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Occupational Therapy and Scleroderma (systemic sclerosis)

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Objectives

• Identify symptoms of systemic sclerosis (scleroderma)
• Discuss occupational therapy intervention to increase joint motion, reduce pain, and manage daily tasks, fatigue, and Raynaud’s phenomenon
• Review the evidence for occupational therapy interventions
Systemic Sclerosis (SSc)

- Progressive multi-system autoimmune disease characterized by thickening of the skin, vascular involvement and fibrosis of the internal organs
- Prevalence: 240/1 million
- Both prevalence and incidence are 4 times greater in women than in men
- Onset between 30-40 years of age
- Average 10-year survival rate is now 70% to 80%

http://scleroderma.org/
http://www.niams.nih.gov/Health_Info/Scleroderma/default.asp

Subtypes of SSc

**Limited cutaneous**
- Gradual skin thickening limited to the distal extremities and face; later involvement of the internal organs
- Includes CREST
  - Calcinosi
  - Raynaud’s phenomenon
  - Esophageal dysfunction
  - Sclerodactaly
  - Telangiectasia

**Diffuse cutaneous**
- Skin thickening proximal to the elbows and knees (i.e. upper arms, thighs or trunk)
- Early involvement of the internal organs
Typical Contractures in the Hand

- Decreased flexion of the Metacarpophalangeal (MCP) joint
- Decreased extension of the Proximal Interphalangeal (PIP) joint
- Decreased thumb abduction

Other hand symptoms

- Calcium deposits
- Puffy fingers
- Raynaud’s
- Digital ulcers and scars
Appearance changes
Scleroderma

Organ Involvement in SSc

• Raynaud’s phenomenon
• Gastroesophageal problems
• Arthralgias or arthritis
• Pulmonary fibrosis
• Cardiac involvement
• Renal involvement
• Myopathy
Assessment

- Joint range of motion
- Hand strength
- Hand function
- ADL/IADL
- Observation – sores, scars on fingers/fingertips, calcium deposits, puffy fingers

Role of Occupational Therapy

- Overall goal is to provide individuals with the tools and information to resume participation in activities of daily life
  - Improve joint motion and strength
  - Provide assistive devices/adapted equipment or alternative methods to accomplish daily tasks
  - Client education
Range of motion / stretching exercises

- Purpose is to prevent or slow down development of contractures
- Do frequently and beyond resistance
- Maintain position of stretch 3-5 seconds even if skin blanches or turn white
- Probably should be started before there is any noticeable loss of motion

Range of Motion Exercises for Flexion

FOR the MCP joint
Make a fist – heel of one hand may need to press on back of proximal phalanx of the other hand

FOR the smaller finger joints
Bend all the joints in one finger to touch the tip to the palm. Gently push with the other hand to stretch. Repeat with each finger
Range of Motion Exercises for PIP Joint

- Push hand flat
- Press fingers against each other
- Use three points of pressure

Exercises to help spread fingers (stretch web spaces between fingers)

- Interlace fingers and try to slide fingers all the way down so that web spaces are touching
- OR slide a smooth bottle cap between fingers
Range of Motion Exercises for Thumb

ABduction

Flexion

How to monitor the motion in key hand joints

Draw a hand out line to help monitor finger extension
How to monitor the motion in key hand joints

Templates to monitor MCP flexion

Find the largest size object that will fit in the web space with all sides of web space touching object

Thumb abduction

Gap; object too large
Self-administered Stretching (range of motion only)

<table>
<thead>
<tr>
<th>Author</th>
<th>Participants</th>
<th>Treatment</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mugli et al, <em>J Rheum</em>, 2006; 33:1586-1592</td>
<td>N = 45 (32 diffuse; 13 limited)</td>
<td>Individual fingers stretched for 10s, 3-10 times once/day; monitored 1/month for 1 year <strong>Exercises</strong>: MCP flexion, PIP and DIP flexion, PIP and DIP extension</td>
<td>Total passive motion significantly ↑ in each finger after 1 mo. Improved or maintained at 1 year. Gripping and eating component scores on HAQ ↓ significantly at 1 year follow-up</td>
</tr>
</tbody>
</table>

Modalities to help increase joint motion

• Heat – paraffin wax or hot packs
• Connective tissue massage
• Manual lymph drainage

Paraffin wax

- 126-130° or less
- do not use with open sores
- keep on 20 minutes
- place dipped hands on wax paper
- place over heavy towels and redip as wax cools

Evidence for Paraffin + Exercise

<table>
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<tr>
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<tbody>
<tr>
<td>Askew et al. Br J Rheum 1983; 22:224-232</td>
<td>N = 12</td>
<td>-Paraffin bath, friction massage and AROM -One session; pre post measures</td>
<td>Greater increase in PT groups for ROM, skin compliance and function</td>
</tr>
<tr>
<td></td>
<td>Tx PT = 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Control = 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pils et al. Phys Med Rehabil 1991; 1:19-21</td>
<td>N = 16</td>
<td>All 16 had 12 paraffin tx Tx continued paraffin for 3 months Control – stopped paraffin</td>
<td>Initial 12 tx → ↑ joint motion, ↓ stiffness. Maintained in Tx group but not controls</td>
</tr>
<tr>
<td></td>
<td>Tx = 8</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Control = 8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sandqvist et al., Disability Rehab, 2004; 26: 981-987</td>
<td>N = 17</td>
<td>Tx hand received paraffin + exercise for 1 month Control hand received exercise only</td>
<td>Tx hand-finger extension, stiffness and skin elasticity improved significantly more than control hand</td>
</tr>
<tr>
<td></td>
<td>RCT</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tx = one hand</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Control = other hand</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mancuso &amp; Poole J Hand Ther 2009; 22: 71-77</td>
<td>N = 3</td>
<td>Paraffin + exercise for 8 weeks</td>
<td>↑ROM, grip, pinch strength ↑ in hand function not as significant as ↑ impairments</td>
</tr>
<tr>
<td></td>
<td>Single case studies</td>
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</tbody>
</table>
### Connective tissue massage and joint manipulation

<table>
<thead>
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</thead>
</table>
| Maddali Bongi, et al., Clin Rheum 2009; 28:1167-73. | N = 40 RCT, Tx = 20, Control = 20 | Tx hand: Combination tissue massage, McMennell joint manipulation for 1 hr, 2X/week for 9 weeks, plus a home exercise program  | Tx group: fist closure, joint motion, hand and overall QoL increased and maintained at 9 week follow-up.  
Control group: fist closure improved |

### Evidence for Manual Lymph Drainage

<table>
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</tr>
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</table>
| Maddali Bongi et al., AC&R 2011; 63:1134-1141 | N = 35, Tx = 20, Control = 15 | Tx for edema: manual lymph drainage 1 hr, 1X/week for 5 weeks  | Tx group: hand volume, joint motion and perception of hand disability improved.  
Control group: no improvements |
Evidence for Dynamic Splints

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Seeger &amp; Furst, Am J Occup Ther 1987: 41: 118-121</td>
<td>N = 19 (PIP flexion contracture in each digit &gt; 15°)</td>
<td>Tx hand: Dorsal splint with wrist in 15° extension, MCP 0° and dynamic PIP extension outrigger. Worn 8 hr/day for 2 months. Weekly splint checks. Control hand: unsplinted hand</td>
<td>8/19 completed study. No significant change in PIP extension in either group.</td>
</tr>
</tbody>
</table>

Exercise for other upper extremity joints

- Shoulder Flexion
- Shoulder Extension
- External Rotation
- Supination
- Wrist extension and flexion
Oral manifestations in scleroderma

- Resorption of the mandible
- Reduced mouth opening (microstomia)
- Xerostomia (dry mouth)
- Difficulty eating and oral hygiene
- Increased dental caries and periodontal disease occur because of Sjögrens syndrome and microstomia (small mouth)

How to monitor mouth opening (why is this important?)

- Open mouth as wide as possible and measure from bottom front teeth to top
- Make a card or find an object (sterile) that is the same width to use as a template
Temporomandibular Joint Exercises

- Manual stretching of mouth with fingers
- Exaggerated facial movements such as exaggerated smiling, pursing lips, blowing up cheeks, open mouth wide
- Augmentation with tongue depressors

(Naylor et al., 1984)

ORAL HYGIENE

- Electric toothbrushes, water jets, curved bristle brushes, children’s toothbrushes
- Toothbrushes for decreased hand dexterity

Electric toothbrush

Water pik
### Evidence for Oral Intervention

<table>
<thead>
<tr>
<th>Author</th>
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</tr>
</thead>
</table>
Tx = 5  
Control = 4 | Tx: Mouth stretching 3 sets of 5 stretches 1X/day & augmentation 2X/day for 3 months  
Control: facial grimacing, 3 sets of 5 stretches 1X/day | Tx group: ↑ mouth opening  
Control: no significant increase |
| Pizzo et al. Clin Oral Invest 2003; 7: 175-178 | N = 10 | Tx: Mouth stretching 15 min, 2X/day and augmentation 1X/day for 8 weeks |Tx group: ↑ mouth opening; ↑ speaking and eating abilities |
| Poole, et al. Disabil Rehab 2010; 32: 379-384 | N = 17 | Tx: Dental exam and cleaning, educ on brushing/flossing, individualized adapted dental appliances, Mouth exercises (stretching and augmentation) & hand exercises 1X/day | ↑ mouth opening and improved oral hygiene |
| Maddali-Bongi et al. Rheumatol Int 2011; 31: 895-901. | N = 40  
Tx = 20  
Control = 20 | Tx: 1hr 2X/wk for 9 weeks: massage to face, PNF stretch and resistive exercise and face exercises  
Control: home exercises for mouth & face | Tx: ↑ mouth opening  
Control: no change |

### Evidence for Oral Intervention cont.

<table>
<thead>
<tr>
<th>Author</th>
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<th>Treatment</th>
<th>Results</th>
</tr>
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</table>
Tx = 26  
Control = 22 | Both: brush teeth 2 min, 2X/day for 6 mo.  
Tx: provided rechargeable toothbrush and reach flosser. If oral aperture < 40 mm, face, mouth stretching & oral augmentation exercises 2X/day  
Control: manual toothbrush and floss | Tx: ↑ oral hygiene as shown by reduction in Gingival Index scores that was 8% larger and significant at 6 mo. compared to control |
| Yuen et al. Disabil Rehab 2012; 34:84-89 | N = 48  
Tx = 26  
Control = 22 (same as Yuen, 2011) | Tx: If oral aperture < 40 mm, face, mouth stretching & oral augmentation exercises 2X/day. Each exercise held 15-20 s; kept records of daily hygiene. Also issued toothbrush & flosser as described above  
Control: manual toothbrush and floss |Tx: ↑ mouth opening at 3 mo. Compared to controls but not at 6 months. Adherence to exercise as low (48.9%) |
Assistive/Adapted Devices

- Manipulation
  - large handles
  - universal cuffs
  - hourglass or stem glasses

Dressing devices

- Reaching
  - reacher
  - sock aid
  - long shoe horn

- Button hooks
Key holders

Push button pill organizer

Good grips and Oxo

Jar and Can Openers

3-in-1 opener

JarPop
Suggestions for proximal weakness

- Prioritize
  - Make a list of priorities and the order by importance; delegate
- Plan ahead
- Pace yourself and avoid fatigue; slow down
  - Balance rest and activity: short frequent rests
- Posture
  - Sit when possible but alternate positions too
  - Use good posture
  - Use good body mechanics
Energy management ideas used by working people with scleroderma

- Ask/accept help from co-workers
- Modify work hours – 4 day weeks or shorter days (start later)
- Work from home
- Keep WARM
- Switch tasks and take breaks to cut fatigue or stress
- At home – renegotiate tasks at home, sleep on weekends, prepare for workweek

Energy management ideas for leisure activities

- Always have hand warmers and gloves with you
- Rest and pace activities
- Internet shopping instead of mall shopping
- Be prepared – gloves and blankets to concerts, theatre, restaurants, etc
Management of Raynaud’s Phenomenon

Client Education for Raynaud’s Phenomenon

- Insulate hands from cold, strong detergents, irritating chemicals, and bacteria (wear gloves)
- Dress warmly/layer to insulate body – always bring sweater, mittens/gloves
- Use chemical hand warmers
- Avoid cold temperatures
- Take care of skin – keep skin moist
- Biofeedback
IDEAS FOR THOSE WITH RAYNAUDS

www.coldhands.me

Insert chemical heat packs into wrist bands

www.wristies.com

POSSIBLE “WARM” CAR SOLUTIONS

Remote car starters

Heated seats or covers

Accessible Parking

continued
Keyboard ideas

“Voice activated”

“Stickykeys

• Keyboarding aids

Job Accommodations

• Sick days or extra days can be requested
• Work at home, more breaks, light work, equipment can be requested
• Explore Family Medical Leave Act
• Explore Flextime schedule

Resources

Job Accommodation Network  www.jan.wvu.edu
www.disability.gov
www.eeoc.gov  www.dol.gov
Leisure ideas

- Kneeler/stool for gardening or planter gardens
- Bionic gloves - grip

Evidence for Occupational Therapy Techniques (Review articles)

Conclusions

• Occupational therapy is indicated for persons with scleroderma

• Range of motion exercises should be aggressive, involve stretching and be started before obvious deformities

• Do not forget the face

• Do not forget Raynaud’s phenomenon

• Assistive devices and alternative techniques should be investigated to help with independence AND save energy

• Some evidence available for rehabilitation interventions with persons with scleroderma.