Psychological Effects on the Chronically Ill and Their Families

Andrew Roth, MD
Memorial Sloan Kettering Cancer Center
Weill Cornell Medical College

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Disclosure
Let’s Get Started

• A chronic condition is a human health condition or disease that is persistent or otherwise long-lasting in its effects, but without an accurate crystal ball.
• Focus on symptoms vs illness control vs cure
• One disease does not describe all affected by it:
  – Long bone involvement
  – Chronic uncontrolled inflammation
  – Extraskeletal: kidney, skin, brain, lung, heart
  – Bone pain: lower limbs, knees and ankles; lower back and stomach pain
  – Diabetes insipidus
  – Ataxia
  – Dyspnea
  – Kidney failure
  – Hypopituitarism
  – Liver failure
  – Problems with coordination, slurred speech, behavior disorders, vision problems
• It's common to experience a range of emotions:
  – Guilt, anger, sadness, fear, anxiety and depressed mood
  – The roller coaster: accepting one day, and angry the next.
• Family members also experience emotional reactions
Treatment

• Surgical debulking
• Corticosteroids
• Cyclosporin
• Interferon
• Chemotherapy
• Vemurafenib
• Radiation Therapy
Triggers for Distress

- Blood tests
- Scans
- EKGs
- Anticipatory anxiety
Coping Strategies

• Facing and accepting the diagnosis may take time.
• Ask your doctor what specific steps you can take to optimize your health.
• Active coping may help:
  – Take medications as prescribed
  – Eating better
  – Some activation is better than none (paced)
  – Continuing to socialize
  – Can you let go of unnecessary obligations, or ask for more help?
  – Build a support network you can rely on, and communicate with them about how they can best help you manage your disease
• Be aware of ups and downs of ‘positivity’ strategies
  – Focus on problems or emotions
  – What is ‘good-enough’?
  – Slippery slope of stability or ‘new-normal’
Chronic Illness

- Fatigue
- Pain
- Appearance
- Physical abilities and independence
- Impact on work and finances
- If stress, anxiety, depression and anger brought on by the illness are interfering with life, it is important to seek help and attempt to regain a feeling of control.
- Support groups might help:
  - To know you are not alone
  - To potentially learn some new tips on how to cope
- Improved management with more information (up until a point)
  - Make sure the information is reliable
  - It is important to find a health care provider that you can trust.
Social Cognitive Processing to Enhance Coping and Reduce Distress

• Reframe issues of illness (ie, loss)
• Problem solve daily challenges
• Put the past in a tolerable perspective
  ➢ Life review to note strengths, manage anxieties
  ➢ Using coping tools that worked before
• Increase social ties/new behaviors
  ➢ To overcome loneliness
• Processing uncertainty about mortality
  ➢ How to make peace with one’s life/impart wisdom
  ➢ Enhance sense of meaning and purpose
Social Cognitive Processing Theory

- Adjustment following adverse or traumatic events
- Proposes that an adverse event such as an ECD diagnosis and continued treatment can shatter a person’s beliefs about him/herself and the world.
- For previously healthy older adults:
  - assumptions about mortality, body integrity, and ability to control their daily lives are challenged.
- For those with other pre-existing illnesses:
  - Illness challenges assumptions about control, while an additional diagnosis of ECD can crystallize fears of mortality.
Psychotherapeutic Flexibility
You don’t need to be crazy to get psychological help

• May need to decrease length or frequency of sessions
• May need to focus on physical and psychological symptom interplay and relief
• May need to be flexible with therapy style:
  ➢ Education
  ➢ Support
  ➢ Cognitive-behaviorally oriented
  ➢ Insight-oriented
  ➢ Existential
• May need to have spouse/family member in session
Distress, Anxiety and Depression: Treatment in Psycho-Oncology

• Psychotherapy
  - Cognitive behavioral, supportive, insight oriented, Dignity, Meaning Centered psychotherapies
  - Reframing, progressive relaxation, guided imagery, meditation, hypnosis, behavioral activation
  - Understand the illness in context of life continuum
  - In-person: individual or group; or telephone counseling

• Pharmacotherapy
  - Benzodiazepines: Sedation, confusion, falls
    - Paradoxical agitation
  - Neuroleptics: Low doses effective; EKG; sedation; DM
    - Good alternative or addition to benzodiazepines
  - Antidepressants and Psychostimulants
Coping with a Chronic Illness

• Families:
  – It's not unusual for couples to experience strain on their relationship.
  – Try to see things from the other's perspective
  – Keep the lines of communication open
  – Plan for some alone time with your partner
  – Encourage your partner to make time to care for himself or herself
• Finding ways to help others and be a role model
• Groups vs individual therapy
Conclusions

• There is no ‘right’ way to coping with a chronic illness
• You may find new weaknesses and strengths
• Try to stay active physically and socially
• The ‘glass half full’ approach may lead you to ‘even fuller’
• Be aware of how others around you are impacted as well
• The old ways of coping and communicating may not work well now
• Get help if you are feeling stuck