have a history of C-spine involvement</td>
</tr>
<tr>
<td>require x-ray of C1 and C2</td>
</tr>
<tr>
<td>Systemic or HLA-B27 associated arthritis</td>
</tr>
<tr>
<td>require cardiovascular assessment</td>
</tr>
<tr>
<td>Micrognathia (open bite and exposed teeth)</td>
</tr>
<tr>
<td>require mouth guards</td>
</tr>
<tr>
<td>Uveitis</td>
</tr>
<tr>
<td>ophthalmologic assessment recommended</td>
</tr>
</tbody>
</table>

### A Qualitative Study of Fitness Instructors Experiences Leading an Exercise Program for Children with Juvenile Idiopathic Arthritis (Huntz 2009)

### Considerations for Sports and Physical Activity

<table>
<thead>
<tr>
<th>Static and Dynamic Postural Balance (Houghton 2013)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Decreased single limb balance</td>
</tr>
<tr>
<td>• Mild impairments in double limb balance</td>
</tr>
<tr>
<td>Kinematics and Kinetics of Lower Extremities (Hartmann 2010)</td>
</tr>
<tr>
<td>• Decreased walking speed and step length</td>
</tr>
<tr>
<td>• Differences in kinematic, kinetic and spatio-temporal patterns</td>
</tr>
<tr>
<td>Land-Jump Performance (Ford 2009)</td>
</tr>
<tr>
<td>• Differences compared to controls with drop vertical jump maneuver</td>
</tr>
</tbody>
</table>

### Determining appropriate Sport or Activity (Kegger 2003)

<table>
<thead>
<tr>
<th>What are the child’s interests?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the activity within a reasonable distance of the family’s home?</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>What are the demands?</td>
</tr>
<tr>
<td>• Contact collision potential</td>
</tr>
<tr>
<td>• Aerobic</td>
</tr>
<tr>
<td>• ROM</td>
</tr>
<tr>
<td>• Static and dynamic muscular</td>
</tr>
<tr>
<td>• Neuromuscular skill</td>
</tr>
<tr>
<td>Does the child have the physical attributes for safe and successful participation?</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Ask further questions</td>
</tr>
<tr>
<td>• Inform coaches</td>
</tr>
<tr>
<td>• Is there a prescreen</td>
</tr>
<tr>
<td>• Safety equipment</td>
</tr>
<tr>
<td>Remediate impairments</td>
</tr>
<tr>
<td>• ROM</td>
</tr>
<tr>
<td>• Strength, endurance</td>
</tr>
<tr>
<td>• Aerobic capacity</td>
</tr>
<tr>
<td>• Neuromuscular skills</td>
</tr>
</tbody>
</table>

### To Do

- Explore other activities
- Considerations for Sports and Physical Activity
- A Qualitative Study of Fitness Instructors Experiences Leading an Exercise Program for Children with Juvenile Idiopathic Arthritis
- Splinting for ROM
- Determining appropriate Sport or Activity
- Considerations for Sports and Physical Activity (Rice 2008)
- Static and Dynamic Postural Balance (Houghton 2013)
- Kinematics and Kinetics of Lower Extremities (Hartmann 2010)
- Land-Jump Performance (Ford 2009)
The Evolving Role of PT in the Biologic Era

**Biologics - What are they?**

- First introduced in 1999 to treat children
- They change how your immune system works by stopping the chain that causes inflammation at different stages
- Why the term "biologic"?
  - because they are genetically engineered as opposed to chemically engineered

**Effectiveness of Biologics Assessed** (Sawhney 2010)

1. Physician global assessment of disease activity
2. Parent/patient assessment of overall wellbeing
3. Functional ability
4. Number of joints with active arthritis
5. Number of joints with limited ROM
6. Erythrocyte sedimentation rate

**Table: Biologic Effectiveness Clinical Presentations Reference**

<table>
<thead>
<tr>
<th>Biologic</th>
<th>Effectiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Etanercept</td>
<td>80% ACR Pedi 30</td>
</tr>
<tr>
<td></td>
<td>72% ACR Pedi 50</td>
</tr>
<tr>
<td></td>
<td>44% ACR Pedi 70</td>
</tr>
<tr>
<td></td>
<td>Improved CHAQ</td>
</tr>
<tr>
<td></td>
<td>Improved Joint ROM</td>
</tr>
<tr>
<td></td>
<td>Less morning stiffness</td>
</tr>
<tr>
<td></td>
<td>Decreased pain</td>
</tr>
<tr>
<td>Adalimumab</td>
<td>30-63% ACR Pedi 30</td>
</tr>
<tr>
<td></td>
<td>63-74% ACR Pedi 50</td>
</tr>
<tr>
<td></td>
<td>52-63% ACR Pedi 70</td>
</tr>
<tr>
<td></td>
<td>42% ACR Pedi 90</td>
</tr>
<tr>
<td></td>
<td>Woo (2007)</td>
</tr>
<tr>
<td></td>
<td>Shepherd (2016)</td>
</tr>
<tr>
<td>Abatacept</td>
<td>84-5% ACR Pedi 30</td>
</tr>
<tr>
<td></td>
<td>79.3% ACR Pedi 50</td>
</tr>
<tr>
<td></td>
<td>55.2% ACR Pedi 70</td>
</tr>
<tr>
<td></td>
<td>41.4% ACR Pedi 90</td>
</tr>
<tr>
<td></td>
<td>31% inactive disease</td>
</tr>
<tr>
<td></td>
<td>Improved CHAQ/QAL</td>
</tr>
<tr>
<td></td>
<td>Decreased pain</td>
</tr>
<tr>
<td></td>
<td>Improved participation</td>
</tr>
<tr>
<td></td>
<td>Lovell (2015)</td>
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<tr>
<td>Tocilizumab</td>
<td>89.9% ACR Pedi 30</td>
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<tr>
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<td>82.3% ACR Pedi 50</td>
</tr>
<tr>
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<td>48.4% ACR Pedi 70</td>
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<td>Fan (2016)</td>
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</tbody>
</table>

**How Has The Presentation Changed**

- Decreased active joint count (Boiu 2012, Shepherd 2016)
- Improved physician global assessment (Boiu 2012, Shepherd 2016)
- More cases of inactive disease (Boiu 2012, Shepherd 2016)
- Improved functional ability (Boiu 2012, Ungar 2013, Klotzsche 2014, Callhoff 2013)
- Improved quality of life (Lovell 2015)
- Decreased pain (Shepherd 2016, Klotzsche 2014)
Survey Methods

- 3 listservs
  - APTA pediatric section listserv
  - Rehab directors listserv
  - Pediatric Rheumatology bulletin board list serve
- Contacted pediatric hospitals and other pediatric therapists directly
  - >40 hospitals
  - 2 clinics
  - 85 therapists (100% answered all questions)

Institutions Who Participated

<table>
<thead>
<tr>
<th>Institution</th>
<th>Region</th>
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</thead>
<tbody>
<tr>
<td>Alberta Children's Hospital (2)</td>
<td>Canada</td>
</tr>
<tr>
<td>Shriners Hospital for Children</td>
<td>Australia</td>
</tr>
<tr>
<td>Chicago (2)</td>
<td>Germany</td>
</tr>
<tr>
<td>McLane Children's Hospital (1)</td>
<td>Northeastern US</td>
</tr>
<tr>
<td>Legacy Salmon Creek Hospital (2)</td>
<td>Western US</td>
</tr>
<tr>
<td>Health Sciences Centre Winnipeg</td>
<td>Southwestern US</td>
</tr>
<tr>
<td>- Child Health (2)</td>
<td>Midwestern US</td>
</tr>
<tr>
<td>Children's Hospitals and Clinics</td>
<td>Southeastern US</td>
</tr>
<tr>
<td>of Minnesota (2)</td>
<td></td>
</tr>
<tr>
<td>Children's National Medical Center (2)</td>
<td></td>
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<tr>
<td>Sydney Children's Hospital Randwick Australia (1)</td>
<td></td>
</tr>
<tr>
<td>Children's Hospital of Philadelphia (2)</td>
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<tr>
<td>Primary Children's Hospital (2)</td>
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<tr>
<td>La Bonheur Children's Hospital (1)</td>
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</tbody>
</table>

Regional Distribution

- Canada: 46%
- Australia: 15%
- Germany: 13%
- Northeastern US: 9%
- Western US: 9%
- Southwestern US: 4%
- Midwestern US: 2%
- Southeastern US: 2%

Are you a PT or OT?

- Occupational Therapist: 27
- Physical Therapist: 58

How many years have you been a pediatric PT or OT?

- >10 years: 60
- 6-10 years: 40
- 3-5 years: 20
- 1-2 years: 10
- <1 year: 0

Prevalence of overweight in children and adolescents with juvenile idiopathic arthritis (Schenck 2014)

Methods:
- Data from the German National Paediatric Rheumatological Database
- 2003-2012
- Mean age 11.5 y/o
- 19,048 JIA patients

Results:
- Use of biologics increased by approximately 50%
- Increased participation in school sports from 41% to 62%
- Overweight prevalence decreased from 14.2% to 8.3%
How has the focus changed?

- assessment of medications
- less need for assistive devices
- shorter episodes of care
- participation in community activities
- monitor
- less splinting/casting

Key Points

- Evolving role for PT and OT
- Decreased casting/splinting (ie seeing less contractures)

Getting patients into community activities including sports and promoting a healthy lifestyle

Patients With JIA Are Still Less Active Than Their Peers

Authors

Subjects
- *133 pts - 7-20 y/o
- *Moderate to severe JIA
- *Denmark
- *76 pts - 8-13 y/o
- *JIA
- *50 pts - 8-17 years

Outcome Measures
- accelerometer, JADAS, global disease activity, CHAQ, pain
- Joint counts, disease activity, CHAQ, pain, activity diary
- Activity diary, MET, CHAQ, JADAS

Results
- PAL
- MVPA
- sedentary

Discussion
- active disease not a factor in PA
- 4% meet PA requirements
- active disease or functional ability not a factor in PA

Patients with JIA spend More Time Participating in Sedentary Leisure Activities

Participation in Leisure Activities by Children and Adolescents with Juvenile Idiopathic Arthritis
(Cavallaro 2015)

Methods:
- 107 children with JIA ages 8-17 y/o (compared to siblings)
- Children’s Assessment of Participation and Enjoyment (CAPE)

Results:
- Children and adolescents with JIA tend to participate more in sedentary activities
- Older children tended to participate in more social activities
- Active disease related less participation in physical activities
Why are they less active??

- Severe fatigue among adolescents (Nijhof 2016)
- Can pain still be an issue? (Kemna 2014)
- Decreased aerobic capacity (Takken 2002)
- Proprioception and balance issues (Houghton 2013)
- Expectations of the parents or fears of patients (Wakusa 2002)
- Impaired motor performance in preschool aged (van der Net 2008)
- Is there something we are missing?

Gross Motor Proficiency

Factors Associated With Physical Activity in Older Children with Juvenile Idiopathic Arthritis (Horonjeff 2015)

Methods:
- Children ages 8-12 y/o compared to norms
- BOT-2, CHAQ both patient and parent perspective and the CAPE

Results:
- Population scored significantly lower than compared to general population on the BOT-2 and in the 19th percentile on the normative curve

Exercise is Good For JIA

- Exercise is safe and does not exacerbate disease (Epps 2005, SIng-Grewal 2007)
- Improves BMD (Sandstedt 2012)
- Improves quality of life (Mendonsa 2013, Takak 2012, Apt 2014)
- Decrease disability in adulthood (Long 2010)
- WB exercises can help combat musculoskeletal changes (Long
- Socialize and interact with peers (Murphy 2008)
- Improved aerobic capacity (Apt 2014)
- Improved ROM (Apt 2014)

Therapists acting as “Preventionists”

American Physical Therapy Association

Practice statement (2015)

The American Physical Therapy Association advocates for prevention, wellness, fitness, health promotion and management of disease and disability

- Appropriate physical activity and exercise goals and objectives put forth by government and other nationally recognized agencies and organizations
- Consumer recognition of the value of the physical therapist to provide services for prevention, wellness, fitness and health promotion, and for the management of disease and disability for all populations and conditions
- Physical education, physical conditioning and wellness instruction at all levels of education, from preschool to higher education
- Physical therapists making healthy personal lifestyle choices that include meeting national guidelines for participation in physical activity and exercise

Intervention vs Prevention

Agree in the prevention model

Intervention

Both are still important

Limited by medical model

Education is key
Survey results

How do we implement this?

Many times therapists will see patients with rheumatic disease and see they are functioning well and not in pain and do not implement physical activity promoting approaches.

I believe there is a big miss on this in the current clinical environment. In many ways the disease process can mimic chronic pain and control the inflammatory process will allow us to have a health in regular intervention.

I think that prevention is a significant missing piece of our current health model.

Physical Activity Promoting Approaches

(Bezner 2015)

• Educate patients about the health benefits of exercise
• Make clients aware of the current recommendations
• Explore perceived barriers
• Promote self efficacy
• Encourage goals setting

What didn’t work

Impact of a Pediatric Rheumatology Wellness Education Program to Improve Fitness and Activity Levels

Methods:
• 21 patients ages 8-18 y/o with confirmed pediatric rheumatologic diagnoses
• Given 3 education modules over 3 visits

Results: There were no significant changes in any of the outcome measures which included the 6MWT, CHAQ, The children’s activity questionnaire

Wellness Promotion Beliefs and Practices of Pediatric Physical Therapists

(Goodgold 2005)

Methods:
• 257 physical therapists from the APTA pediatric section
• 4 section questionnaire on wellness beliefs

Results:
• 54.5% reported incorporating wellness into practice
• 1/3 thinking about preparing to incorporate this into their practice
• Barriers included resources, time and the child/family

What did work

Do Pedometers with or without Education on Exercise Increase Functional Walking Capacity and Physical Activity Level in Adolescents with Juvenile Idiopathic Arthritis?

Methods:
• 13 adolescents, ages 11-19 years with JIA
• 3-phase walking program that introduced the use of a pedometer and an education seminar at 6 weeks

Results:
• Six-minute walk distance significantly increased from baseline (458.0±70.8m) to the end of phase 1 (501.4±59.8 m) (p = 0.035), prior to receiving the pedometer
• No significant changes for the remaining visits
New Directions

• Community activities
• Sports participation (Taxter 2012)
  Preparing appropriately for sports
• Encouraging physical activity (accountability?)
• Go for 100%
  Movement
  Strength
  Function
  Participation

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JDM


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