What We Know About the Symptoms and Quality of Life of MDS Patients

**FATIGUE** 89%
- Bruising/bleeding 55%
- Night sweats 43%
- Bone pain 39%
- Fever 28%
- Skin rash 25%
- Weight loss 25%
- Work disabled 25%
- Restricted social & physical activities Most

Steensma et al. Leukemia Research, 2008, 691-698 (N=359)

Fatigue and Quality of Life

- Fatigue: On a score of 0 (no fatigue) - 10 (extreme)
  - MDS average = 5.8
  - Normal’average = 2.2
- Fatigue and quality of life were not related to hemoglobin level or need for transfusions.
- MDS patients are less than half as active as ‘normals’.
  - Steensma et al. Leukemia Research, 2008, 691-698

Quality of Life in MDS Patients

- Quality of Life:
  - On score of 0 (poor) –10 (excellent):
    - MDS average = 5.1
    - ‘Normal’ average = 7.7

Steensma et al. Leukemia Research, 2008, 691-698

Depression/Anxiety

- No specific studies
- 34% with depression/anxiety in a study examining value of transfusion free living in 47 MDS patients
- In cancer patients
  - 30%
  - In “serious medically ill”
    - 25%

QOL: Unhealthy & Activity
Limited Days/ Month

Impact of MDS on Quality of Life

- Emotional reaction
  - More difficult than physical impact
  - Varied – anger, shock, anxiety and depression

- Spiritual well being
  - Often improved
  - New perspective on life, relationships and faith

- Thomas. Supportive oncology 2012

Overview

- What do we know about symptoms & quality of life for MDS patients?

- What are good ways to cope with these illnesses?

- How should you advocate for the best care, in an environment that many are not familiar with?

- What about anxiety, depression & fatigue?

What is Coping?

- Finding ways to manage the stress you are having

- Being able to enjoy things that you used to despite limitations

- Finding ways to deal with uncertainty

- Managing main symptoms of disease (i.e. Fatigue!)

Perspective

- Everyone has developed their own coping mechanisms

- Not every coping strategy is going to work for every person

- Some coping strategies are healthier than others

- What has worked for you in the past, is likely to work now

Changes

- As with any serious medical illness, being diagnosed with MDS will result in many changes to your life.
  - change in daily routine
  - new medicines/treatments
  - spending much more time with health care providers
  - fear and anxiety
  - fatigue
  - depression
Early Days of Diagnosis

- **shock**
  - "I didn't really feel bad"

- **worry**
  - "What does the future hold?"

- **confusion**
  - "What does MDS mean?"

- **betrayal & anger**
  - "How could my body have failed me?"

After the diagnosis has “sunk in”

- **Able to cope with things the way you used to**

- **Family members may have a harder time emotionally during this period**

- **But sometimes, feeling like you can’t move on and feeling depressed**

Typical reactions & experiences can include:

- **Upheavals and adjusting to a new normal/new reality**
  - Life changing and life threatening

- **Some coasting times**

- **Overall, a lot of unpredictability**

Coping with the Illness

- **Taking one day at a time & focus on the real issues**

- **Realistic optimism**

- **Keeping a sense of balance**

- **Manage stress levels**

- **Accepting your feelings**

- **Using your support network and asking for help with you need to**

- **Working with your healthcare team**

Control what you can

- **What you DON’T control:**
  - Feelings (fear of symptoms, disease, dying)
  - Biological effects of disease and treatment
  - Other people and how they respond

- **What you DO control:**
  - Your health behaviors
  - How you respond to feelings

Healthy Coping

- **Physical**
  - Exercise, nutrition, beating fatigue

- **Emotional**
  - Support networks, relationships, keeping perspective

- **There is an overlap!**
Relaxation Techniques

- Good to try a few and find what works for you
- Ideal if can be done in any location
- Start with easy techniques
- Practice & practice

Some quick relaxation techniques

- Breathing
  - Many different types
  - Key is to slow the breathing and quiet the mind
- Progressive muscle relaxation
  - Tensing and then relaxing muscle groups
- Guided visualization
  - Breathing while focusing on a positive image

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Being a “powerful” patient

- Start with the “right” treatment team
  - Know what works best for you
    - Lots of information, not a lot of information
    - Communication style
  - Get a second opinion

“Powerful” Patient Tips

- Write down questions before appointments
  - Binder of all your info
- Be an active participant in your treatment, maintaining your health, and in making it your life
- Gather information
- Make a health plan
- Ask about treatment options
- Get a mentor or join a support network
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Fatigue

- Persistent symptom
- Subjective feeling of tiredness or exhaustion
- Related to bone marrow failure disease or its treatment
- Not proportional to recently performed activity
- Can interfere with the usual functional capacity

Fatigue studies in the Cancer population

- Fatigue remains underreported
- Often goes untreated
- Patients report that fatigue as one of the most important and stressful symptoms
- Associated with decrease in personal satisfaction and quality of life

Fatigue is underreported & untreated – why?

<table>
<thead>
<tr>
<th>PHYSICIANS</th>
<th>PATIENTS</th>
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</thead>
<tbody>
<tr>
<td>Insufficient knowledge on fatigue &amp; treatment</td>
<td>Inevitable consequence of the illness or treatment</td>
</tr>
<tr>
<td>Underestimate impact on quality of life</td>
<td>Fear of receiving a less aggressive treatment</td>
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What causes Fatigue?

- Anemia
- Decreased physical activity
- Immune system
- Brain – impact of chemotherapy
  - Cytokines
- Hormones
- Sleep problems
- Depression/Anxiety

Treatment of Fatigue – non-pharmacologic

- Exercise
- Accepting that your normal has changed
- Energy conservation
- Good nutrition
- Sleep
- Avoiding alcohol, heavy meals, boring meetings, etc.
- Having an exit plan or backup plan
- Cognitive-behavioral therapy
- Alternative and complementary medicine
**Exercise benefits**

- Reduces fatigue
- Stress management
- Improved muscle tone
- Weight management
- Quicker recovery from surgery or medical procedures
- Feeling of control
- Studied extensively in the cancer population

**Exercise - continued**

- Talk with your physician before you start any exercise program
- Start slow and keep your expectations low
  - Walking programs tend to be the easiest
  - Start with only 5 minutes a day
  - Best to do small amounts of exercise every day
  - Incrementally increase the amount on a weekly basis, if you tolerate it

**What type of exercise?**

- Aerobic/cardiac activity
  - Walking, running, yard work, swimming
- Strength training
  - Resistance bands or machines, weights
- Mind-body
  - Yoga, Tai-Chi, Pilates
- Stretching

**Generally not a good idea to exercise if...**

- High dose IV chemo the day prior
- Platelet count below 50,000
- White blood count below 3,000
- Absolute granulocyte count below 2,500
- Chest pain, pressure or rapid heart beat
- Or - your physician advises against exercise

**Nutrition**

- Try small meals and snacks all day.
- When you are hungry, eat more than usual.
- Keep ready-to-eat snacks handy to nibble on during the day.
- If you are not interested in eating, try a liquid or powdered meal replacement product for extra calories and protein.
- Hydrate!

**Sleep**

- Really important to have good sleep to maintain energy level!
- Insomnia (sleeping too little)
- Hypersomnia (sleeping too much)
- Have a set sleep schedule
  - Go to bed each night at the same time & get up in the morning at the same time
  - If you are not asleep within 30 minutes, get out of bed until you feel tired

**Stretching**

- Certain treatments can weaken your body’s immune system - you may be told to avoid some foods

- Hydrate!
Energy Conservation Strategies

- Plan around transfusion schedule
- Exercise early in the day if you crash and burn in afternoon
- Pacing activities vs. paying for them later (sleeping to catch up on energy)
- Modify activities so you can still do those that you enjoy

Treatment of Fatigue - Pharmacologic

- Stimulants
  - Wakefulness-promoting agents
- Antidepressants
- Complementary and alternative medicine

When is it Depression?

- 2 weeks or longer of depressed mood or not enjoying things like you used to along with
  - Sleep disturbance
  - Decreased interests
  - Feelings of guilt
  - Fatigue
  - Impaired concentration
  - Change in appetite
  - Feeling slowed or speed up internally
  - Thoughts of death or suicide

Treatment of Depression

- Selective serotonin reuptake inhibitors
- Serotonin-norepinephrine reuptake inhibitors
- Others – buproprion
- Some are very energizing!
- Psychotherapy

Anxiety

- Normal response to threat, uncertainty and loss of control
- Very common in seriously medically ill patients
  - Especially after initial diagnosis & at “crisis points”
  - Intrusive thoughts, insomnia, anorexia
- Can be mimicked by meds, pain or other medical problems
  - Antiemetics, pulmonary embolus, delirium

Specific Anxiety

- Can prevent a person from having treatments
  - Claustrophobia
  - Needle phobia
- Anticipatory anxiety
- PTSD
  - Pitman et al. 2001; Kettwich et al. 2007
Treatment of Anxiety

- Same as for Depression
- Short term or as needed use of benzodiazepines
  - Typically avoided long term because:
    - Can add to fatigue
    - Can worsen the anxiety
    - Can become addictive

In Summary

- Patients with bone marrow failure diseases are at high risk for lower quality of life, fatigue, depression and anxiety
- There are ways to manage the stress healthfully, including working towards being an advocate for your own health
- Make sure to recognize any problems with fatigue, depression and anxiety, as there are effective treatments

Questions?


Relaxation exercise

- Guided imagery

references