Psychosocial Issues & Intestinal Failure

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Disclosures

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Mental Health is a BROAD Topic

- Anxiety
- Depression
- Quality of life
- Intimacy
- Stigma
- Insomnia & fatigue

- PTSD
- Body Image
- Sexuality
- Uncertainty
- Social life
- Relationships
So What Can We Cover Today?

• What Does the Research Say?
• What Are We Doing About It?
• What Can You (Patient) Do?
"If, in addition to being a life-sustaining procedure, TPN is to restore the psychological stability of patients, all team members must be aware of the psychosocial factors involved."
- Price & Levine, JPEN, 1979
What Does the Research Say?
How HPEN Impacts Mental Health

**Neuro-Cognitive Impacts**
- Attention
- “Executive” Function
- Memory
- Learning
- Language Skills
- Motor Skills

**HRQOL Impacts**
- Loss of autonomy
- Role limitations
- Self-Esteem
- Social challenges
- Increased sense of vulnerability

“The importance of food and feeding in reliance upon nutrition support incorporates more than the biological value of nutritive food.”

**Eating Impacts**
- Missing favorite foods
- Food takes on new meaning
- Preoccupation with cravings
- Embarrassment
- Not having options

Some Statistics

- 70% of HPN patients have “reasonably good” QOL
- 10% to 80% have depression – from mild to severe
- 41% have frequent anxiety
- 35% to 42% report social impacts
- 27% to 60% report sexual concerns
- 32% to 53% report difficulty traveling
- 23% to 54% report substantial fatigue
- 11% to 26% report concentration difficulties

Huisman-de Waal et al., 2007. The impact of home parenteral nutrition on daily life- A review. Clinical Nutrition
HRQOL

700 Patients from 14 countries

‘I'm alive now and I think without it I wouldn't be here ... definitely’

I have more energy, I wasn't as tired. It has completely stopped me needing blood transfusion as well’

‘I'm on [HPN] twelve hours a day every other day, and I just could not go anywhere, completely anywhere’

‘It rules your life. You've got to live around it. It's a case of you live or you die so everything revolved round it’

‘The feeling of not being altogether complete ... having to do this [HPN] every night and every morning ... just takes its toll’

Wong et al., 2018. Patient experiences with home parenteral nutrition: A grounded theory study.
Body Image

Body image is how you see yourself when you look in the mirror or when you picture yourself in your mind.

Body image is what you believe about your own appearance.

Body image is how you feel about your body including your height, shape, and weight.

Body image is how you sense and control your body as you move; how you physically experience or feel in your body.
How Might HPEN Impact Body Image?

‘For me, even to shower, you know, is a difficult thing because I have to make sure I don't get my line wet. So I can't just get into the shower and let the water run over me. I have to have a sponge bath or have the shower with the water on my back and then sponge my body.’

‘I feel everyone can see through my clothes and see what I see underneath. I am constantly covering myself with a cushion or handbag.’

‘I am much less confident about my appearance, hair, nails, and body. I look like an exhausted chipmunk and haven't been able to work, socialize, date or leave the house.’
What Are We Doing About It?
To be scientific, a model for medicine must include the psychosocial dimensions (personal, emotional, family, community) in addition to the biological aspects (diseases) of all patients.

By integrating these multiple, interacting components of the patient experience, medicine becomes more humanistic.
A Poll

Raise your hand if you have experienced a multidisciplinary approach to managing your HPEN.

This includes MDs, dietitians, specialty nurses, and mental health (social worker, psychologist).
A Poll

Raise your hand if you have experienced a multidisciplinary approach to managing your HPEN.

This includes MDs, dietitians, specialty nurses, but NOT mental health.
What About Guidelines?

• Guidelines for the Provision and Assessment of Nutrition Support Therapy in the Adult Critically Ill Patient (ASPEN)
  – “A committee of multidisciplinary experts in clinical nutrition composed of physicians, nurses, pharmacists, and dietitians…”

• Mental health and quality of life are not included
What About Guidelines?

• Guidelines for the Provision and Assessment of Nutrition Support Therapy in the Pediatric Critically Ill Patient: Society of Critical Care Medicine and American Society for Parenteral and Enteral Nutrition

• “A task force of multidisciplinary experts in clinical nutrition—representing physicians, nurses, pharmacists, dietitians, and statisticians”

• Mental health and quality of life are not included
What About Guidelines?

• ESPEN Guidelines on Parenteral Nutrition: Home Parenteral Nutrition (HPN) in adult patients

• Quality of life is included:
  – Patients should be affiliated to a specific specialist team, and if possible to a national supportive organization since studies show that the outcomes are then improved, in terms of fewer complications and better quality of life.
  – Specific guidelines to assess specific areas of QOL likely to be impacted
  – Brief mention of depression
Biomedical Model

BIOLOGY
What Can You (Patient) Do?
Self-Efficacy

• The level of confidence a person has in their ability to accomplish life’s tasks.

• When applied here, how confident a person is in managing life with HPEN.
A Poll:

Raise your hand if you feel confident in your own ability to manage life with HPEN.
What Helps?

• The passage of time
• Maintaining job, family, & financial stability
• Being younger at diagnosis/need for HPEN
• Send supplies ahead when traveling
• Positive social support
• Being connected to a patient organization
Social Support

• Have I told people I’m on HPEN?
  – Research shows that disclosing illness is the better, less stressful option*

• Who are the people in my network?
  – Who can I count on?
  – Who might not be the most helpful?

• What online resources do I use?
  – Are they helpful?
  – How do I feel after I use them?

• How is my relationship with my doctor?
<table>
<thead>
<tr>
<th>Chronic Illness Bingo</th>
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<tbody>
<tr>
<td>You need to get out more</td>
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<tr>
<td>Are you getting enough sleep?</td>
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<td>You sleep too much</td>
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<td>You don’t look sick</td>
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<td>Positive thinking</td>
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<td>My friend was cured by...</td>
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<td>Yesterday you ___ Why can’t you today?</td>
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<td>Have you tried ___?</td>
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<td>You need to exercise</td>
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<td>I wish I had time to nap</td>
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<td>You should try this diet</td>
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<tr>
<td>Oh, I get that too</td>
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<td>Dr. Oz says...</td>
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<tr>
<td>I wish I didn’t have to work</td>
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<td>It could be worse</td>
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<tr>
<td>It’s made up by big pharma</td>
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<td>You should stop ___</td>
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<tr>
<td>Are you better yet?</td>
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<tr>
<td>You’re just stressed</td>
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<tr>
<td>You have that because ___</td>
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<tr>
<td>You take too many medications</td>
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Acceptance

"Acceptance doesn't mean resignation. It means understanding that something is what it is and there's got to be a way through it"

- Michael J. Fox
Acceptance Strategies

- **Being Present**: Focus on the here and now
- **Acceptance**: Be willing to experience difficult thoughts
- **Defusion**: Observe your thoughts without being ruled by them
- **Values**: Discover what is truly important to you
- **Commitment**: Take action to pursue the important things in your life
- **Self as Context**: See yourself as unchanged by time and experience
Acceptance Resources

The Bus Technique:  https://www.theemotionmachine.com/the-mindbus-technique/


The Struggle Switch: https://www.youtube.com/watch?v=rCp1l16GCXI

The Sushi Tray: https://youtu.be/tzUoXJVI0wo

Many other short exercises to try: http://eightfoldcounseling.com/act-metaphors/
Resilience is very different than being numb. Resilience means you experience, you feel, you fail, you hurt. You fall. But, you keep going.

Yasmin Mogahed
What the Heck Is Resilience?

• **Natural resilience**: What you’re born with, your human nature and drive to survive

• **Adaptive resilience**: ”Trial by Fire” or how we learn to change and adapt after challenges.

• **Restored resilience**: Aka ”learned”. Strategies to help tap into your natural resilience.
# Strategies

**The 4-factor Approach**
1. Stating the facts.
2. Placing blame where it belongs.
3. Reframing.
4. Giving yourself time.

**Scenario:** Need to have my catheter replaced again.

<table>
<thead>
<tr>
<th>Step</th>
<th>Example Things to Say or Do</th>
</tr>
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<tbody>
<tr>
<td>Talk about problem without magnifying it</td>
<td>“My catheter needs to be replaced and that’s annoying, but I caught it before I got an infection.”</td>
</tr>
<tr>
<td>Take ownership but don’t beat yourself up</td>
<td>“Ok, my catheter is bad. It happens. I took really good care of it and did my best. I’m OK.”</td>
</tr>
<tr>
<td>Re-frame and Re-evaluate</td>
<td>“Things could have been worse. I could have gotten an infection. I’ve only had to have my catheter replaced one other time many years ago.”</td>
</tr>
<tr>
<td>Take time to heal and adjust</td>
<td>Make time for solitude. Cultivate humor. Do a relaxation exercise.</td>
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Resilience Resources

• https://www.apa.org/helpcenter/road-resilience
• https://positivepsychologyprogram.com/resilience-activities-worksheets/
• https://www.mindful.org/how-to-cultivate-the-resources-for-resilience/
Other Strategies

Wong et al., 2018. Patient experiences with home parenteral nutrition: A grounded theory study.

‘They let you decide how long you want to have it [the feed infusion] ...I like it over twelve [hours] because I’m free the rest of the day’ #8

I had to change one night because I needed to be up early so I thought I’ll give myself a night off [from HPN]. And then I went back to the normal pattern the following week’ #11

‘We’re married and my wife asked to be trained to set up the HPN feed infusion ...she won’t take no for an answer so I just let her do it’ #12

Action strategies for maintaining HPN as well as daily activities and social interactions

‘I’m diabetic with retinopathy & neuropathy in my feet. I asked her [clinical nurse specialist for HPN] to train my daughters-in-law because they will help me’ #4

‘The pump is fantastic. It’s not obtrusive, it’s small and when you got it on in the bag [rucksack], nobody knows that there is a pump in there’ #9

‘I can’t see with my right eye so my husband puts me on it [HPN] at twelve o’clock’ #1
Funny Thing About Statistics

- 30% of HPN patients have “reasonably bad” QOL
- 90% to 20% don’t have depression
- 59% don’t have frequent anxiety
- 65% to 58% don’t report social impacts
- 73% to 40% don’t report sexual concerns
- 68% to 47% don’t report difficulty traveling
- 77% to 46% don’t report substantial fatigue
- 89% to 74% don’t report concentration difficulties
When To Seek Help

• You’re not able to do things you’d like to do
• You’ve tried many things on your own but they’re just not working
• You’re withdrawing from your social relationships
• You don’t enjoy things you once enjoyed
• You’re using drugs or alcohol to self-medicate
Who To See?

• Clinical Psychologist (PhD or PsyD)
  – Specialization in “Health Psychology” or “Behavioral Medicine”

• Licensed Clinical Social Worker (LCSW)

• Psychiatrist (MD)

• Licensed Clinical Professional Counselor (LCPC)
Questions to Ask

✓ How many clients have you seen on HPEN?
✓ How many clients have you seen with a chronic illness?
✓ Do you have any specialty training in working with people with a chronic illness?
✓ What’s your approach to treatment?
✓ How will you work with my physician?
✓ What are your fees?
✓ Do you accept insurance?
✓ Do you have any references?
Wrapping Up

• HPEN impacts mental health across a vast spectrum of areas
• Guidelines related to HPEN mental health are lacking in the US and limited in the EU
• There are many things patients can do to improve their mental well being
• Many patients do not have major mental health impacts
• Mental health professionals can help if you’re struggling
How to Find Me

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