Decreasing the Risk of Suicide Among those with Chronic Invisible Illnesses

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Chronic Invisible Illnesses

- Chronic illnesses: Prolonged, don’t resolve spontaneously, and are rarely cured completely
  - Debilitating, but not fatal
- Invisible: Lack of diagnostic tests
  - Blood tests normal
  - Urine tests normal
  - MRI, CT, ultrasounds normal
- Found predominantly in women

https://upload.wikimedia.org/wikipedia/commons/e/ee/Vacutainer_blood_bottles.jpg

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Chronic, Invisible Illness:
Postural orthostatic tachycardia syndrome (POTS)

- 500,000 to 3 million cases in US
- 75% cases in women age 15-50
- ~1 million teens have POTS

Dysfunction of autonomic nervous system that affects
- Heart rate → tachycardia
- Blood vessel diameter → blood pooling, dizziness, headaches
- Pupil diameter → light sensitivity
- Food movement → gastroparesis
- Body temperature → hot flashes, chills

[Link to Standing Up To POTS website]
Chronic, Invisible Illness:
Myalgic encephalomyelitis and chronic fatigue syndrome

- 1 million cases in US
  - Most often in adult women

Symptoms
- Unrefreshing sleep → fatigue
- Headaches
- Loss of memory/concentration
- Enlarged lymph nodes
- Unexplained muscle/joint pain
- Extreme exhaustion more than 24 hours after physical or mental exercise

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http://bigeddyfilmfest.com/unrest/
Chronic, Invisible Illness: Ehlers-Danlos Syndrome

• Genetic condition - 13 types
  – 1 in 5,000 people have EDS
• Disrupts connective tissue
  – Loose joint articulation → subluxations, dislocations
  – Soft, velvety skin → stretchy, bruising, abnormal scarring
  – Tearing of blood vessels → internal bleeding, organ rupture (particularly vascular type)

[Image of a person doing a yoga pose]

http://nimbusmassage.com/2018/05/01/massage-ehlers-danlos-syndrome/
Chronic, Invisible Illness: Fibromyalgia

- ~4 million people in US
  - 75-90% are adult women

Symptoms
- Widespread pain > 3 months
  - Both sides of body
  - Above and below waist
- Fatigue
- Cognitive difficulties
  - Trouble concentrating

https://prsrehabservices.com/patcenter/articles/dry-needling-fibromyalgia/

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Chronic Invisible Illness: Lyme Disease

• ~ 300,000 diagnosed annually

• Symptoms of chronic Lyme
  – Severe headaches
  – Dizziness
  – Problems with short term memory
  – Neck stiffness
  – Facial palsy
  – Rashes
  – Arthritis
  – Intermittent pain in tendons, muscles, joints and bones

Information from https://www.cdc.gov/lyme/
Common Symptom of Chronic Illness: Chronic Pain

- Prevalent in
  - Ehlers-Danlos syndrome (EDS)
  - Fibromyalgia
  - Lyme disease
  - Myalgic encephalomyelitis, chronic fatigue syndrome (ME, CFS)
  - Postural orthostatic tachycardia syndrome (POTS)

- Chronic pain
  - Interferes with activities of daily living
  - Increases suicide ideation and attempts\textsuperscript{1,2}

Common Symptom of Chronic Illness: Chronic Pain

- Neuropathic pain
  - Shooting
  - Stabbing
  - Burning
  - Stinging
- Headaches
- Abdominal pain
- Chest pain
- Joint pain
- Pain is self-reported
  - No good diagnostic tool
  - Not objectively quantified
Common Symptom of Chronic Illness: Sleep Disturbance

- Decreased sleep efficiency
- Insomnia
- Nightmares

- Can be related to:
  - Pain
  - Sympathetic surges
  - Lack of exercise
  - Poor sleep hygiene
  - Increased risk of suicide

Common Symptom of Chronic Illness: Fatigue

- Unrelenting exhaustion not relieved by rest
  - Not the same as being tired
- Reduces
  - Energy
  - Motivation
  - Concentration
  - Emotional wellbeing
- Often the most debilitating symptom of chronic illness

http://standinguptopots.org/
Common Symptom of Chronic Illness: Depression

• Link between chronic medical illness and depression
  – Heart disease
  – Cancer
  – Other well understood illnesses
• 50% of people with chronic pain are depressed¹
• 35% of those with POTS reported severe to extreme depression²

Chronic Illness Significantly Impairs Quality of Life

• Problems with
  – General health
  – Sleep
  – Brain fog
  – Bodily pain
    • Neuropathic pain
    • Migraine headaches
    • Abdominal pain
    • Muscular and joint pain
  – Physical and social functions


Chronic Illness Significantly Impairs Quality of Life

• Significant minority (30% with POTS) require help with activities of daily living
  – Eating
  – Bathing
  – Brushing teeth/hair
  – Dressing
  – Moving around house


Challenges for the Chronically Ill

• Lack of quality medical care
  – Difficult to diagnose
  – Difficult to treat
  – Best case: manage symptoms well

• Physical barriers
  – Decreased mobility
  – Poor memory
  – Confusion
  – Poor quality of life

• Financial pressures from
  – Medical bills
  – Medication
  – Inability to work

http://standinguptopots.org/learning/pots-symptoms
Challenges for the Chronically Ill

• Stigma
  – Not really sick, “all in your head”
  – Symptoms from psychological rather than physical problems

• Grieving the loss of a healthy body
  • Feelings of isolation and loneliness
  • Struggling to find a new role in school, work, and relationships
  • Loss of hope

• Perceive themselves as a burden
  – Feel judged
  – Withdrawal of love and/or support

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Risk Factors for Suicide

- Major physical illness
- Sense of isolation
- Hopelessness
- Job or financial loss
- Loss of relationships
- Lack of good health care
- Stigma with asking for help
- Easy access to lethal means
- History of trauma or abuse
- Previous suicide attempt
- Family history of suicide or knowing others who died by suicide

https://www.thefyi.org/risk-factors-for-suicide-infographic/

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The Problem: Elevated Suicide Risk

• Increased risk of suicide documented for
  – Myalgic encephalomyelitis, chronic fatigue syndrome
    • Second leading cause of death\(^1\)
    • 20% of ME, CFS patients die by suicide\(^2\)
  – Postural orthostatic tachycardia syndrome
    • 48% with POTS were at high risk for suicide
    • 15% had attempted suicide\(^3\)
  – Fibromyalgia
    • 33% with fibromyalgia experience suicidal ideation\(^4\)
  – Hypermobile EDS
    • 4% had attempted suicide\(^5\)
  – Lyme disease
    • 1,200 deaths by suicide chronic Lyme\(^6\)

Why Increased Suicide Risk?

• Physical illness\(^1\) or multiple illnesses\(^2\)
• Chronic invisible illness\(^3\)
• Functional disability\(^4\)
  – Require help with activities of daily living, i.e. eating, bathing, moving around
• Chronic pain\(^5\)
  – Neuropathic pain
  – Migraine headaches or abdominal pain
• Sleep disturbance\(^6\)

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Is Suicide Linked with Depression in Chronic Illness?

• Many with chronic illness have no mental health diagnosis\(^1\)
• Suicidal ideation response to suffering
  • Mechanism to permanently relieve distress\(^2\)
  • Life weariness\(^3\)
  • Negative treatment by healthcare practitioners\(^4\)

Is Suicide Linked with Depression in Chronic Illness?

• Must be diagnosed carefully
  – Most depression screenings include questions about physical symptoms
    • Chronic illness symptoms artificially increase depression scores
  – Overlapping symptoms, including changes in
    • Appetite
    • Weight
    • Sleep
    • Fatigue
    • Ability to work
    • Worry about health
    • Interest in sex

Why Increased Suicide Risk?

• Interpersonal theory of suicide
  — Perceived burdensomeness
    • Feeling like a burden to family and friends
    • 97% of POTS patients limited by illness\(^1\)
      — 30% need help with basic personal care
      — 25% can’t work or attend school
    • Elevated in chronic pain patients\(^2\)

  — Low belongingness
    • Feeling that you don’t belong in a social group
    • 71% of POTS patients reported low belongingness\(^1\)
    • 76% reported high/very high levels of loneliness\(^1\)
      — Physical limitations
      — Different life experiences


https://miamioh.edu/cas/academics/departments/psychology/

Why Increased Suicide Risk?

• Perceived burdensomeness
  – May be more important suicide risk factor than
    • Low belongingness¹, ²
    • Loneliness¹, ³
    • Depression¹

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Honing your Skills in Small Groups

• Thinking about chronic illness
  – What questions would you ask to detect chronic illness?
    • What symptoms would you be most concerned about?
  – How would you refer them if you suspect a chronic illness?
    • What is an appropriate referral?
    • What barriers must be overcome?
Accessibility for the Chronically Ill

- Office
- Home based therapy
- Community Psychiatric Supportive Therapy
- Alternative
  -Teletherapy
  -Online therapy
  -Others?


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Decreasing the Risk of Suicide

- Of those who attempt suicide
  - 64% visited healthcare practitioner in previous month
  - 38% visited the previous week

- Actively screen chronically ill patients for suicidal thoughts
  - Online questionnaires
  - Ask during appointment

Decreasing the Risk of Suicide

• Practice compassionate care
  – BELIEVE patients when they talk about their illness

• Recent studies show physical anomalies for
  – Myalgic encephalomyelitis, CFS
  – Lyme disease
  – POTS

– LISTEN without judgment
– BE GENUINE in your concern
– INSTILL HOPE for the future
– EXPRESS CONFIDENCE in their ability to make good decisions


https://woundcareadvisor.com/compassionate-care-the-crucial-difference-for-ostomy-patients_vol2-no5/
Decreasing the Risk of Suicide

- Identify suicidal thinking in early stages to give time for
  - Medications and other treatment
  - Counseling
  - Improving relationship dynamics
    - Decreasing feelings of burdensomeness
    - Increasing socialization via text, phone, or home visits

Confronting Invisible Illness
Therapeutically

• Treat the psychological aspects of chronic pain
  – Person Centered Care
  – Strong Therapeutic Alliance
  – Openness to Learn about Illness
  – Accessible Care
  – Therapy Approaches
    • Mindfulness based stress reduction
    • Cognitive behavioral therapy
    • Acceptance and commitment therapy
    • Dialectical behavioral therapy

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Confronting Invisible Illness Therapeutically

- Decrease the Loneliness, Perceived Burdensomeness, and Hopelessness
  - Supportive Listening
  - Understanding Grief
  - Psycho-Educational
  - Support Groups
    - Online
    - Community
- Therapy
  - Group Therapy
  - Family Therapy

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http://www.firstchoiceforwomen.org/services/options-counseling/
Collaborative Assessment and Management of Suicidality (CAMS)

• Problem focused clinical intervention to target and treat suicidal “drivers”

• Enhance therapeutic alliance
  – Suicide-specific assessment
  – Suicide-specific treatment planning
  – Tracking of ongoing risk
  – Clinical outcomes and dispositions

• Uses Suicide Status Form

"Counselors and other clinicians have an obligation to familiarize themselves with how to best work with those who are suicidal in a way that is compassionate, responsive and effective."


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Collaborative Assessment and Management of Suicide (CAMS)

- Understand the function of suicidal thoughts
- Help determine ways to decrease suicidal thoughts
- Be clear that suicide prevention is the goal
- Review limitations of confidentiality and potential for hospital admission openly (Jobe, 2009)
Collaborative Assessment and Management of Suicide Approach

- Initial Assessment
- Ongoing Assessments
  - Suicidal Ideation
  - Suicide Plan
  - Suicide Intent
  - Suicide risk decreases when three sessions without Suicidal ideation, Plan, or Intent
- Final Assessment
Applying the CAMS Approach to People with Invisible Illnesses

• Does the individual feel that they have any control over their condition or treatment plan?
• How does the thought of suicide provide comfort?
• Does the individual feel that assessment and treatment planning occur in a collaborative and non-judgmental manner?

[Image]

[Link to CAMS]

https://www.conncoll.edu/media/header-images/student-experience/health-safety-and-counseling/counseling-header.jpg

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Limitations of CAMS for Chronic Illness Community

- Requires multiple sessions for administration
- Clinician must understand physical symptoms of chronic illness(es)
- Low belongingness among chronic illness community differs from traditional social isolation


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Rationale for the Suicide Screening Tool – Chronic Illness

• Elevated rate of suicide for those with chronic illness
• No measures exist to assess suicidal ideation in members of the chronic invisible illness communities
• Eliminate questions related to physical illness which would falsely elevate risk

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Rationale for the Suicide Screening Tool – Chronic Illness

• Address specific risk factors for this population
  – Perceived Burdensomeness
  – Loneliness
  – Hopelessness

• Administration that could be done in one visit across settings

Suicide Screening Tool – Chronic Illness

- Full survey is 14 questions
- Currently in press at Measurement and Evaluation in Counseling and Development

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<tr>
<th>Suicide Screening Tool – Chronic Illness</th>
<th>Strongly Disagree (1)</th>
<th>Disagree (2)</th>
<th>Neutral (3)</th>
<th>Agree (4)</th>
<th>Strongly Agree (5)</th>
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<tbody>
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<td>1. I often feel hopeless</td>
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<td>2. Sometimes I wish I were dead.</td>
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<td>3. I am frequently lonely.</td>
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<td>4. I am not looking forward to anything.</td>
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Chronic Invisible Illness Example

Unrest coverage of Jennifer Brea
Honing your Skills in Small Groups

• How would you broach suicide even if person not depressed?
• How would you assess risk factors linked to chronic illness?
  — Perceived burdensomeness?
  — Sleep disturbance?
  — Hopelessness?
  — Chronic pain?
  — Loneliness?
• When would you feel the need to refer to a higher level of care?
Decreasing the Risk of Suicide

• Support Caregivers of the Chronically Ill
  • Caregivers can develop
    – Compassion fatigue
    – Burnout
    – Isolation
  • Empower caregivers to
    – Guard their own health
    – Find a support group
    – Learn psycho-educational information about specific condition
Call to Action

• Consider the possibility of an invisible illness
• Assess suicidal ideation
• Educate the family/friends
• Empower caregivers
• Listen and try to understand
• Funding and coverage for comprehensive treatments
• Access to health insurance, Social Security, and Disability

http://medsin.org/public/images/diagram.png

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