Overcoming Stress and Anxiety in Chronic Illness: *Strategies that Work*

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**Objectives for Our Discussion**

*Increased understanding of:*

- Stress and illness
- Patient factors in coping with illness
- Caregiver factors in coping with illness
- Communication challenges in healthcare
- Strategies for promoting resilience
What is Stress?

- People generally think stress is something outside of themselves causing strain or tension
- Mind and body’s response or reaction to real or imagined threat, event or change
- Threats, events, or changes are stressors
  - Internal: thoughts, beliefs, attitudes
  - External: loss, tragedy, change
- Reaction to excessive pressures or demands
- Stress arises when you worry that you can’t cope

"The chief cause of stress is reality."
--Lily Tomlin
What Causes Stress?

- External Stressors
  - Physical/Environmental
  - Social
- Internal Stressors
  - Biological
  - Psychological

Social Sources of Stress

- Work pressure
- Pressure, pace of daily routine and home life
- Expectations or behavior of others
- Family/cultural values, patterns
- Daily hassles
- Interactions with or isolation from others
- Family, friends, bosses, coworkers, etc
Stress Feelings

- Worry
- Tense
- Tired
- Frightened
- Depressed
- Anxious
- Anger

This is not fun!

Happiness is not the absence of problems, but the ability to cope with them.
Stress and Negative Thinking

- People are disturbed not by things, but by the view which they take of them.
  —Epictetus

- There’s nothing either good or bad but thinking makes it so.
  —William Shakespeare

- A person’s attitudes toward life determines their emotional experiences. No experience itself causes positive or negative feelings.
  —Albert Ellis, PhD

How We See Our Illness Determines How We Feel

<table>
<thead>
<tr>
<th>When a man is ill nothing is so important to him as his own illness.</th>
<th>Illness has always brought me nearer to a state of grace.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anthony Trollope</td>
<td>Abbe Pierre</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The secret of learning to be sick is this: Illness doesn’t make you less of what you were. You are still you.</th>
<th>My illness has taught me something about the nature of humanity, love, brotherhood and relationships that I never understood, and probably never would have. So, from that standpoint, there is some truth and good in everything.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tony Snow</td>
<td>Lee Atwater</td>
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</table>
Uncertainty and Stress

- It is the not knowing that is the worst
- Unsure how to react
- Unable to prepare
- Unable to reassure others

Patient Stress Factors
Patients’ View of How it All Starts

“After tonight, you are going to need a prescription”

Psychological Adjustment to Illness: Social Role Theory

- People act according to learned expectations and status
- People in sick role act according to new expectations:
  - Exempt from social responsibility
  - Can’t be expected to take care of self: are incapable, need to be cared for, incompetent
  - Should wish to get well because health is necessary for optimal performance of life tasks
  - Should seek medical advice and cooperate with medical experts

—Talcott Parsons (1958)
Major Adaptive Tasks of Illness

- Illness-Related Adaptive Tasks:
  - Dealing with pain, discomfort
  - Dealing with incapacitation – fatigue (MDS)
  - Learning terminology
  - Synthesizing information
  - Dealing with medical environment
  - Dealing with medical treatments – meds/transfusions
  - Finessing relationships with professionals

—Rudolph Moos & Vivien Tsu (1977)

And Dealing With Others’ Ideas

Your disease means you:
- Should take care of yourself in certain ways
- Should have had certain beliefs
- Are being punished
- Are lucky it’s not ______
- Should see Dr. ___ at Hospital ____
- Should have had an apple/day to keep the doctor away
Major Adaptive Tasks of Illness

General Adaptive Tasks:
- Preserving a reasonable emotional balance
- Preserving a satisfactory self-image
- Preserving relationships
  - Family
  - Friends
- Preparing for an uncertain future

—Rudolph Moos & Vivien Tsu (1977)
Being sick doesn’t make you immune to other types of problems!

Coping With Chronic Illness

Chronic illness is a stressor leading to changes in:

- Comfort
- Innocence- “Just World Belief”
- Physical activity/Energy
- Independence
- Relationships
- Work/Income
- Sense of being in control
- Sense of self/well-being
- Spontaneity

LOSS
Patient Fears of Being Sick

Uncertainty - The What Ifs?
- Course/Progress of disease
  - Protracted illness
  - Longevity
  - Pain
- Ability to manage/Tolerate treatment/Pain
- Impact on family
- Dysfunction/Disability
- Transplant
- Being Alone
- Death

You could scream…but

- People around you wouldn’t understand why because they think you look OK
- It wouldn’t change things…things are now different
Unwanted Effects of Cancer Therapy

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Long-term side effects</th>
<th>Late side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Start during therapy</td>
<td>Start (years) after therapy</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>Fatigue, Neuropathy, Chemobrain</td>
<td>Cataracts</td>
</tr>
<tr>
<td></td>
<td>Early menopause, Infertility, Heart failure,</td>
<td>Osteoporosis &amp; osteonecrosis, Second primary</td>
</tr>
<tr>
<td></td>
<td>Kidney failure, Liver problems</td>
<td>cancers</td>
</tr>
<tr>
<td>Radiation therapy</td>
<td>Fatigue, Skin sensitivity</td>
<td>Cataracts, Cavities and tooth decay, Heart</td>
</tr>
<tr>
<td></td>
<td></td>
<td>problems, Hypothyroidism, Infertility, Lung</td>
</tr>
<tr>
<td></td>
<td></td>
<td>disease, Intestinal problems, Memory problems,</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Second primary cancers</td>
</tr>
<tr>
<td>Surgery</td>
<td>Scars / Disfigurement, Chronic pain</td>
<td>Lymphedema</td>
</tr>
</tbody>
</table>

Finding a “New Normal”

- Different world post treatment
- Celebrating resiliency
  - Positive outcomes of experience
- Managing Challenges
  - Emotional
  - Social
  - Physical
- Recognize there can be different emotions at different life stages
Anxiety Symptoms

- Unrealistic and persistent fears, worry, obsessing, anticipation of doom, fear of symptoms, death
- *Shortness of breath, can’t catch breath*
- Insomnia
- Feeling tense, dizzy, jumpy, on edge, hypervigilance, muscle aches
- Shaking/tremors, pounding heart, sweating
- Numbness and tingling of extremities
- Dry mouth, lump in the throat, butterflies in stomach, GI distress, urge to go to bathroom
- Desire to flee

Continuum of Worry

- What, me worry?
- The sky is falling!
- Don’t worry, be happy!
Depression = Symptoms x 2 weeks

- Prolonged sadness, unexplained crying
- Diminished interest or pleasure in most activities
- Significant changes in appetite or weight
- Insomnia or hypersomnia
- Psychomotor agitation or retardation
- Fatigue or loss of energy
- Feelings of guilt or worthlessness
- Diminished concentration or indecisiveness
- Recurring thoughts of death or suicide, suicide plan or attempt

How Common is Depression?

- >15 million (5%) of Americans suffer some type of clinical depression at any given moment
- At risk groups: teens, elderly, chronic illness
- One person in six has a serious, or “major” depressive episode at some point in life
- Average age at diagnosis is slowly dropping
  - Common among elderly people
  - Increasing in young people

*The common cold of mental health problems*
Prevalence of Depression

- In general population, lifetime risk of depression is:
  - 10% to 25% for women
  - 5% to 12% for men

Depression in Chronic Illness

- Chronic disease and depression often go hand-in-hand
  - Depression is a common, and potentially dangerous, complication of chronic illness
- Estimates of comorbidity of depression and illnesses vary

**Chronic illnesses** can trigger depression

**Depression** may exacerbate some illnesses
The Depression - Illness Connection

- Depression can aggravate effects of illness
  - ↑ Pain
  - ↑ Fatigue
  - ↑ Disruption of social life
  - ↓ Self-care/compliance with treatment regimen

- Depression *may* intensify health risks
  - ↓ Immune function
  - ↑ Premature mortality

- Illness may affect dosing requirements and risk of adverse effects of antidepressants

Prevalence of Depression in Medical Illnesses

<table>
<thead>
<tr>
<th>Illness</th>
<th>Prevalence of depression (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>5–50 (most studies: 20–25)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>14–22</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td>20–71</td>
</tr>
<tr>
<td>Myocardial infarction</td>
<td>18–25 (40–65 sx)</td>
</tr>
<tr>
<td>Alzheimer’s dementia</td>
<td>15–57</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>25–75</td>
</tr>
<tr>
<td>Stroke</td>
<td>10–40</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>34–40</td>
</tr>
<tr>
<td>Parkinson’s Disease</td>
<td>40</td>
</tr>
</tbody>
</table>
Good News About Depression

- *Most medical patients have no diagnosable mood disorder*
- Living with chronic illness doesn’t mean having to be depressed
- As depression is treated, mood can brighten, making chronic illness easier to endure and manage

Living With Disease

“This secret of health for both mind and body is not to mourn for the past, not to worry about the future, but to live the present moment wisely and earnestly…”

—Buddha
Living With Chronic Disease

- People can lead rich, stimulating, meaningful lives
- People can be content, *even though* they are sick
- People can maintain high quality relationships with friends, families, co-workers, students
- People can be productive despite their limitations

Caregiver Issues
Caregiver Fears of Illness

- Progress of disease
- Helplessness/powerlessness
- More to do
- Loss
- Death
- Personal failure/incompetence
- Finances

Caregivers’ Dilemma

Caring too little  Caring too much
Relationships

- Maintaining strong relationships helps with adjustment and coping
- Treatment and survivorship impact relationships in a variety of ways
  - Increased closeness, depth in relationships
  - Feel different, grow apart

Relationships - Family

- Illness/Treatment affects all family members
- Different coping styles
- Parents and children
  - Independence vs. overprotection
  - Dependence
  - Long term hopes
- Siblings
Becoming and Staying Resilient

What is Resilience?

“Process of adapting well in face of adversity, trauma, tragedy, threats, or even significant sources of stress—such as family and relationship problems, serious health problems, or workplace and financial stressors.

… bouncing back from difficult experience.”

—American Psychological Association
Resilient ≠ Unaffected

- Emotional pain and sadness often go hand in hand with adversity
- Road to resilience is likely to involve emotional distress

No Matter How Resilient You Are

It Can Feel Like a Wild Ride
Resilient ≠ A Trait

- Resilience is dynamic with situations
- It involves thoughts, behaviors, and characteristics that can be learned and developed

Factor #1 in Resilience

- Caring and supporting relationships within and outside family
- Relationships that:
  - Create trust and love
  - Provide role models
  - Offer encouragement and reassurance
Other Factors in Resilience

- Capacity to make and follow realistic plans
- Positive self-view
  - Confidence in personal strengths and abilities
- Communication skills
- Problem-solving skills
- Ability to manage personal feelings

Strategies to Build Resilience

Get the information you need

- From your health providers
- The library
- The Internet, but be careful
- Know yourself and how much you need
- Pace yourself
- Avoid TMI
Strategies to Build Resilience

Ask Questions/Keep notes
- Bring questions to your appointments
- Keep health records
  - Diagnoses/tests
  - Medications/doses
  - Adverse effects
  - Surgeries
  - Procedures

Strategies to Build Resilience

Make Connections
- Accept help and support
  - Talk, money, chores, errands, affirmation
- Communicate your thoughts and feelings
- Affiliate (e.g., Aplastic Anemia & MDS International Foundation, American Cancer Society, church, civic groups)
- Help others
Strategies to Build Resilience

Don’t see crises as insurmountable

- “Stuff happens” – you can’t control
- You DO control how you interpret “stuff”
- Look beyond present to future and how you can make change to get there
- Notice changes as you start feeling better

Strategies to Build Resilience

Accept change

- Accept things you can’t change so you can focus on things that you can
- Develop realistic expectations for yourself, your patients, families
- Learn to cope with morbidity and mortality
Learn to “Let Go”

- Challenge yourself to *not* need to be in control
  - Take one day at a time
  - Focus on present

- Seek “*the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference*”

- If altering your lifestyle, find worthy substitutes

Change Your Focus

Avoid focusing on fears and worries

- Distract yourself
- Pay attention to things you enjoy
- Focus on what you can do each day
- Don’t focus on what you can’t change or just wish for things to go away
Strategies to Build Resilience

Move toward your goals

- Develop realistic plans
  - Short-term, intermediate, long-term
  - Strive to enjoy each day
- Work toward goals

Strategies to Build Resilience

Keep things in perspective

- Even in face of adversity, try to consider broader context and longer-term perspective
- Don’t blow things out of proportion
  - Take things one step at a time
  - Be patient with yourself and others
Strategies to Build Resilience

Take decisive actions

- Find meaning and purpose in things you do or your work
- Act on adverse situations as much as you can

Strategies to Build Resilience

Look for self-discovery

- Crises are opportunities for growth
- Learn about yourself while going through difficult situations
- “That which does not kill us makes us stronger”
Strategies to Build Resilience

Nurture a positive view of yourself

- Trust your gut
- Develop confidence in your problem-solving
- Focus on your strengths

Strategies to Build Resilience

Maintain a hopeful outlook

- Let yourself look forward to good things to come
- Focus on achieving what you can, rather than worrying about what you fear
Strategies to Build Resilience

Take care of your health
- Get enough sleep and rest
- Exercise
- Eat healthily
- Follow your medical regimen
- Develop good collaborations with your health providers
  - See them when you need to

Take care of yourself
- Attend to your needs and feelings
- Accept your feelings
- Be flexible
- Pace yourself
  - Simplify your routine/off-load stressors
- Relax/meditate/pray
- Keep a journal
Given the Connection Between the Mind and Body:

Consider consultation with mental health professionals:

- Health Psychology
- Social Work
- Consultation-Liaison Psychiatry

Remember—it Could be Worse

Phrases for Foreign Emergencies

- Is there a doctor in the building?
- Help, I’ve been seriously wounded
- May I use your belt as a tourniquet?
- Please take me to a clean hospital
- May I borrow a towel to wipe up the blood?
- Why is the water brown?
- Please don’t injure me
- Where is the nearest embassy?
- Do you know a place where I can hide?
- How far is it to the border?
- You will never make me talk
“Thank you.
Thank you very much.”