

Psychological Well-Being and Myelodysplastic Syndrome

Hermioni Amonoo, MD, MPP

Carol C. Nadelson, MD Endowed Chair in Psychiatry | Director, Well-Being and Cancer Research Program
Brigham and Women's Hospital

(Notes from 4/22/2023 Webinar)

1. Psychological well-being is crucial to every aspect of the Myelodysplastic Syndrome (MDS) Care Continuum below:
 - a. Pre-diagnosis ⇒ Diagnosis ⇒ Treatment ⇒ Survivorship
2. Patients with MDS and their caregivers experience significant psychological distress. What does this look like?
 - a. About 40% of patients with blood cancers including myelodysplastic syndrome report symptoms of depression and anxiety. About 25% report post-traumatic stress symptoms and poor adjustment and coping.
3. Psychosocial well-being can be described as a toolbox with different tools and resources to help you achieve psychological well-being. Some of these tools include (in no particular order of importance):
 - a. Health behaviors: physical activity, medication adherence, and eating a nutritious diet.
 - b. Pharmacological interventions: different medications including antidepressants which have good scientific evidence to help manage symptoms of depression and anxiety.
 - c. Social support
 - i. Strong evidence exists that social support from peers makes a difference for psychological well-being, quality of life, cancer management, and survivorship.
 - ii. Maintaining social networks which may entail family, friends, or other meaningful relationships can also contribute to well-being, and should not be ignored.
 - d. Psychotherapeutic interventions and skills building
 - i. *Cognitive behavioral therapy skills*: A powerful way to notice how our thoughts impact our emotions which impact our behaviors as we navigate and cope with the various stressors that can accompany survivorship.
 1. It is normal to feel sad or discouraged, and it is a myth that these negative feelings are not allowed in survivorship.
 2. Some of these feelings are automatic and natural in the wake of living with cancer and possible treatment side effects.
 3. It is important to be aware of these negative feelings and how they affect you.
 4. People's negative thoughts, feelings, and coping behaviors are strongly related to each other.
 5. When facing a difficult situation, these connections can make distress feel worse or better. For example, thoughts such as "Will my cancer return or will my treatment fail?" often lead to feelings such as fear or sadness.
 6. These feelings, in turn, may lead a behavior such as a person calling a family member or friend for support, or perhaps withdrawing and staying in bed, or doing some other activity to cope.
 7. Identifying the connections among your negative thoughts, feelings, and behaviors can help you better manage how to respond to difficult situations.
 - ii. *Mindfulness and meditation*: Purposefully paying attention to the present moment without judgement
 1. Key steps of mindfulness are:
 - a. Purposefully paying attention and being fully present in the moment.
 - b. Observing your experience without judging it.

2. Practicing mindfulness:
 - a. Try to notice your breath and focus on relaxing your body.
 - b. Practice letting go and recognize your thoughts and feelings don't define you.
 - c. Observe your emotions and become aware of feelings and label them
 - d. Let go of judgmental thoughts, remind yourself that there are no "right" or "wrong" ways to think.
 - e. Tune into your senses and your environment, sights, smells, and sound. Ask yourself, what am I feeling, hearing, or smelling at this moment?

iii. *Self-compassion*

1. Self-kindness vs. Self-judgement: Being gentle and kind to yourself when we fail or suffer.
2. Common humanity vs. Isolation: When things are not the way we want, we can feel isolated. However, all humans suffer, are mortal, vulnerable, and imperfect.
3. Mindfulness vs. Over-identification: Maintaining a balanced approach to our negative emotions so we don't suppress or exaggerate. Maintaining a larger perspective, being nonjudgmental, and mindful, can be helpful.

iv. *Positive psychology skills*

1. Lack of Stress \neq Well-being
2. Positive psychology entails noticing and reflecting on your positive thoughts and emotions as a way to achieve well-being.
3. Positive psychological constructs contribute significantly to psychological well-being.
 - a. Happiness, enthusiasm, and joy constitute *hedonic* well-being or an approach to wellbeing that focuses on pleasure attainment and pain advocate.
 - b. Meaning/purpose or satisfaction constitute *eudaimonia* which focuses on meaning and self-realization.
 - c. Gratitude and optimism.
 - d. Religiosity and spirituality.
 - e. Self-efficacy and self-esteem.
4. Noticing positive thoughts and feelings can also be helpful in navigating various aspects of survivorship.
5. Naming positive thoughts and feelings.
 - a. For example: gratitude journal, expressing gratitude, acts of kindness
6. Positive psychology \neq tyranny of positive thinking
 - a. Patients feel pressured to think positively and may think that failure to be positive is a character flaw that can lead to poor clinical outcomes and disease setbacks

e. Professional help

- i. If you notice that painful feelings are causing severe distress or interfering with your ability to get through your day, it would be helpful to seek professional help
- ii. No one has to suffer alone, there are plenty of resources to help
- iii. Your oncology team and/or social worker can help facilitate a referral