Life After Transplant: Cultivating Resilience and Growing from Trauma

Celebrating a Second Chance at Life Survivorship Symposium

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Learning Objectives

• The incidence, type and duration of emotional challenges survivors face after transplant.
• An understanding of what resilience and emotional growth after transplant means.
• Strategies for growing resilience after emotional and physical struggles.
• The benefits of professional counseling, when to ask for help and where to find it.

Emotional Challenges Faced after Transplant

• Distress
• Anxiety
• Depression
• Post-traumatic Stress Disorder
Distress Following Transplant

- Distress is the MOST common, yet under-reported, side effect of treatment
- Distress ranges from feelings of vulnerability, sadness and anger – to problems such as severe depression, anxiety, panic and post traumatic stress
- Unaddressed, these symptoms will decrease the quality of your life
- Distress can be addressed effectively

Common Signs of Distress

- Crying often
- Feeling “under the weather”
- Tense or jittery
- Change in eating or sleep habits
- Avoiding people or things that remind you of cancer
- Needing a lot of reassurance
- Withdrawal from people and activities
- Overreacting to situations
- Feeling irritable and moody
Understanding Anxiety

- Restlessness
- Impending sense of danger
- Easily fatigued
- Difficulty concentrating
- Irritability
- Muscle tension
- Uncontrolled worry
- Sleep problems
- Increased startle response

Understanding Depression

- Hopelessness
- Helplessness
- Guilt
- Loss of interest
- Changes in sleep
- Sadness/irritability
- Problems with memory/concentration
# Common Symptoms of Trauma Exposure

<table>
<thead>
<tr>
<th>Emoional</th>
<th>Mental</th>
<th>Behavioral</th>
<th>Physical</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loneliness</td>
<td>Loss of concentration</td>
<td>Withdrawal from others</td>
<td>Aches/pains</td>
</tr>
<tr>
<td>Fear/Anxiety/Panic</td>
<td>Disorientation/confusion</td>
<td>Impulsive behavior</td>
<td>Fatigue/tiredness</td>
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<tr>
<td>Anger/frustration</td>
<td>Memory loss</td>
<td>Aggression</td>
<td>Racing heart</td>
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<tr>
<td>Mood swings</td>
<td>Obsessive thoughts</td>
<td>Crying</td>
<td>Nausea/vomiting</td>
</tr>
<tr>
<td>Sadness</td>
<td>Distractibility</td>
<td>Being argumentative</td>
<td>Shakiness/trembling</td>
</tr>
<tr>
<td>Hopelessness</td>
<td>Indecisiveness</td>
<td>Changes in sleep</td>
<td>Headaches</td>
</tr>
<tr>
<td>Helplessness</td>
<td>Thoughts about death/dying</td>
<td>Changes in appetite</td>
<td>Numbness/tingling</td>
</tr>
<tr>
<td>Feeling numb</td>
<td>Racing thoughts</td>
<td>Easily startled</td>
<td>Diarrhea</td>
</tr>
<tr>
<td>Nightmares</td>
<td></td>
<td>Increased drug/alcohol use</td>
<td>Hot flashes</td>
</tr>
<tr>
<td>Lack of confidence</td>
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</tbody>
</table>

(Tedeschi & Moore, 2016)

# Post-traumatic Stress Disorder (PTSD) Symptoms

<table>
<thead>
<tr>
<th>Intrusive Symptoms</th>
<th>Avoidance Symptoms</th>
<th>Negative Thoughts/Mood</th>
<th>Arousal/Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pervasive/intrusive memories</td>
<td>Avoidance of trauma-related thoughts, memories and feelings</td>
<td>Trauma-related memory problems</td>
<td>Irritability/anger/aggressive</td>
</tr>
<tr>
<td>Nightmares</td>
<td>Avoidance of reminders of the event</td>
<td>Negative beliefs</td>
<td>Reckless behavior</td>
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<tr>
<td>Flashbacks/dissociation</td>
<td>Persistent blaming</td>
<td>Being on guard</td>
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<tr>
<td>Extreme distress)</td>
<td>Negative/distressing emotions</td>
<td>Easily startled</td>
<td></td>
</tr>
<tr>
<td>Increased physiological reactions</td>
<td>Loss of interest/pleasure</td>
<td>Concentration problems</td>
<td></td>
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<tr>
<td></td>
<td>Feeling disconnected</td>
<td>Difficulty falling/maintaining sleep</td>
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</tr>
<tr>
<td></td>
<td>Lack of positive emotions</td>
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</tr>
</tbody>
</table>

(DSM-5, 2013; Tedeschi & Moore, 2016)
Risk Factors for PTSD

- 6 months post HCT 18.9% of patients experienced clinically significant PTSD symptoms
- Lower financial/education status
- History of mental illness
- Physical injury
- Having seen people hurt/maimed or killed
- Feeling a sense of helplessness/horror/fear
- Little or no support
- Managing other difficult stressors

Protective Factors for PTSD

- Support groups
- Relying on family or friends
- Low levels of guilt, shame, embarrassment
- Natural optimism
- Sense of humor
- Having more life experience
- Successful experiences with difficult life events
- Effective coping strategies
Periods of Vulnerability

• Ongoing
  • Tests/Scans/Appointments
  • Anniversaries
• Transitions
  • Between treatment phases/off of treatment
  • Life changes (career, life insurance, family planning)
• New events
  • Others diagnosed
  • Loss of others in the transplant community
  • New symptoms/health problems or recurrence

Defining Resilience vs. Post-traumatic Growth

• Resilience:
  • The ability to recover/bounce back from difficulties
• Post-traumatic Growth:
  • Moving from a struggle to bounce back to finding personal growth
  • Challenges personal beliefs
  • Endurance through psychological struggle
The 5 Gifts of Trauma Resilience

- New possibilities
- Increased strength
- More meaningful relationships
- Greater appreciation
- Spiritual development

(Tedeschi & Moore, 2016)

New Life Paths and Possibilities

- Making small or large changes associated with your experience
- New set of priorities
- Adjustments to doors that may have closed
- Focus on what would be most satisfying and important when setting new goals
- Know that you may experience some grief
Increased Personal Strength

- Strength to handle challenges
- Helpful to acknowledge the strength
- Look at your self-reliance, better problem-solving or significant changes made in your life.
- Honor your ability to make room for and tolerate difficult emotions.
- Acceptance can bring a strong sense of strength and resilience.

Improved or More Meaningful Relationships

- Learn to find and accept support
- Thinking of others as a part of your team
- Learning to accept our own limitations and vulnerabilities
- Increase in empathy and compassion
- There will be people who were or are unable to support you and you can forgive those people
- Explore deeper and more meaningful relationships
Greater Appreciation of Life

- A greater understanding and acknowledgement of what they have.
- Appreciation of everyday experiences
- Focus on a sense of how precious life can be which may change priorities
- Recognition of the fortune that comes with being alive.
- Gratitude and ability to savor the daily enjoyment
- Perspective on taking risks may change

Spiritual Change or Development

- A change in the meaning and purpose in life
- Struggle to to figure out how to fit what has happened into existing beliefs
- Previous struggles may now seem trivial/unimportant.
- Focus is on finding your own truth for how to live life well
- Changes in spiritual understanding
- Help from others
- Deep examining of yourself and your ideas
Things to Keep in Mind about Resilience

- Growth can be uncomfortable and may take time.
- Goal is focus on leaning into this change
- You may have to explore a number of life experiences
- Look for signs that you are changing
- Look at how your life has changed related to family, work and other social relationships

Coping Mechanisms that Work

- Meditation
- Deep breathing/relaxation
- Humor/laughter
- Reading/watching tv/go to the movies/listen to music
- Take a bath/shower
- Engage in spiritual activities
- Be creative
- Talk with friends/family
- Hobbies
- Exercise
- Take a nap
Social Support

• Find people who can support you
• Find others who are easy to be with
• Find others who can be with you on good days and bad
• Find a people who understand that their role is often passive
• Find others who have faith in your ability to understand your journey
• They are comfortable with the idea that the endpoint may not be clear
• They can provide feedback on things you may not see while still trusting your own process

Active Coping Strategies

• Accept that the problem exists
• Take action to get rid of the problem
• Look for advice and information
• Adopt a new perspective: make the most of a bad situation
• Become aware of your feelings and express how you feel to others
Avoidant Coping

• Deny the problem exists
• Withdraw from social life
• Avoid the problem with alcohol or drugs (the use of prescribed drugs to help actively cope, is different)
• Blame yourself for the problem and criticize yourself

When to Seek Professional Counseling

• The impact of your symptoms interferes with love, work and play
• You find it challenging to move forward with what is meaningful to you
• You have thoughts about suicide or self-harm
• When symptoms interfere with medical care
Types of Professional Help

• Therapist - talk therapy to assist with trauma-related symptoms
• Psychiatrist - medication to manage trauma-related symptoms
• Medical Team - referral for mental health assistance
• Support Group – run by a professional provider to offer support

Where to Find Professional Help

• Contact your medical center for a referral
• BMT InfoNet Mental Health Directory (bmtinfonet.org/mh-directory)
• Reach out to your insurance company
• State and local psychological associations
• Psychology Today
Recommended Reading


References

References


• What is Trauma retrieved from center for anxietydisorders.com

Questions?

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