TRAUMA & OTHER PSYCHOLOGICAL RESPONSES IN IV NUTRITION & TUBE FEEDING

The Oley Foundation 2021 – A Virtual Experience

Kathryn Tomasino, PhD
Clinical Psychologist
Assistant Professor of Medicine
Northwestern University Feinberg School of Medicine
Division of Gastroenterology & Hepatology
DISCLOSURES

- I have nothing to disclose.
OVERVIEW

Trauma & Post Traumatic Stress Disorder

Medical trauma

Post traumatic growth

Psychological response to medical illness + IV/tube feeds

Coping & Growth
WHO AM I?

- Clinical psychologist
- Work with adults
- Specialize in health psychology and subspecialize in psycho-gastroenterology
- Currently work at Northwestern Medicine in the Department of Gastroenterology
- Collaborate with Dr. Tiffany Taft on a variety of research projects, including a trial investigating post traumatic stress symptoms in people with IBD
WHAT IS TRAUMA?

According to the DSM-5, trauma is defined as exposure to actual or threatened death or serious injury...
RESPONSES FOLLOWING TRAUMA

May be delayed onset post traumatic stress symptoms without acute stress reaction

Trauma Event(s) -> Acute Stress

Diagnosed after 3 days of at least 9 symptoms in these 5 categories:
1. Recurring intrusive thoughts about the event
2. Avoidance
3. Low mood
4. Hyperarousal (fight or flight)
5. Feeling detached, “out of body”, like things aren’t real

Acute Stress -> Post traumatic stress

If they continue more than a month

Post traumatic stress -> No stress response

Possible Post Traumatic Growth

No stress response

May have no acute stress or post traumatic stress symptoms, may experience post traumatic growth
**Trauma**
- experienced, witnessed, loved one, or indirect exposure

**Reexperiencing the trauma**
- repeated memories of the event
- flashbacks and/or distressing dreams
- intense mental or physical distress in response to reminders of the event

**Avoiding reminders of the event**
- thoughts, memories, feelings, or talking about the traumatic event
- activities, objects, situations, people who trigger memories of it

**Negative changes in thoughts or mood**
- inability to remember an important aspect of the event
- excessively negative beliefs about oneself, others or the world from event
- beliefs that lead the individual to blame themselves/others for it (even when uncontrollable)
- negative emotional state
- decreased interest in or participation in significant activities
- feeling detached or estranged from others
- difficulty or inability to experience positive emotions (happiness, joy, contentment)

**Alterations in arousal or reactivity related to the event**
- irritability or angry outbursts, reckless or self-destructive behavior
- problems with concentration
- difficulties with sleep, relaxation
illness or injury may be sudden or life threatening (e.g., bowel perforation requiring emergency surgery; cancer diagnosis)

shock and loss associated with diagnosis and treatment requirements

treatment related to an illness or injury may be unexpected, distressing, with complications (e.g., intubation, emergency surgery, complications after bowel resection)

hospital environment is distressing (poor sleep, light, constant wake ups, noise, machines)

mistreatment by or poor communication from medical providers

confusion or hallucinations due to delirium
Medical trauma has been defined as a specific psychological response to medical experiences or events including:

- injury,
- serious illness,
- pain
- medical procedures, and
- frightening and distressing treatment experiences
WHAT DO TRAUMA SYMPTOMS IN RESPONSE TO MEDICAL EVENTS LOOK LIKE?

- **Reexperiencing** - recurring thoughts/memories about the traumatic medical event

- Significant **emotional distress** when faced with reminders of the trauma

- **Avoidance** of reminders of the event, which may lead to **difficulty following treatment instructions** and attending appointments

- **Negative emotions and thoughts** - about self, the world and others, + lack of positive emotion

- **Hypervigilance** – difficulty relaxing, excessive worry about health, and perhaps extra contact with the health care system

Kasak et al., 2006
Edmondson, D., 2014

From the International Society for Traumatic Stress Studies website
Some people experience a trauma response after these events and some people don’t.

Some people experience acute symptoms, but symptoms go away after a day or two.

Some people qualify for diagnosis of acute stress response, but then symptoms go away before the month is out.

Some people have post traumatic stress symptoms for more than a month.

Some people experience other psychological responses (grief, depression, anxiety, growth).
We don't have specific prevalence data for patients with supplemental nutrition, but we can draw from rates in...

<table>
<thead>
<tr>
<th>Condition</th>
<th>Rate</th>
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<tbody>
<tr>
<td>IBD</td>
<td>21-26%</td>
</tr>
<tr>
<td>ICU stay</td>
<td>22-24%</td>
</tr>
<tr>
<td>GI cancer</td>
<td>20%</td>
</tr>
<tr>
<td>Veterans</td>
<td>11-20%</td>
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<tr>
<td>vs general population</td>
<td>6-8%</td>
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EXPERIENCING TRAUMA DOES NOT MEAN YOU’LL DEVELOP POST TRAUMATIC STRESS
Most studies suggest that tube and IV feeding ultimately improve quality of life for those who are not otherwise able to meet nutritional requirements.

- 70% of HPN patients have “reasonably good” QOL

However,

- 10% to 80% have depression – from mild to severe
- 41% have frequent anxiety
- 35% to 43% report social impacts
- 27% to 60% report sexual concerns
- 32% to 53% report difficulty traveling
- 23% to 54% report fatigue
- 11% to 26% report decreased concentration

G. Huisman-de Waal et al., 2007
From Taft, 2019
How does nutrition support impact quality of life?

<table>
<thead>
<tr>
<th>Challenges to adjustment</th>
<th>• Improved nutritional status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of flexibility/spontaneity</td>
<td>Increased energy</td>
</tr>
<tr>
<td>Impact on sleep</td>
<td>Improved weight</td>
</tr>
<tr>
<td>Change in roles and self image</td>
<td>Better life expectancy</td>
</tr>
<tr>
<td>Changes in socialization</td>
<td>Improved mobility</td>
</tr>
<tr>
<td>Loss related to eating activities</td>
<td>Fewer medical interventions</td>
</tr>
<tr>
<td>Decreased autonomy</td>
<td>Increased autonomy</td>
</tr>
</tbody>
</table>

Wong et al., 2018
Heaney et al., 2018
How does nutrition support impact quality of life?

‘I’m on it twelve hours a day every other day, and I just could not go anywhere, completely anywhere’.

‘I have a nurse coming in five days a week. Just to connect me up and disconnect me [from the pump]’.

‘It’s quite a heavy bag … it’s really restricting, you can’t go out in the evening.’

‘It rules your life… It’s a case of you live or you die so everything revolves round it’.

‘At the end of the day you don’t want to die so you’ve got to have it’.

•‘I’m alive now and without it I wouldn’t be’.

‘[If] I keep on … I’m not going to die’.

‘I have more energy; it has completely stopped me needing blood transfusion’

‘I’m very grateful for it… You get used to it. At first you think ‘ooh golly this is going to be a pain’. But no, you don’t let it be a pain…it is keeping you well and well-nourished…’

‘It made me feel better, I wasn’t tired, I wasn’t lethargic, I wanted to go out … it’s the best thing for me being on it, it really is.’
What factors impact how people respond to medical events and need for nutrition support?

BIO-PSYCHO-SOCIAL = a lot to consider!
Biopsychosocial understanding of response to chronic illness / nutrition support

Biological factors + Event factors

- Disease state (physical symptoms, limitations)
- Exposure to and nature of traumatic medical event (how sudden, how severe, what treatments, length of stay)
- Nutrition deficiencies
- Medication effects
- Infection/wounds
- Pre-existing level of stress reactivity
- Use of benzodiazepines (Valium), alprazolam (Xanax), and clonazepam (Klonopin) can increase risk of PTS
Biopsychosocial understanding of response to chronic illness / nutrition support

- How much help is available (task support + emotional support)
- Cultural views
- Interactions with care team, availability of multidisciplinary support
- Connection to patient community/organizations
- Change in socialization around eating
- Participation in hobbies and activities
- Impact on relationships/intimacy
Biopsychosocial understanding of response to chronic illness / nutrition support

Psychological

- Trauma history
- Coping style/approach
- Changes in roles and autonomy (loss and gain)
- Emotional response to changes in eating, relationship with food, and socialization around food
- Neurological-cognitive impact (thinking, memory, language)
- Self esteem/confidence challenges
- Past or current of anxiety and depression
HOW TO COPE
When we are no longer able to change a situation, we are challenged to change ourselves.

Everything can be taken from a [hu]man but one thing: the last of human freedoms - to choose one's attitude in any given set of circumstances, to choose one's own way.

Viktor Frankl
Man's Search for Meaning
Term defined by **Tedeschi and Calhoun** in the mid 1990s to describe the growth and positive experiences they were seeing in people who had experienced significant trauma.

Develops **as a result of a struggle** after trauma, and **involves re-evaluation of how a person understands themselves, others, and the world**, as well as **making meaning** out of and processing the psychological and emotional impacts of the trauma.

**Distinct from resilience**, which is thought of as the ability to “bounce back” from a trauma or other stressful event.
30-70% of people who have experienced trauma will say they have experienced positive changes of one form or another
- Linley & Joseph, 2004
**WHAT TO DO AFTER STRESSFUL MEDICAL EXPERIENCES**

- **Give yourself time to adjust**
- **Get into a daily routine – your old one, or a new one**
- **Talk (or write about) about what happened**
- **Surround yourself with supportive people**
- **Attend a support group**
- **Learn how to calm down the stress response**
- **Use self-help tools**
- **Seek professional help**
Talk about it…
with a friend, partner, or supportive person you trust
with a fellow patient, a patient advocate
in a support group

Write about it…
in a journal
in a blog post
in an online support group
in a patient networking forum

PROCESS IT
It’s natural to want to avoid it,
but this increases the risk of post traumatic stress
CALM DOWN THE STRESS RESPONSE

Progressive muscle relaxation
Diaphragmatic breathing
Guided imagery
Physical activity
Mindfulness meditation
Biofeedback
SELF HELP RESOURCES

Insight Timer
Breathe2Relax
Headspace
Calm
YouTube
There are psychological treatments developed specifically to treat PTSD.

- These “trauma focused” treatments have been well researched
- Are considered the gold standard approach
- All involve direct discussion (or writing about) the traumatic event
- Include:
  - Cognitive Processing Therapy (CPT)
  - Prolonged Exposure Therapy (PET)
  - Trauma focused cognitive behavioral therapy (CBT)
  - Eye Movement Desensitization Reprocessing (EMDR)
Behavioral and mental health professionals can also help you to...

- learn new pain management strategies
- promote adjustment to new lifestyles or limitations
- reduce depression
- learn coping strategies
- improve communication with caregivers and medical providers
- increase positive emotions and well being
Trauma or general psychotherapy:

Psychologytoday.com therapist finder

Psychologist specializing in GI conditions

https://romegipsych.org/

HOW CAN I FIND A PROFESSIONAL?
Many people on EN and TPN experience multiple traumatic medical events which increases their risk of developing post traumatic stress.

Some people develop acute stress and post traumatic stress in response to medical trauma. Others do not.

Processing traumatic experience - by talking about it with supportive others or writing about it - can help prevent post traumatic stress.

A silver lining after trauma is the potential for post traumatic growth.
THANK YOU!

Email: kathryn.tomasino@northwestern.edu

@DrKateTomasino

Instagram katetomasinophd