Improving Life on Nutritional Support

Mental Health Support of Consumers and Caregivers on Home Parenteral and Enteral (HPEN) Therapy

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Consumers and caregivers of those on HPEN frequently experience an emotional toll from both their diagnosis as well as medical therapy.

- Depression
- Anxiety
- Post-traumatic stress
- Other symptoms
To better understand the emotional and mental health challenges HPEN consumers and caregivers experience and the support they receive.
Is there a need for a mental health professional to be part of an intestinal rehabilitation team?
Methods

**Online Anonymous Survey**: distributed via social media.

- Age
- Consumer or caregiver
- Single practitioner or team of multiple professionals
- Diagnosis
- Therapy
- Experience with mental health challenges
Results
### Results

<table>
<thead>
<tr>
<th>Count</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>161</td>
<td>team of professionals</td>
</tr>
<tr>
<td>23</td>
<td>single practitioner</td>
</tr>
<tr>
<td>45</td>
<td>TPN</td>
</tr>
<tr>
<td>141</td>
<td>TPN + Enteral</td>
</tr>
<tr>
<td>25</td>
<td>Enteral</td>
</tr>
<tr>
<td>64</td>
<td>consumers</td>
</tr>
<tr>
<td>120</td>
<td>caregivers</td>
</tr>
<tr>
<td>41</td>
<td>18-29 years</td>
</tr>
<tr>
<td>78</td>
<td>30-40 years</td>
</tr>
<tr>
<td>34</td>
<td>40-50 years</td>
</tr>
<tr>
<td>31</td>
<td>Over 50 years</td>
</tr>
</tbody>
</table>

ThriveRx Online Survey, 2014.
Should mental/emotional support be provided as part of comprehensive care?

- Yes: 95%
- No: 5%

ThriveRx Online Survey, 2014.
Results

- Fatigue
- Fear/anxiety
- Overwhelmed
- Isolation/loneliness
- Lack of energy
- Grief/depression
- Loss of appetite/overeating
- Guilt
- Moodiness/irritability
- Shame
- Substance abuse
- Anger

Symptoms

- 5 or less: 29%
- 6 or more: 71%

ThriveRx Online Survey, 2014.
Results

At what point did your symptoms begin?

- 29% at diagnosis
- 6% 3-6 months after diagnosis
- 7% 6-12 months after diagnosis
- 5% 1 year or later after diagnosis
- 50% throughout and ongoing

ThriveRx Online Survey, 2014.
Results

Did you seek professional help for these symptoms?

- Yes: 57%
- No: 43%

ThriveRx Online Survey, 2014.
Sought mental health support: type of referral

- Self-referral: 59%
- Clinician Referral: 41%

ThriveRx Online Survey, 2014.
Did not seek professional help: How did you cope?

- **Peer to peer support**: 73
- **Support Group**: 58
- **Family**: 103
- **Social media**: 94
- **Other**: 53

ThriveRx Online Survey, 2014.
Did your practitioner or clinical team provide any type of mental/emotional support?

Caregiver

Consumer

No
Yes

ThriveRx Online Survey, 2014.
Did you have a consumer advocate?

- No advocate: 67%
- Advocate: 33%

- No help: 45%
- Help: 55%

ThriveRx Online Survey, 2014.
Summary
Diagnosis of a chronic disease and associated therapies can create a great emotional and mental burden on individuals and families.

Patients and families expect and need their clinical teams to integrate mental health support into comprehensive IR care.

Clinical care does not always take into account the emotional impact of nutrition support, based on the 41% mental health referral rate.

ThriveRx Online Survey, 2014.
Clinical teams can play an important role in providing:

- Resources to help consumers and caregivers identify signs of mental/emotional stress.
- Referrals to mental health professionals.
- Guidance on coping mechanisms.