Exercise for IBM Patients New to Exercise

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Why Exercise?

- There is no drug available - no other options!

- Based on preliminary results and our experience, it is possible that exercise may *slow down* the progression

- There are additional benefits to general health - preventing cardiovascular events, slowing down age-related muscle weakness, etc.
How Do I Start It?

- Find a therapist or trainer - exercise should be supervised!

- Home exercise - consider getting some exercise equipment, such as therabands, small weights, stationary bikes, etc.

- START EARLY - once muscle becomes a fat tissue, it can’t go back to muscle

- Be organized - consider having exercise journal; use apps; wearable technology, such as fitbit or smart watches
What’s the Prescription for IBM?

RX

3 sets of 15-20RM, EVERYDAY

In the muscles that are affected (proximal and distal)

Rest if Borg scale > 7

Re-assess every 16 weeks

REFILL _____ TIMES ____________________________ , M.D.
DEA NO. _______________ Address ____________________
What Does That Mean?

- Concept of Repetition Maximum (RM)

- Borg Scale
How Do We “Dose” Exercise?

- Exercise can be “dosed” just like drugs
- The problem is some are much stronger than others at baseline
- Then how can you determine what’s “too much” for one, and “too easy” for another?
- Using repetition Maximum
Repetition Maximum (RM)

- **One RM**: the most weight that can be lifted throughout the entire range of motion
- The higher the RM, the lower the weight
- High intensity, typically < 5 - 10 RM
- Low intensity or endurance typically > 15 to 20 RM
- Well validated
Exercise Needs to Progress!

- One RM can change over the course of exercise!
- Need to re-measure RM every 3-4 months
For IBM - How to Progress

- Instead of increasing weights, aim to increase the repetition!

- For example, start with 50-70% of 15-20RM x 3 sets per muscle. Slowly advance to 100% of 15-20RM x 3 sets by 16\textsuperscript{th} week. Re-assess the RM at 16 weeks and go up to 70-80% of 20 to 25RM x 3 sets and increase slowly to 100% of 20- 25RM x 3 sets by the next 16 week.
What is Borg Scale?

- Rating of Perceived Exertion (RRE)
- Visual analog scale of how exerted one feels during exercise
- Reliably reflex the intensity and also reproducible!
- Two versions: 6-20 scores (original) and 1-10 scores
## Borg Scale

<table>
<thead>
<tr>
<th>Borg Scale</th>
<th>Description</th>
<th>Activity Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Nothing at all</td>
<td></td>
</tr>
<tr>
<td>0.3</td>
<td>Extremely weak</td>
<td></td>
</tr>
<tr>
<td>0.5</td>
<td>Just noticeable</td>
<td></td>
</tr>
<tr>
<td>0.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Very weak</td>
<td><strong>Very Light Activity:</strong> anything other than sleeping, watching TV, riding a car, etc.</td>
</tr>
<tr>
<td>1.5</td>
<td>Weak Light</td>
<td><strong>Light Activity:</strong> feels like you can maintain for hours. Easy to breathe and carry a conversation</td>
</tr>
<tr>
<td>2.5</td>
<td>Moderate</td>
<td><strong>Moderate Activity:</strong> feels like you can exercise for hours. Breathing heavily, can hold short conversation</td>
</tr>
<tr>
<td>3</td>
<td>Strong Heavy</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Very strong</td>
<td><strong>Vigorous Activity:</strong> on the verge of becoming uncomfortable. Short of breath, can speak a sentence.</td>
</tr>
<tr>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td></td>
<td><strong>Very Hard Activity:</strong> very difficult to maintain exercise intensity. Can barely breath and speak a single word</td>
</tr>
<tr>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Extremely strong “Maximal”</td>
<td><strong>Max Effort Activity:</strong> feels almost impossible to keep going. Completely out to breathe, unable to talk.</td>
</tr>
<tr>
<td>10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
What Muscles Should I Start With?

- It depends!

- Prioritize the muscles that are affected before the muscle goes atrophied

- If muscles are too weak, focus on the muscles for compensatory function
SAID Principle

- Specific Adaptation to Imposed Demands (SAID)

- Training in certain muscle will only improve that specific muscle

- You have to target the muscles of interest!
IBM Pattern of Muscle Weakness

- Distal Finger Flexors
- Quadriceps Muscles (Knee Extensor)
- Ankle Dorsiflexor
- Swallowing muscles (neck flexor)
Distal Finger Flexors - Mainly Flexor Digitorum Profundus
How To Train Distal Finger Flexors?

- Using exercise putty
- Make sure to use finger pinch!
- Playing musical instruments, such as guitar
- Any ideas?
Quadriceps = Knee Extensors

- Consist of 4 muscles
- Vastus Medialis (VM) seems to get affected the most
- VM muscle is responsible for the last 15 degree of knee extension
- Note that rectus femoris muscle crosses two joints, acting as hip flexor as well!
How To Train Quadriceps (esp. VM)?
How About Swallowing?

- It appear to be related to neck flexor muscles
- More research is needed
- Needs Video Swallowing Study before planning for exercise
Example: Masako Maneuver

1. Stick out the tip of your tongue. Hold it between your teeth or lips.
2. Now, try to swallow your spit with your tongue in that position.
3. Relax.
4. Repeat 5 to 10 times.
Example: Shaker Exercise

Hold for 30 seconds to 1 minute
Example: Mendelsohn Exercise

- Put on hand on the larynx and swallow - did you feel larynx going up and down?

- Then, swallow again, and this time, don’t let the larynx go down and hold it for 2 seconds

- Repeat 30-40 swallows per session
Issues with Exercise

- Muscle pain - is it safe?
- Fatigue - follow Borg scale
- Too many exercises - break it up or periodization
- Boring!!! Combine with fun activity, exercise buddy, etc.
Thank you!
Questions?