

Breaking Point: Learning How to Relax, Relate, and Release

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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?

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

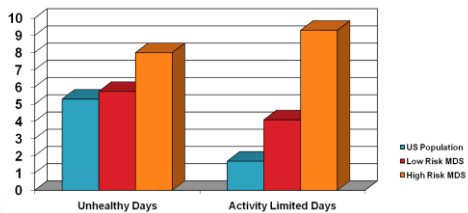
• Steensma et al. Leukemia Research, 2008, 691-698

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%

• Szende et al. Health and quality of life outcomes. 2009

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

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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

TOOMERS

By Buck Cash



While his doctor knew a lot, Gary decided to find a specialist anyway.

“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 & undertreated – why?

Physicians

- Insufficient knowledge on fatigue & treatment
- Underestimate impact on quality of life

Patients

- 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

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!
- 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

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 – 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

• 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?

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