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Active Days and Restful Nights: Managing Fatigue and Insomnia in Bone Marrow Failure Disease

Living With Aplastic Anemia, MDS or PNH
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Primary Aims

- Discuss Relation of Fatigue to Sleep Disturbance
- Assessing and Treating Factors Contributing to Fatigue and Sleep Disturbance
- Review Strategies for Managing Fatigue & Sleep Disturbance

A caveat:

- Very little research has been done investigating management of fatigue with bone marrow failure diseases (Thomas, 2012)
- "Bone marrow failure fatigue management" (9 references on PubMed)
- Most research has been done with cancer-related fatigue
- Therefore, some speculation is necessary

Cancer Related Fatigue

■ **Definition:** "a distressing persistent, subjective sense of tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning."



■ Reported to be one of the most distressing symptoms associated with MDS (Heptinstall, 2008)

NCCN Practice Guidelines in Oncology: Cancer-Related Fatigue

Sleep Disturbance

■ Common Sleep Disorders

- Obstructive Sleep Apnea
 - (snoring, waking gasping for breath, night sweats, waking with headaches)
- Restless Leg Syndrome
 - (aching crawling or cramping sensations in your leg)
- Periodic Limb Movement Disorder
 - (kick or jerk parts of your body during sleep)

Sleep Disturbance

■ **Insomnia Definition:** "complaints of difficulty initiating or maintaining sleep or non-restorative sleep which lasts for at least 1 month and which causes clinically significant distress or impairment in social, occupational, or other important areas of functioning." DSM IV-TR



■ One study estimated 43% of people meet criteria for insomnia syndrome during cycle one of their chemotherapy.

Palesh, et al (2010) Prevalence, demographics, and psychological associations of sleep disturbance in patients with cancer: University of Rochester Cancer Center – Community Clinical Oncology Program. JCO 28: 292-8.

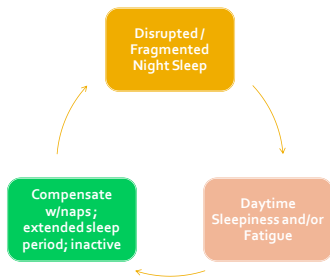
Sleep / Fatigue Relationship

- Correlative Data
 - Often occur simultaneously
 - Positively correlated
- Actigraphy Studies:
 - Fatigue is associated with disrupted circadian rhythms. More fatigue is reported by patients with less stable sleep-wake patterns who frequently nap.



Roscoe JA et al. (2007). Cancer-related fatigue and sleep disorders. *The Oncologist*, 12 (suppl 1), 35-42.

Sleep / Fatigue Relationship



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Assess/Treat Factors Contributing to Fatigue and Sleep Disturbance

Assess

- Periodic screening and evaluation are recommended
- Assessing the Problem
 - Fatigue severity (0 = no fatigue; 10 = worst imaginable)
 - Sleep Diaries
 - Onset and duration
 - Pattern or change over time
 - Alleviating factors
 - Interference with functioning
 - Review of systems and contributing factors

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Bone Marrow Failure-Related Fatigue: Treatable Contributing Factors

- 7 Contributing Factors to Fatigue
 - Comorbidities &/or Treatment Side Effects
 - Anemia
 - Emotional Distress
 - Pain
 - Nutritional Status
 - Low Activity Level
 - Sleep Disturbance
- Many of these factors can impact sleep too

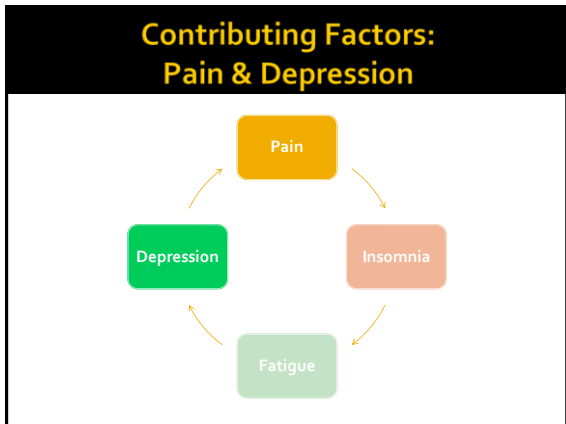
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Contributing Factors: Disease or Treatment

- Treatment and Medication Side Effects
- Anemia
- Other Health Problems:
 - Infection
 - Endocrine Dysfunction (e.g. Hypothyroidism; Adrenal Insufficiency)
 - Other Health Conditions or Dysfunction of the Heart, Lung, Kidney, Liver, or Nervous System





Emotional Distress

- 20-40% of people with bone marrow failure report significant distress at diagnosis
- Insomnia / fatigue can be symptoms of clinical depression or anxiety
- Watch for persistent symptoms:
 - Unmanageable worry
 - Panic
 - Sadness
 - Inability to find enjoyment
 - Difficulty thinking
 - Feeling hopeless, helpless, worthless or guilty
 - Thoughts of self harm or suicide

Managing Emotional Distress & Physical Pain

- Consult with medical team to optimize management of symptoms
 - Medical (e.g. medications)
 - Behavioral (e.g. psychotherapy)
 - Cognitive Behavioral Therapy
 - Alternative treatments (e.g. acupuncture)
- Be mindful that some medications can perpetuate fatigue/insomnia

Contributing Factors: Nutritional Status

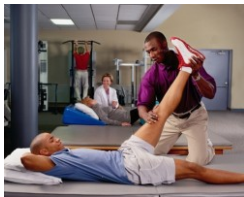
GENERAL NUTRITION TIPS



- Drink plenty of fluids
- 3-6 meals per day
- 5 + servings of fruit/veggies
- 25-35 g of fiber per day
- 50-70 g of protein per day
- 18 mg of iron per day if 50 or younger; 8mg if older
- Keep a food journal or diary
- Consult with a dietician about special needs

- Improving dietary intake can improve fatigue.

Contributing Factors: Low Activity Level



- Exercise is the most strongly supported behavioral intervention for fatigue
- Beneficial to sleep as well
- Surgeon General recommends 30 min moderate activity most days
- Consult with physician and/or physical therapist

Additional Sleep and Fatigue Management Strategies

Managing Insomnia / Fatigue: Common Medication Options

FATIGUE MEDICATIONS

- Psychostimulants
 - Methylphenidate
 - Modafinil
- Corticosteroids
 - Prednisone
 - Dexamethasone
- Medications for Anemia
 - Erythropoietin
 - Darbopoetin

SLEEP MEDICATIONS

- Benzodiazepines
- Non-Benzodiazepines
- Antidepressants
- Antihistamines



Physically-Based Therapies



- Therapeutic Massage
- Acupuncture
- Some preliminary support for efficacy in fatigue
- Literature is small & inconclusive



Symptom Monitoring

- Keep a log of problematic symptoms like fatigue and sleep disturbance to help you:
 - Understanding your fatigue/sleep
 - Notice patterns & contributing factors
 - Adjust your routines appropriately
 - Apply management strategies

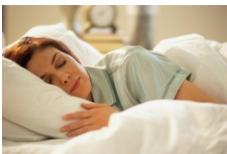
Daytime Distraction

- Pleasurable activities:
 - Playing games
 - Visiting with a friend
- Activities of accomplishment:
 - Trying something new
 - Finishing a project/chore
- Low energy activities:
 - Movies
 - Music
 - Reading

Daytime Energy Conservation

- Prioritize
- Organize
- Pace yourself – Take rest breaks
- Body Mechanics/Posture/Breathing
- Labor or Energy Saving Devices
- Delegate

Sleep Hygiene & Sleep Routines



- Avoid caffeine after noon
- Within 2 hours of bedtime avoid:
 - Tobacco/nicotine
 - Alcohol
 - Exercise
 - Heavy Meals
- Regular bed-time routines including a “wind-down” period can be helpful

Optimize Sleep Environment

- Maintain dark, quiet, clean & comfortable sleep environment
- Blankets, fans, etc to maintain a comfortable temperature
- Ear plugs or white noise machines if noises disturb sleep
- Window coverings or eye masks if lights disturb sleep
- Go to the bathroom & have a light snack if needed (foods high in tryptophan like milk)

Consolidate Nighttime Sleep

- Stimulus Control
 1. Use bed or bedroom for sleep & sex only
 2. Go to bed only when sleepy.
 3. If you do not fall asleep in 15-20 min., get up & do something relaxing in another room. Try again when you feel sleepy again; repeat as needed
 4. If you wake up & do not fall back to sleep in 15-20 min., follow rule 3 again
 5. Use an alarm to get up at same time every morning
 6. Avoid napping (if you must, try to nap before 3 pm)

Relaxation

- Yoga
- Muscle Relaxation
- Guided Imagery
- Visualization
- Mindful Meditation
- Controlled Breathing



www.healthjourneys.com

The Wellness Community
www.thewellnesscommunity.org

Conclusions

- Daytime fatigue & nighttime sleep problems are common in people with aplastic anemia, MDS, PNH
- These symptoms should be periodically reviewed with the medical team
- They are closely and reciprocally related so should be assessed and managed concurrently

Conclusions

- There are a variety of medical, behavioral, & alternative therapy options available for insomnia/fatigue management
- There are multiple factors that contribute to fatigue/insomnia (e.g. mood disturbance, pain, or physical inactivity) & these factors should be addressed
- Optimal management requires collaboration between the individual & their treatment team

Questions