Overview

- What do we know about symptoms & quality of life for bone marrow failure disease 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?

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’.

Fatigue and Quality of Life of MDS Patients

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>89%</td>
</tr>
<tr>
<td>Bruising/bleeding</td>
<td>55%</td>
</tr>
<tr>
<td>Night sweats</td>
<td>43%</td>
</tr>
<tr>
<td>Bone pain</td>
<td>39%</td>
</tr>
<tr>
<td>Fever</td>
<td>28%</td>
</tr>
<tr>
<td>Skin rash</td>
<td>25%</td>
</tr>
<tr>
<td>Weight loss</td>
<td>25%</td>
</tr>
<tr>
<td>Work disabled</td>
<td>25%</td>
</tr>
<tr>
<td>Restricted social &amp; physical activities</td>
<td>Most</td>
</tr>
</tbody>
</table>

Steensma et al. Leukemia Research, 2008, 691-698 (N=359)
Quality of Life in MDS Patients

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

  - Steenma 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%

  - Szende et al. Health and quality of life outcomes, 2009

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

QOL: Unhealthy & Activity Limited Days/ Month

- Unhealthy Days
- Activity Limited Days

- Chart showing days and limitations in MDS patients.
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?

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

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!)

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

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

Healthy Coping

- Physical
  - Exercise, nutrition, beating fatigue
- Emotional
  - Support networks, relationships, keeping perspective
- There is an overlap!

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 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

• 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 is underreported & undertreated – why?

• Insufficient knowledge on fatigue & treatment
• Underestimate impact on quality of life
• Inevitable consequence of the illness or treatment
• Fear of receiving a less aggressive treatment
What causes Fatigue?

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

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

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

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
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

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 Fatigue - Pharmacologic

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

Treatment of Depression

- Selective serotonin reuptake inhibitors
- Serotonin-norepinephrine reuptake inhibitors
- Others - bupropion
- 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

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

Pitman et al. 2001; Kettwich et al. 2007
**Questions?**

**Relaxation exercise**

- Guided imagery

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**references**