Impacting Quality of Life in PSC: Targeting Pain, Sleep, and Fatigue

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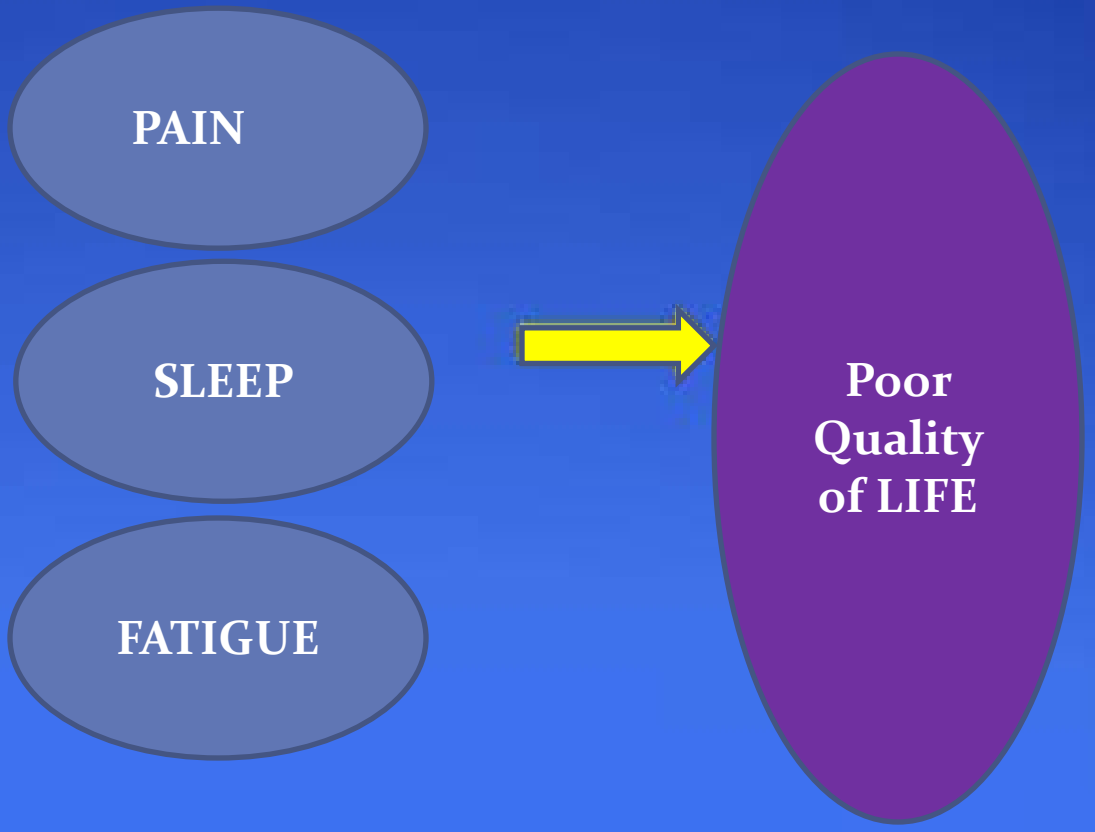
- All medication suggestions in this presentation are off-label uses unless noted otherwise.

PSC in IBD

- Chronic, progressive leading to liver failure
- Up to 7.5% of children and 20% of adults with IBD
- Higher rates in UC and males
- Causes still unclear
  - Genetic?
  - Autoimmune?
- Varied clinical presentation
  - 85% with fatigue
  - Abdominal pain
  - Pruritis
  - Jaundice
- Challenging to treat with liver transplantation for severe progression

Brain effects if PSC in IBD



Brain effects if PSC in IBD

SLEEP

FATIGUE

- Many patients with IBD have persistent pain in absence of active inflammation
- Pain comorbid with depression
- Depression in 25-40% with IBD; 20-72% in IBD plus PSC

Screening for Depression

M	**Mood (depressed or irritable) and Motor (hyper or hypo)**
E	**Energy (fatigue)**
S	**Sleep (insomnia or hypersomnia)**
S	**Suicide and Self Esteem**
A	**Anhedonia (lack of pleasure)**
G	**Guilt**
E	**Eating (change in appetite)**

Courtesy of Eva Szigethy, MD, PhD

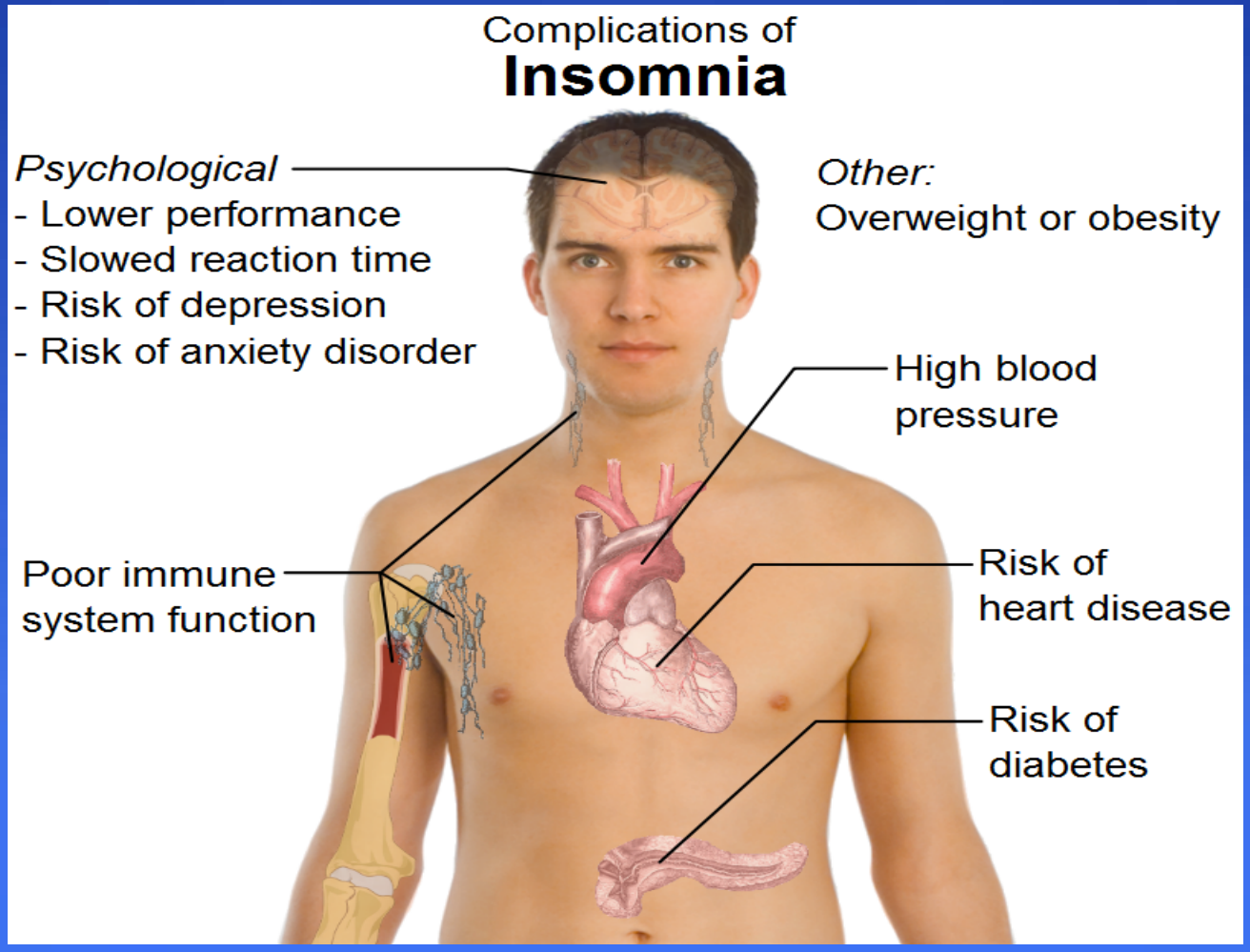
Brain effects if PSC in IBD

PAIN

FATIGUE

- Sleep disturbance common in IBD
- Sleep disturbance associated with fatigue and increase pain
- Poor sleep worsens disease course and body's ability to fight inflammation
- In PSC, poor sleep associated with pruritis

Insomnia


Complications of
Insomnia
Psychological
- Lower performance
- Slowed reaction time
- Risk of depression
- Risk of anxiety disorder
Other:
Overweight or obesity
High blood pressure
Poor immune system function
Risk of heart disease
Risk of diabetes

Brain effects if PSC in IBD

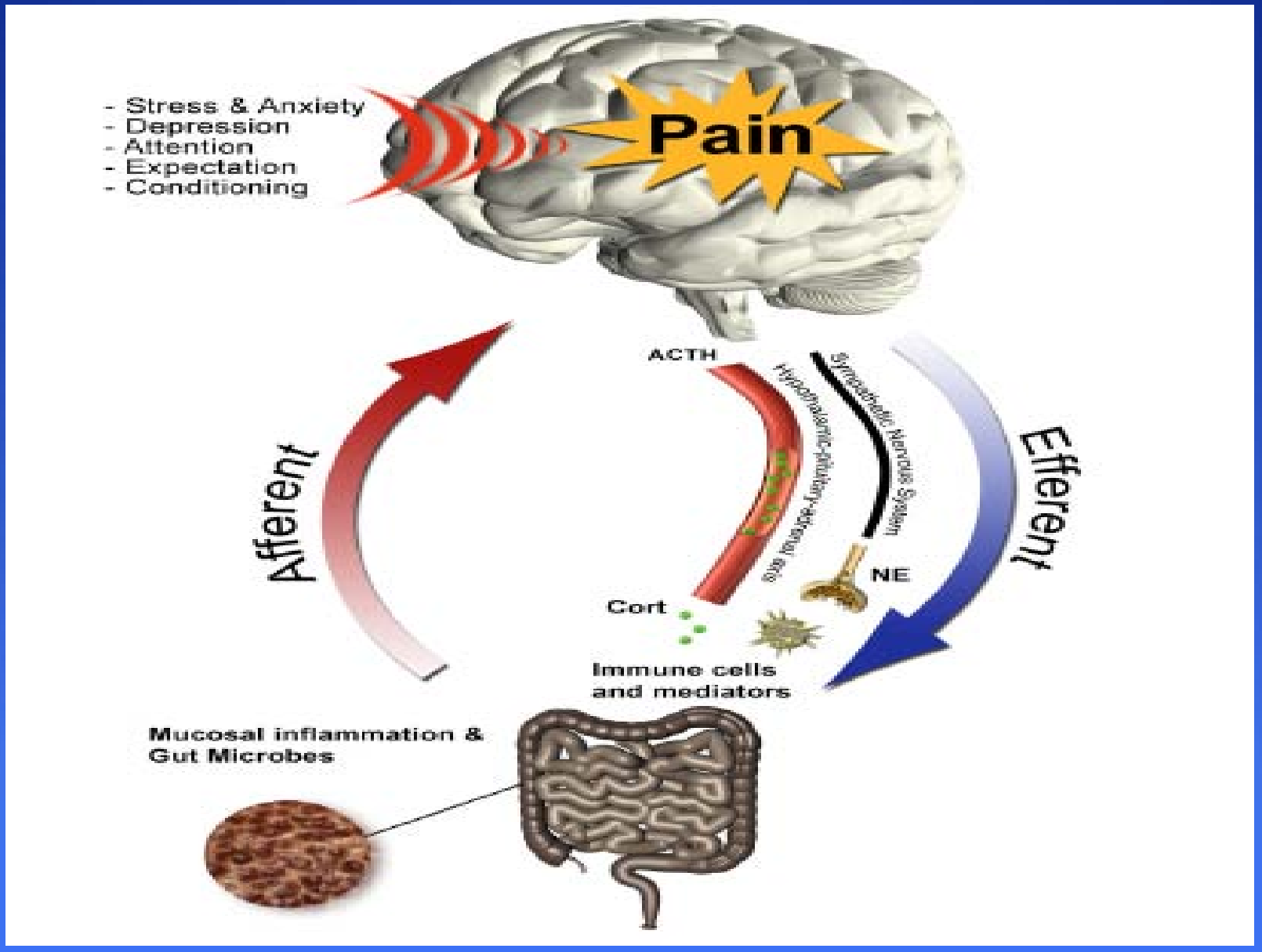
PAIN

SLEEP

- Fatigue present in up to 85% patients with PSC
- Can be part of depression but in PSC not always due to depression
- May be more linked to inflammation (serum sickness)
- Adrenal burn-out?

What can we do to improve pain, sleep and fatigue?

Education: Offering a Validated Explanatory Model for Pain



Cognitive Behavior Therapy for Pain

- CBT alters behavior, perception, and thinking to change mood and sensations
- CBT helps individuals to interrupt automatic emotional processing which maintains negative cognitions and rumination about pain
- CBT teaches problem-solving skills based on personal control and the ability to adjust behavior and thoughts accordingly

ACTS for Adolescents

- **A** Activities (2 sessions)
- **C** Calm (Relaxation) (2 sessions)
- **T** Think positive (2 sessions)
- **S** Sleep hygeine (1-2 session)

Modified CBT for Depression in Youth with Physical Illness (Szigethy 2004,2007)

- Target physical illness narrative and problems such as medication adherence.
- Incorporate education about depression and IBD.
- Hypnosis for anxiety, abdominal pain, immune functioning.
- Phone sessions and coupling of therapy with medical visits.

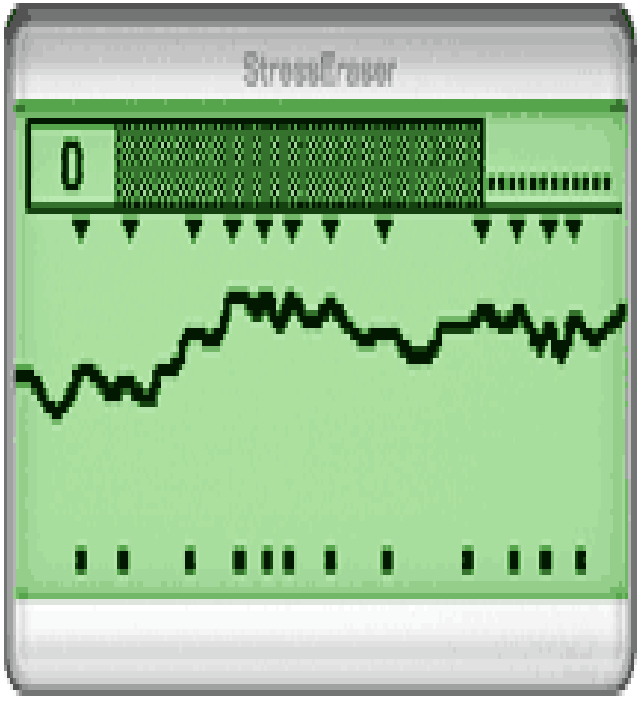
Activity- Exercise

- Reduces stress and depression
- Low intensity better than exhaustive program
- Exercise better than sedentary life style

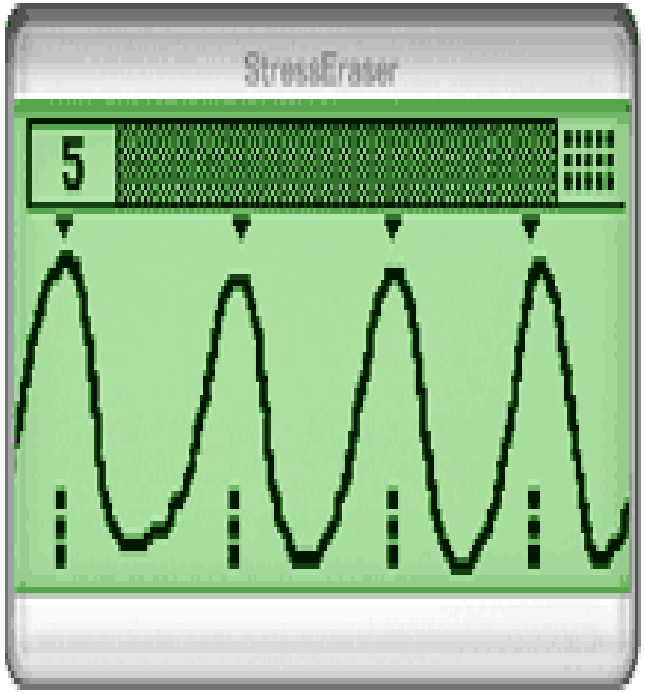
ACT : Calm (Relaxation)

- Purposes
  - To address the tension often associated with depression (frequently accompanying worry)
  - To teach that an uncomfortable state in their bodies, like other adverse conditions, may be amenable to their control
  - To teach two approaches: Deep muscle with imagery *and* "secret calming"
  - 4-4-8 Breathing

CALM: Breathing pattern before and after practice using biofeedback device



[Fig. 6]



[Fig. 7]

Relaxation/hypnosis shown to decrease autonomic arousal via stimulation of the parasympathetic nervous system

ACTS :THINK: BLUE Chart

- How to catch yourself having a negative thought?

Blaming yourself

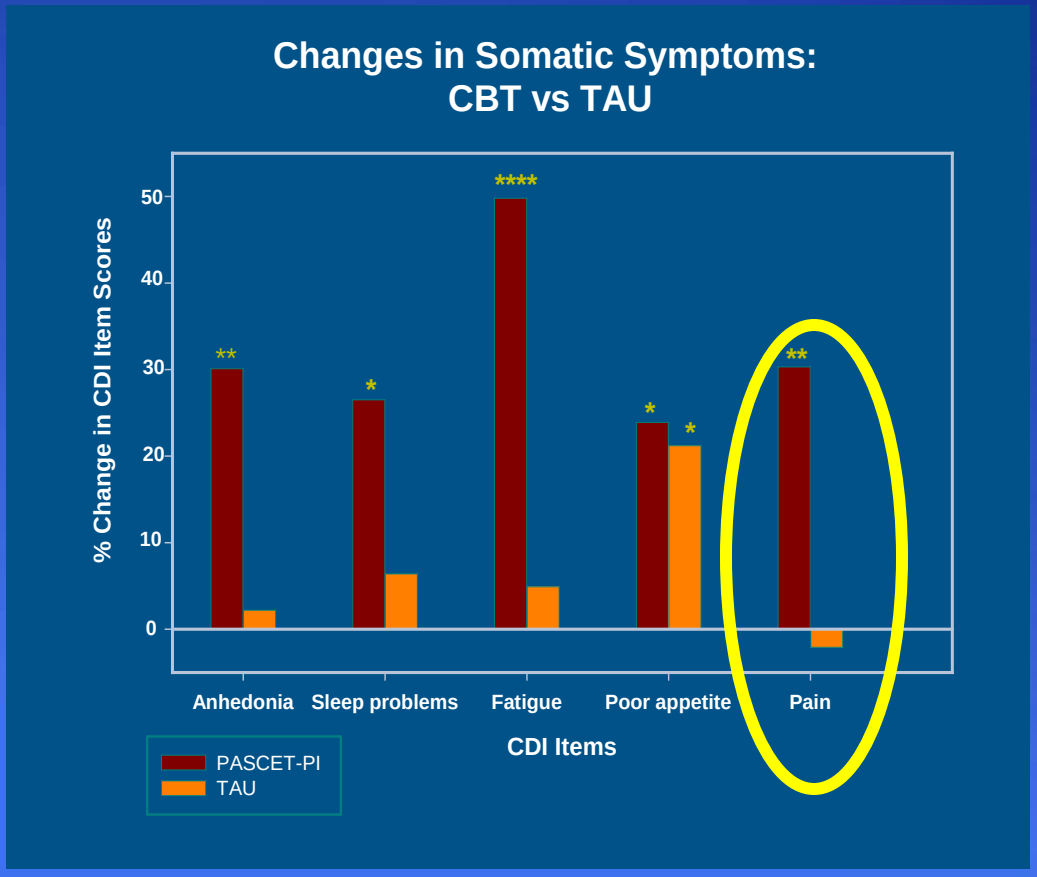
Looking for the negative

Unhappy guessing

Exaggeration

Cognitive Behavioral Therapy versus TAU for Depressed Adolescents with IBD

- Decreased depression
- Improved brain functioning
- Improved quality of life
- More optimistic illness narrative
- Decreased fatigue
- Improved pain



Medical Hypnotherapy for Functional Pain

- Mobilizes attention inward to block out stressful or interfering external stimuli- induces trance.

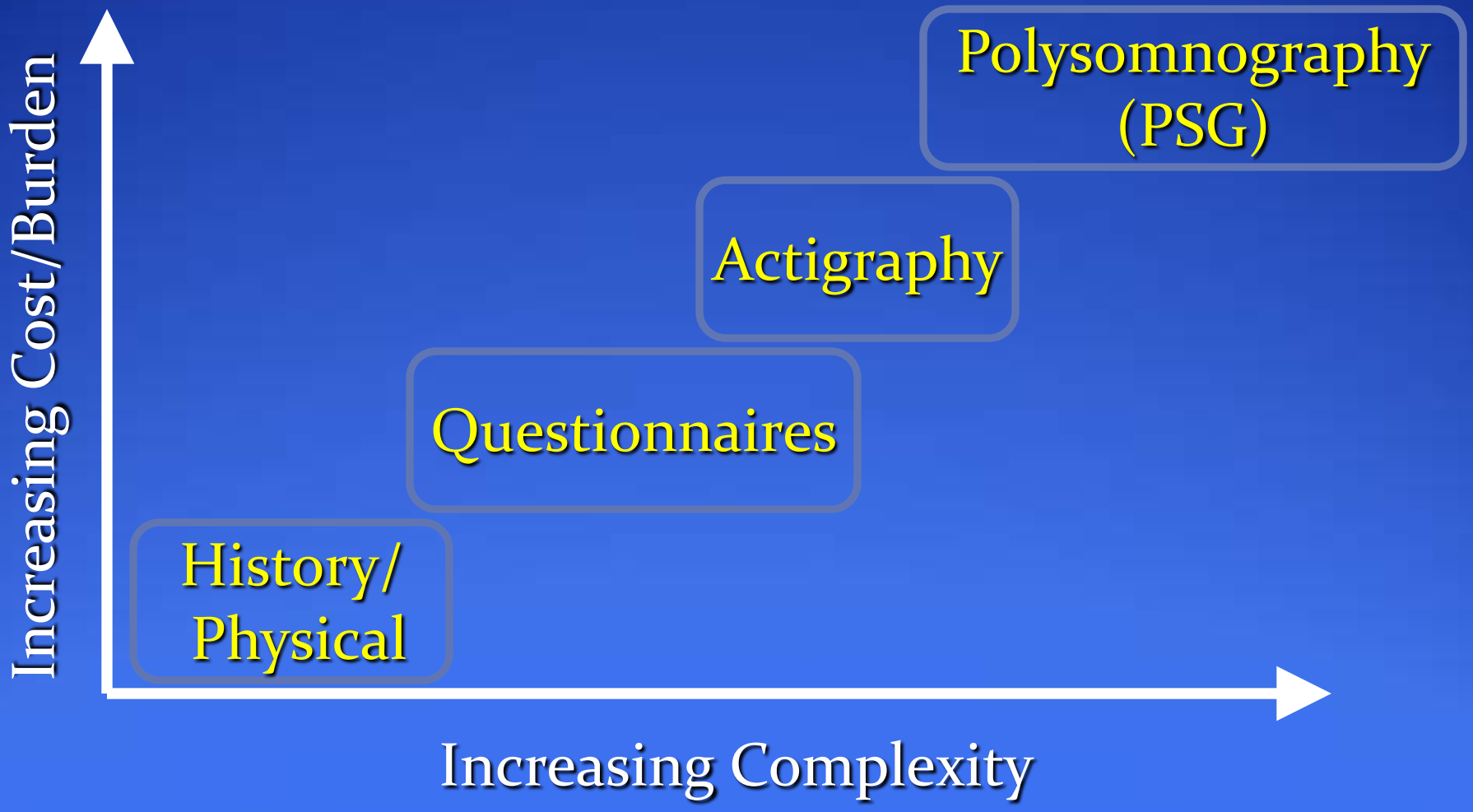
- Using the brain to ignore the body.
- .
- Alter the autonomic nervous system's stress response

Empirical Support for Hypnosis

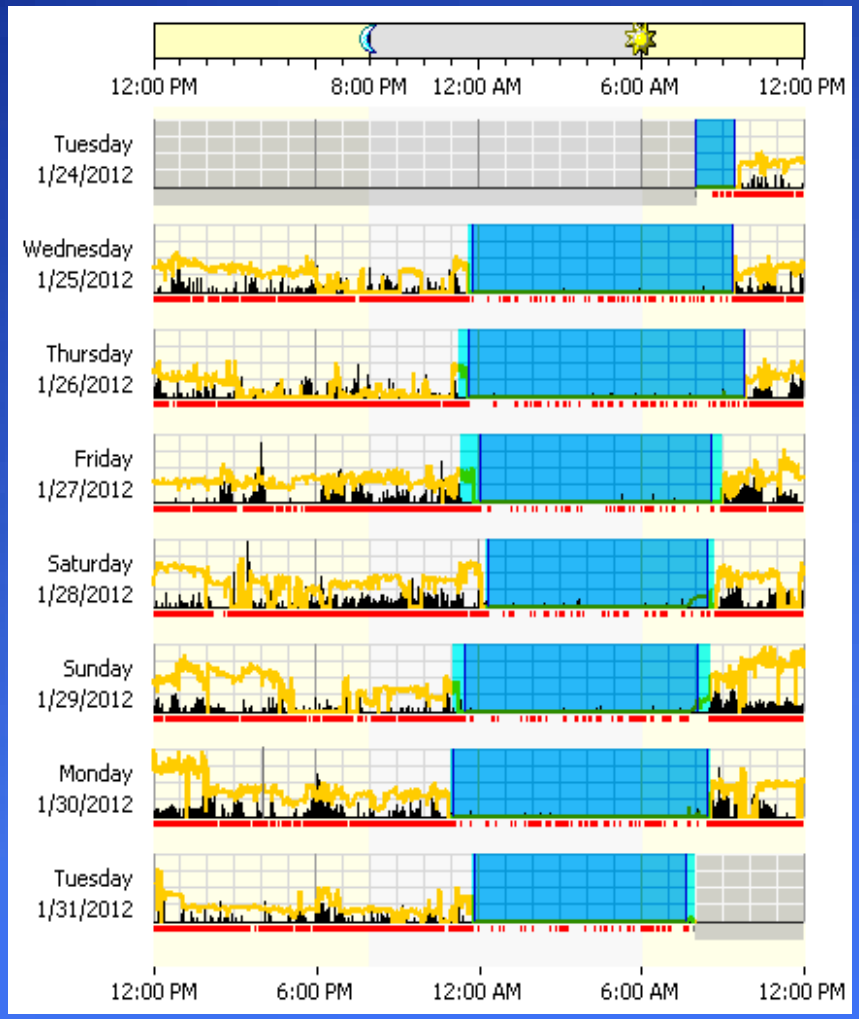
- Lower blood pressure, heart rate, and respiratory rates
- Alleviate abdominal pain in adults with irritable bowel syndrome (IBS)
- Reduce pain, both acute procedural pain and more chronic pain
- Change intestinal motility; decrease nausea
- In IBD, reduce inflammation acutely

Importance of Sleep

Assessing Sleep Disturbance



Actigraphy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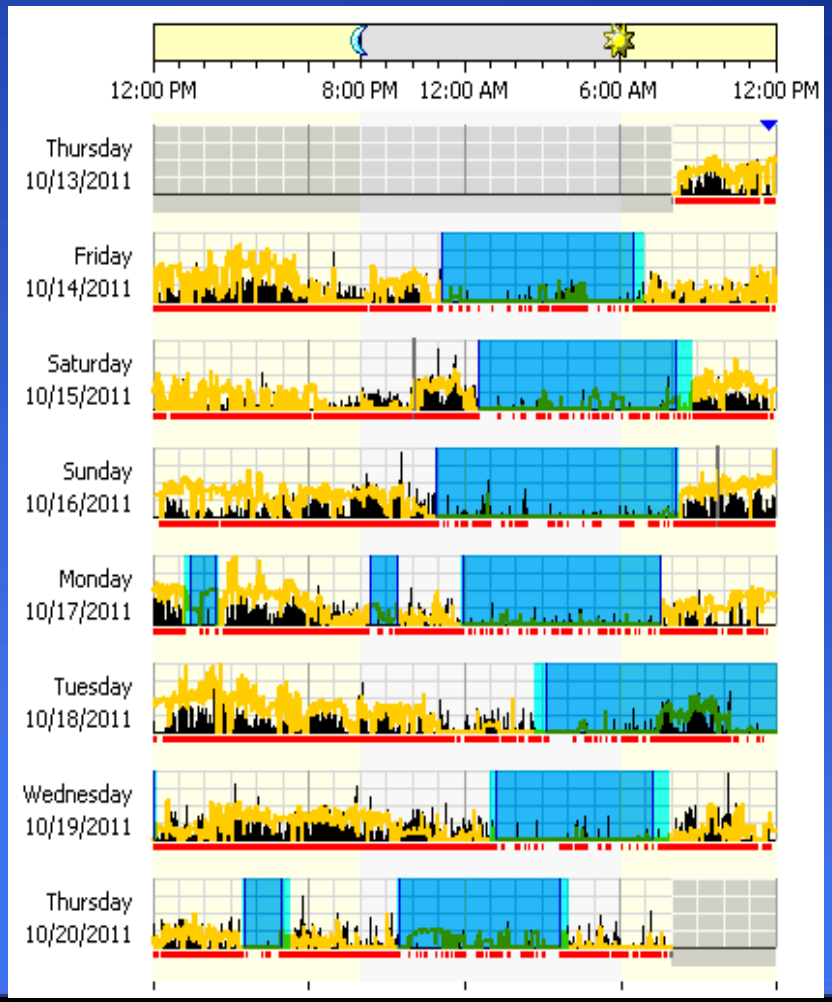
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Sleep History

- History
  - **B**edtime Routine
  - **E**xcessive Daytime Sleepiness
  - **A**rousals
  - **R**egularity
  - **S**noring

Potential Reasons for Poor Sleep in IBD

- Depression
- Anxiety
- Social stressors (bullying)
- Nighttime bowel movements
- Pain
- Pruritis
- Prednisone
- Active disease (hypersomnia)

Interventions for Sleep Disturbance

- Behavioral
- Pharmacological
- Equipment (CPAP/BiPAP)
- Phototherapy

Brief behavioral treatment of insomnia: Four easy steps! (Buysse)

- Reduce your time in bed
- Get up at same time every day of the week regardless of how much you slept night before
- Don't go to bed unless your sleepy
- Don't stay in bed unless you're asleep (Eliminate iphones, caffeine, worries, bad bed)
- Working with nocturnal diarrhea/ostomies

GOAL: **Time in bed = Actual Sleep time**

Pharmacotherapy for Sleep

- Antidepressants
- Antihistamines
- Benzodiazepines
- Benzodiazepine-like medications (zolpidem, eszopiclone)
- Melatonin

Pros and cons to medications for sleep

- Medications work, and work quickly
- Can alter sleep architecture (REM versus nREM sleep)
- Addictive potential (benzodiazepines)
- Side effects/adverse effects (drowsiness, amnesia)

Antidepressants in IBD

- **Buproprion and phenelzine** associated with improved **depression,** IBD course and bone density in adults
- **Bupropion** improved fatigue in other chronic diseases
- **SSRIs (Sertraline)** improved steroid-induced psychotic depression
- **SSRIs (Sertraline)** improved pruritis and related insomnia but not fatigue in PSC
- **…..The studies have not been done to support use of antidepressants for depression, pain or sleep**

Other Biological Treatments for Fatigue and Pain

- Stimulants and attention-enhancing medications?
- Other classes of antidepressants/mood stabilizers?
- Phototherapy?
- Accupuncture?
- Chronic opiate use linked to increased visceral pain, poor sleep, concentration problems, and fatigue

Biopsychosocial Treatment of IBD

BIOLOGICAL	PSYCHOLOGICAL	SOCIAL
Treat underlying organic problem	Cognitive restructuring/ Monitoring symptoms	Education
Exercise	Behavioral-activation/distraction	Enable/expect return to life
Medications	Conflict resolution	Family/Parent therapy
Stress Management	Hypnosis/Meditation	School/ work modification
Sleep	Activity scheduling	Social network

VISCERAL INFLAMMATION & PAIN (VIP) CENTER

- Integrates behavioral health into medical care
- Reduces stigma of behavioral health when seen as part of a comprehensive medical treatment plan
- Facilitates screening for stress and psychological issues during medical visits
- Personalized medicine for pain management, sleep and fatigue
- Decreases medical utilization and medical costs
- **412-802-6696**

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