Psychosocial Concerns for People Living with MDS

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Agenda

• Cancer Survivorship
• MDS-related psychosocial issues
• Psychiatric symptoms associated with MDS
• Models for psychological treatment
• Mindfulness exercise
“We respect that everyone who is affected by cancer can choose to identify with the term they feel best describes their experience, whether it be “survivor,” “thriver,” “person living with cancer,” any other term that resonates, or even no label at all...”
Cancer Survivorship

“...The real challenge of cancer is to live as best as one can for as long as one can. The strength one must have to face the unknown every day; the courage one must muster each time they enter a doctor’s office, wait for test results, or receive treatment; and the vulnerability they must endure throughout the cancer journey regardless of the outcome, defines the experience.”

-National Coalition for Cancer Survivorship
Cancer Survivorship

(Shapiro, 2018)
Common Psychosocial Issues

• Disruption of life and routine
• Changing interpersonal dynamics with partner, family, friends, community
• Sense of self, or identity
  – Grief over the loss of the “old self”
• Decreased sense of control; reliance on others
• Living with uncertainty
Gaps in Psychological Care

• 25-45% of cancer patients in outpatient clinics have significant levels of distress
• Patients reluctant to ask oncologists for help with psychosocial distress
• < 10% referred for any type of supportive service
Depression (DSM-5)

• Depressed mood
• Loss of interest in previously enjoyed activities
• Significant weight loss/gain
• Sleeping too much or too little
• Restlessness/fidgety OR moving very slowly
Depression (DSM-5)

- Fatigue or lack of energy
- Feelings of worthlessness or excessive guilt
- Decreased ability to concentrate or indecisiveness
- Recurrent thoughts of death or suicidal thoughts
Anxiety (DSM-5)

- Restlessness, feeling keyed up or on edge
- Excessive worry about many things
- Inability to control worry
- Difficulty concentrating or mind going blank
- Irritability
- Muscle tension
- Sleep problems
Models for Treatment

- Cognitive Behavioral Therapy
- Acceptance and Commitment Therapy
- Mindfulness
Cognitive Behavioral Therapy (CBT)

- Common type of “talk therapy”
- Helps you become aware of inaccurate or negative thinking so you can view challenging situations more clearly and respond to them in a more effective way
CBT
CHANGING PERCEPTIONS

THOUGHTS
What we think affects how we feel and act

EMOTIONS
What we feel affects how we think and act

BEHAVIORS
What we do affects how we think and feel
Cognitive Distortions

- **All or nothing thinking**
  - Sometimes called ‘black and white thinking’
  - "If I’m not perfect I have failed"
  - "Either I do it right or not at all"

- **Over-generalising**
  - "everything is always rubbish"
  - "nothing good ever happens"

- **Mental filter**
  - Only paying attention to certain types of evidence.
  - "Noticing our failures but not seeing our successes"

- **Disqualifying the positive**
  - Discounting the good things that have happened or that you have done for some reason or another
  - "That doesn’t count"
Cognitive Distortions

- **Jumping to conclusions**
  - There are two key types of jumping to conclusions:
    - Mind reading (imagining we know what others are thinking)
    - Fortune telling (predicting the future)
  - 2 + 2 = 5

- **Magnification (catastrophising) & minimisation**
  - Blowing things out of proportion (catastrophising), or inappropriately shrinking something to make it seem less important

- **Emotional reasoning**
  - Assuming that because we feel a certain way what we think must be true.
  - I feel embarrassed so I must be an idiot

- **Shoul...**
  - Using critical words like ‘should,’ ‘must,’ or ‘ought’ can make us feel guilty, or like we have already failed
  - If we apply ‘shoulds’ to other people the result is often frustration

- **Labelling**
  - Assigning labels to ourselves or other people
  - I’m a loser
  - I’m completely useless
  - They’re such an idiot

- **Personalisation**
  - Blaming yourself or taking responsibility for something that wasn’t completely your fault.
  - Conversely, blaming other people for something that was your fault.
  - “This is my fault”
Cognitive Behavioral Therapy (CBT)

- While you cannot control every aspect of the world around you, you can take control of how you interpret and deal with things in your environment.
Acceptance and Commitment Therapy

• Learn to stop avoiding, denying, and struggling with your inner emotions

• Accept that these deeper feelings are appropriate responses to certain situations that should not prevent you from moving forward in their lives
Acceptance and Commitment Therapy

• Valid alternatives to trying to change the way you think:
  – Mindful behavior
  – Attention to personal values
  – Commitment to action
Acceptance and Commitment Therapy

• Taking steps to change behavior while, at the same time, learning to accept psychological experiences, can eventually change attitude and emotional states
Mindfulness

• Being in the “here and now”
• A basic human ability
  – to be fully present
  – aware of where we are and what we’re doing
  – not overly reactive or overwhelmed by what is going on around us
Mindfulness Exercise
Resources

CANCER CARING CENTER

LEUKEMIA & LYMPHOMA SOCIETY

NATIONAL COALITION FOR CANCER SURVIVORSHIP