Experience of pain and fatigue in myositis

Helene Alexanderson

PhD, Ass professor, RPT

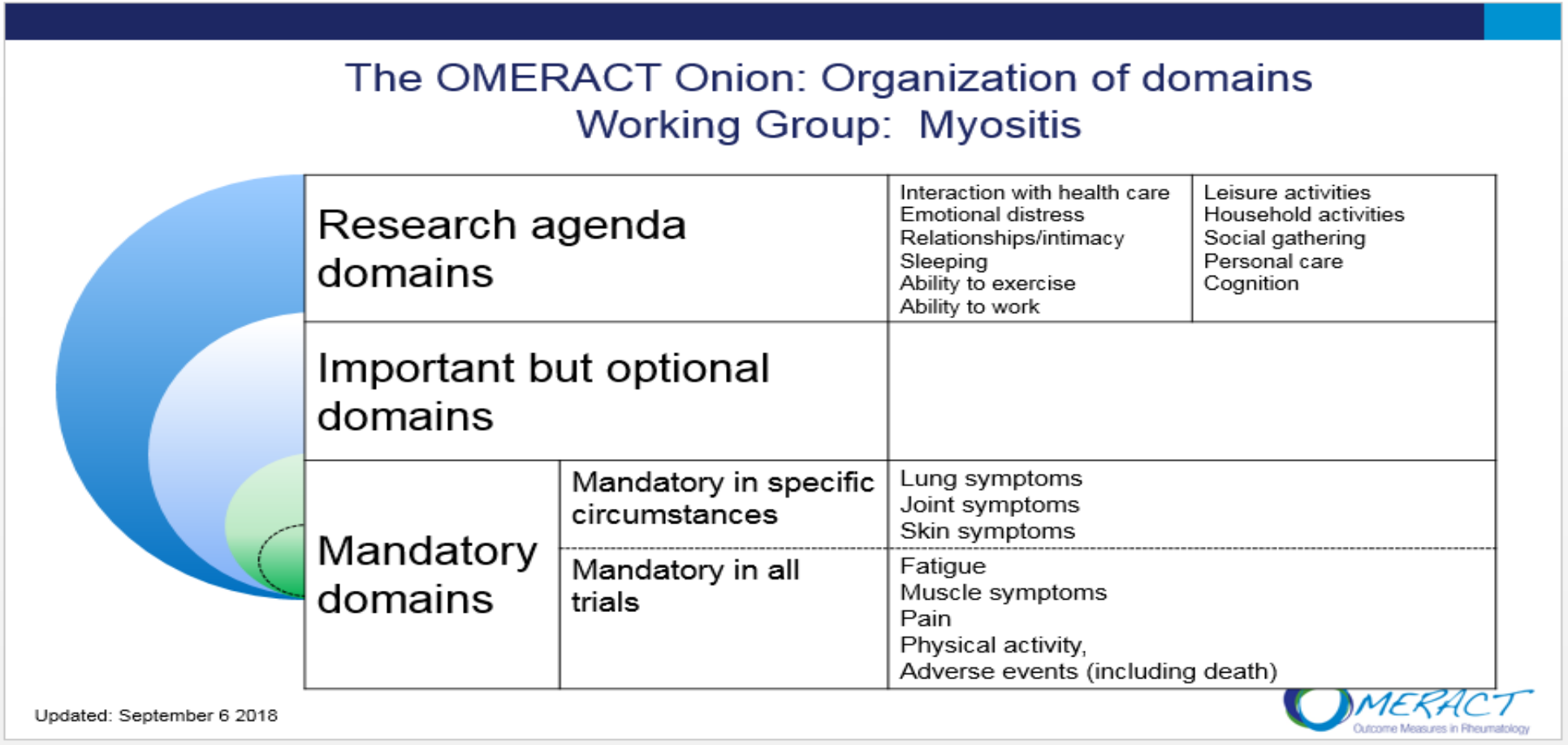
Karolinska University Hospital/Karolinska Institutet

Stockholm, Sweden

Background

- Myositis has previously been described as the “pain-less muscle weakness”
- Several studies using the SF-36 quality of life survey show that patients have more pain and fatigue than population-based reference values (Sultan SM et al 2002, Ponyi et al 2005, Regardt M et al 2011)
- Clinical experience suggest that the majority of patients with PM and DM experience pain at some point, while some patients do not
- International focus groups with patients with PM/DM revealed that pain, fatigue, cognitive impairment are important symptoms
- There are no published studies exploring patients’ own experience of pain and fatigue

Life impact core domain set of patient-reported outcomes in adult PM/DM



(Regardt M, et al. J Rheumatol 2018)

Qualitative study on experience of pain in myositis

- The aim was to study experience of pain related to myositis in patients with PM and DM

- 6 patients with PM/DM, 4 women, 2 men
- Median age 52 (24-73)
- SF-36 Bodily pain: 22-74 (100 = no pain)

Conclusions and reflection

- Pain is a myositis symptom affecting many aspects of life and quality of life
- Pain could be first symptom, is relieved by prednisolone treatment and adapted exercise but worsens with tapering of prednisolone and over exertion
- Information about pain related to myositis is very important
  - Important to include patients and family members/partners
  - Important to ask about pain and share our experience of pain in myositis
  - Important that the patients feel that HCP take their pain seriously to reduce anxiety

What could cause pain?

- Inflammation / degeneration
  - Impaired blood circulation – muscle ischemia, Raynaud's phenomenon
  - Muscle weakness with secondary tendinosis – degenerative changes in muscle tendons
  - Skin rash – ulceration in DM
  - Arthritis
  - Osteoarthritis: Normal ageing or secondary to muscle weakness, especially in IBM

(Pain and inflammation. Studentlitteratur 2019)

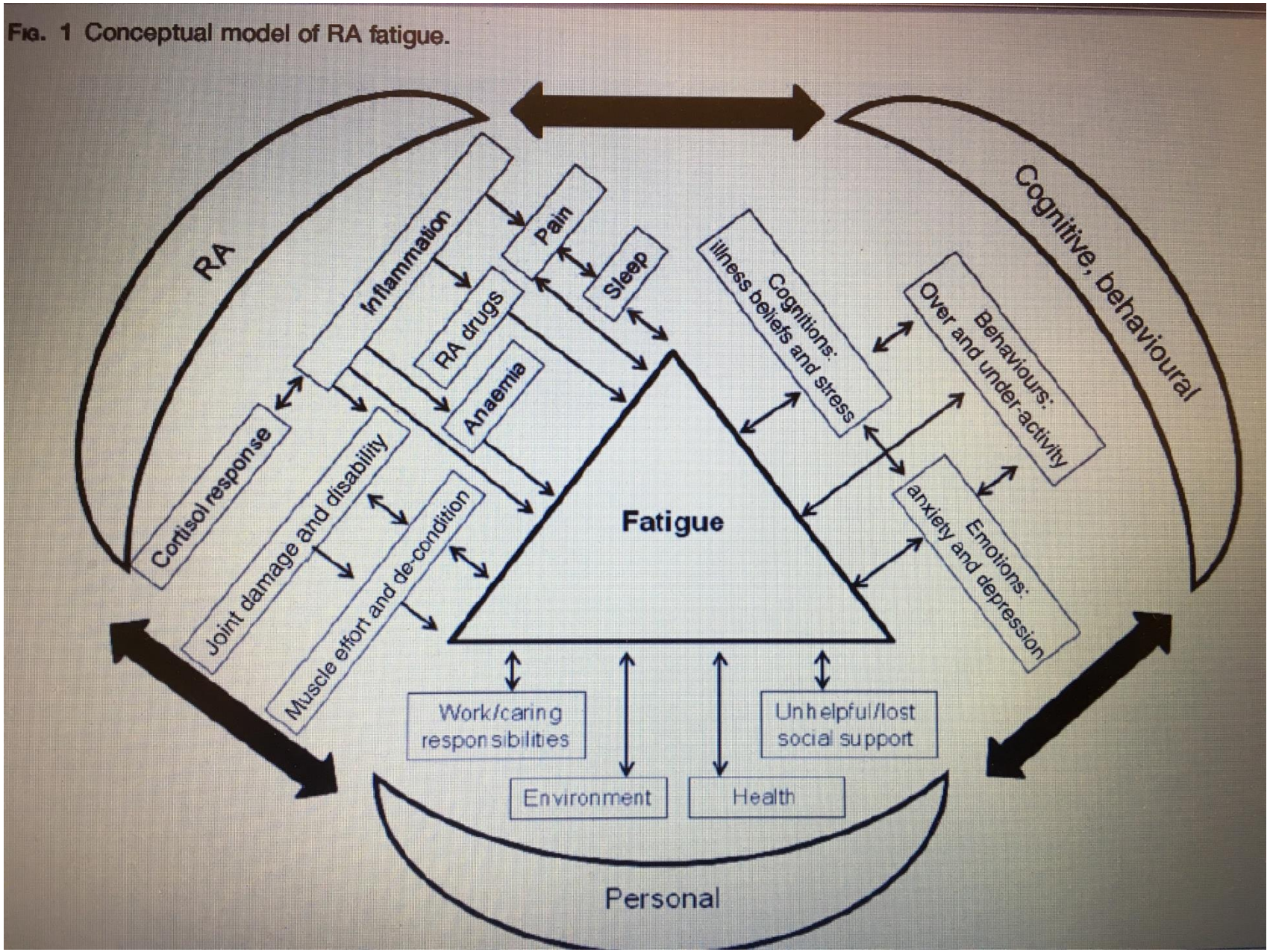
What could cause pain?

- Fibromyalgia – wide-spread pain (WSP)
  - Peripheral mechanisms – tender points/generall tenderness
    - Unspecific signs of muscle ischemia (low circulation) – potent mechanism to induce peripheral sensitization of pain receptors in muscle leading to increased flow of pain signals to the brain
    - Muscle work usually leads to increased blood flow in muscle via activation of the sympathic nerv system. In WSP there is a dysfunction of the nerve system with increased activation of the sympathic nerve system with less reaction to muscle work.

    - Central mechanisms
    - Lower pain threshold and hyper-sensitive pain stimulation for all tissues in the body
    - Dysfunction of the body's own pain-reducing system that is modulated by physical activity – reduced release of endorphins

    (Pain and inflammation. Studentlitteratur 2019)

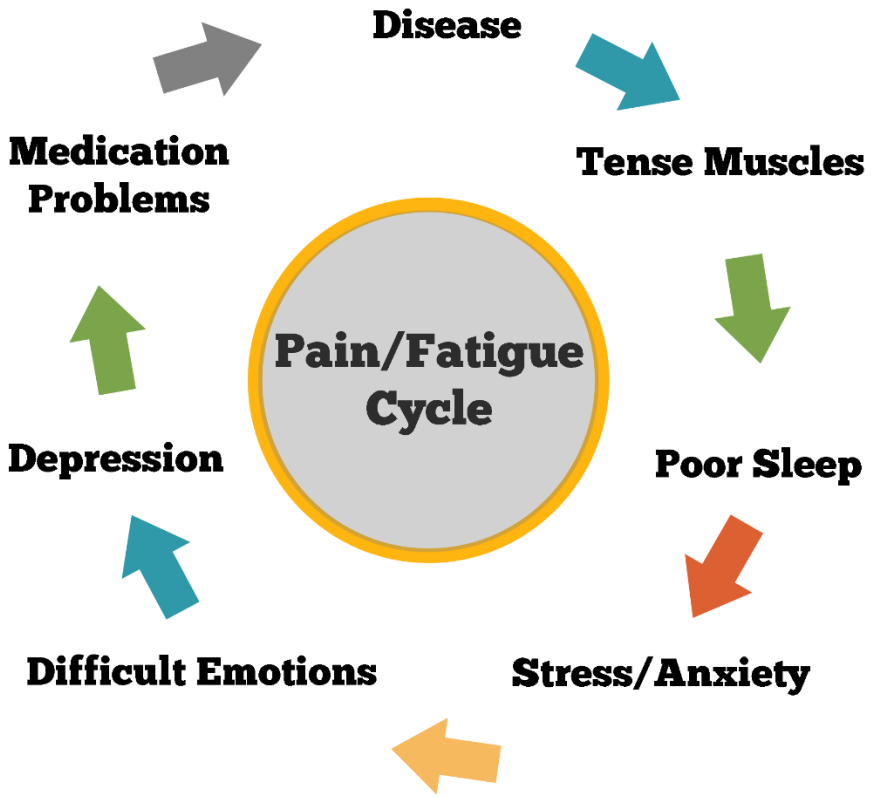
Conceptual model for fatigue in RA



(Hewlett S, Rheumatology 2011)

Fatigue

- Pain and fatigue are associated to each other



Pain/fatigue affect physical and psychological health

Definitions of physical activity/exercise

- Physical activity (PA): Any body movement requiring energy consumption above resting level – any daily activity
- Exercise: Physical activity performed with a goal to improve any aspect of physical capacity (aerobic fitness, muscle function, mobility, balance etc)
- PA/exercise can be modulated as to
  - Frequency (times/week)
  - Duration (min/session)
  - Intensity (exercise heart rate/loads/nb or repetitions)

Possible health benefits from PA/exercise

- Reduced risk of cardiovascular disease, diabetes, osteoporosis, some forms of cancer
- Treat and prevent depression
- Improved physical capacity
- Improved sleep
- Improved quality of life

Effects of exercise on pain

- Increase blood flow in muscle – possibly reduced pain sensitivity
- Increased number of capillaries in muscle tissue
- By muscle contraction – activate release of endorphins (body's own pain-reducing system)
- Reduced inflammation with intensive aerobic and resistance training
  - Less disease activity, down-regulation of inflammatory genes

Effects of exercise on fatigue

- Reduced inflammation
- Reduced pain
- Improved sleep

- Fatigue and pain could influence each other in a non-favorable way but if you have less pain you might also get less fatigue and vice versa

How to modulate exercise in relation to pain and fatigue

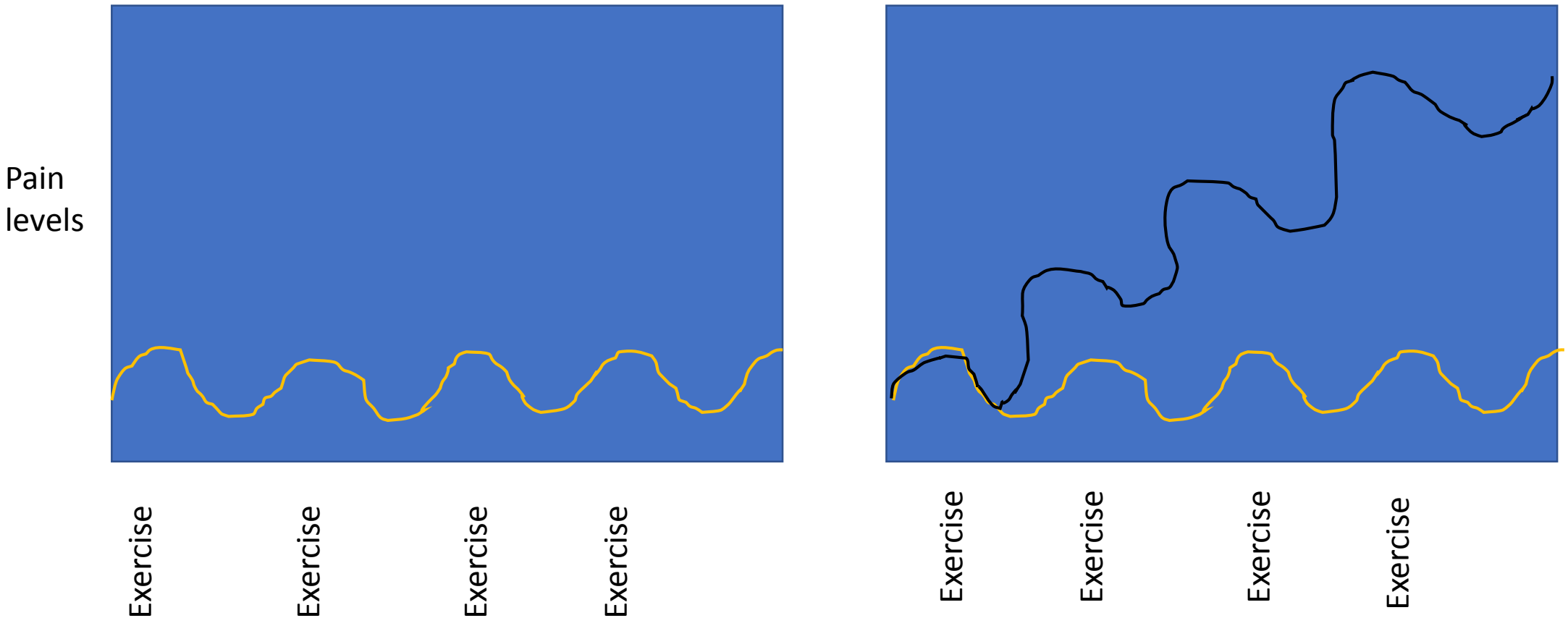
- Initiate physical activity / exercise on a very low intensity
  - Shorter sessions, perhaps divide program in 2 – take a break – interval training
  - If possible: Initiate exercise under supervision of a physical therapist who can measure current physical capacity and help you find a feasible program and intensity/frequency/duration and also follow-up and adapt the program
  - Swap between different muscle groups during the same exercise session – circle training – and try to swap between different types of PA/exercise for different sessions
  - Common to experience increased pain during/after exercise in the beginning
    - Important to adapt exercise frequency so that pain levels are down to normal before next exercise session
    - All PA/exercise need to be modulated so that you can incorporate it in daily life – be able to continue with the rest of the day and the next day
    - Increase frequency/duration/intensity carefully, in small steps. Increase intensity/duration for only parts of your program at the time

- Try to find activities that you enjoy and set short and long term goals

Modulate exercise to pain levels

Exercise modulated in relation to pain levels

Exercise not modulated to pain levels



Ongoing research and efforts

- TMA works to increase knowledge and awareness of exercise to health-care providers via educating students, literature and a planned campaign – Exercise is medicine
- International consensus on exercise guidelines for myositis via International Myositis Assessment and Clinical Study group (IMACS)
- Ongoing research on experience of pain/fatigue and how to assess pain/fatigue with validated patient-reported outcome measures
- Much more research needs to increase knowledge of pain and fatigue in different subgroups of myositis
- More education to health-care providers is needed

Conclusions / discussion

- PA/Exercise part of the treatment in myositis
- Important to adapt PA/exercise to levels of pain, fatigue, disease activity
- Adapted PA/exercise can reduce pain and fatigue levels over time
- Start on short-duration low-intensity PA/exercise so that pain/fatigue levels do not increase over time
- Progress PA/exercise slowly
- If possible:
  - Start under supervision of physical therapist with frequent follow-up
  - Important with support from health-care providers, peers, or family friends

- TMA www.myositis.org provides specific exercise programs
- MSU and other patient-support groups