

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?

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



161 team of professionals

23 single practitioner

64 consumers

120 caregivers

45 TPN

141 TPN + Enteral

25 Enteral

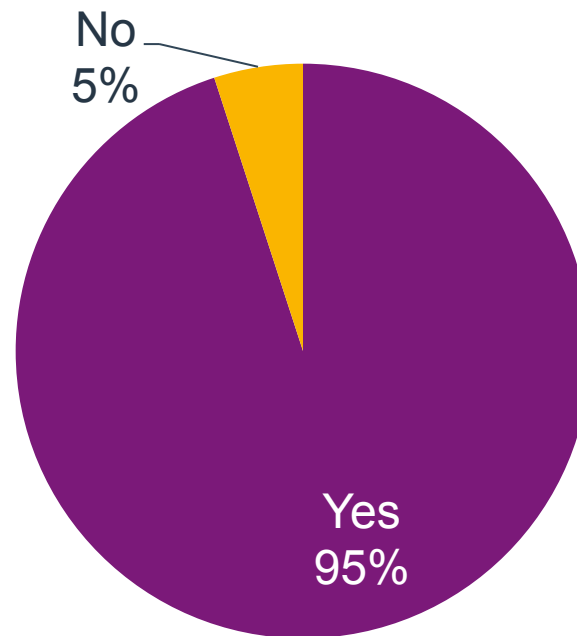
41 18-29 years

78 30-40 years

34 40-50 years

31 Over 50 years

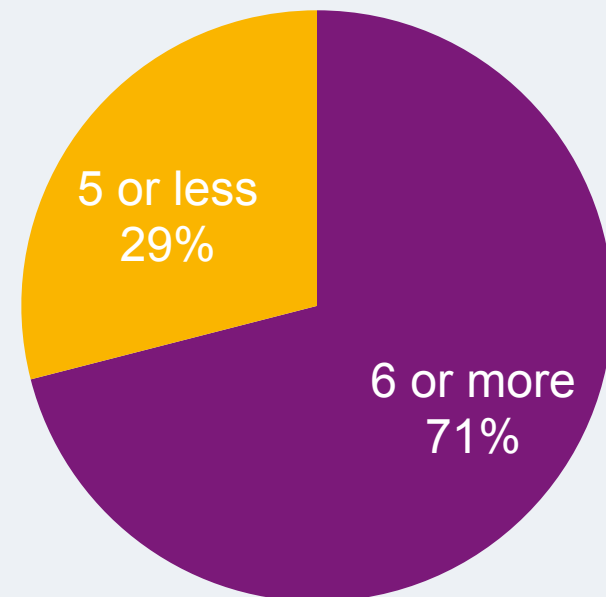
Should mental/emotional support be provided as part of comprehensive care?



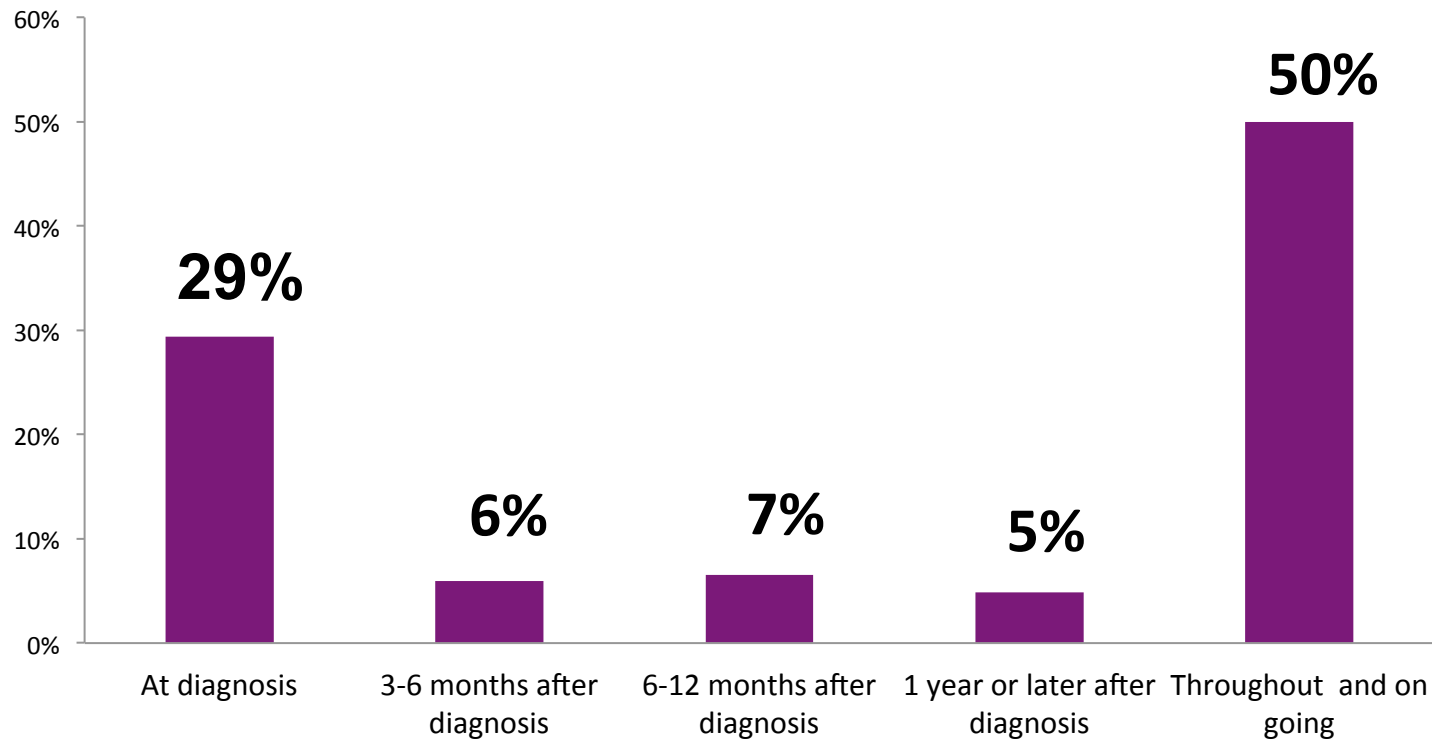
ThriveRx Online Survey, 2014.

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

Symptoms

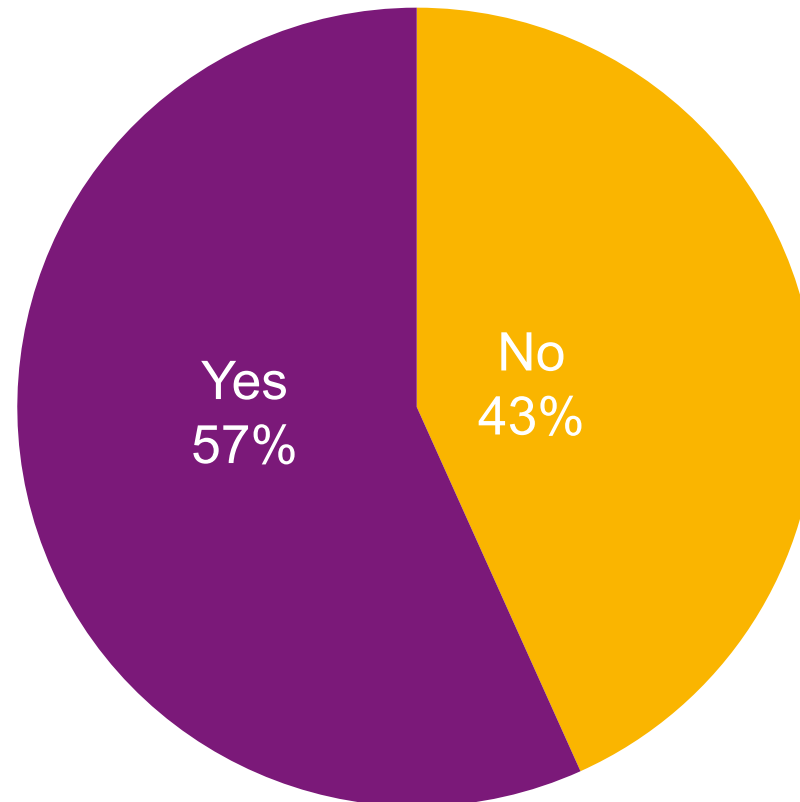


At what point did your symptoms begin?



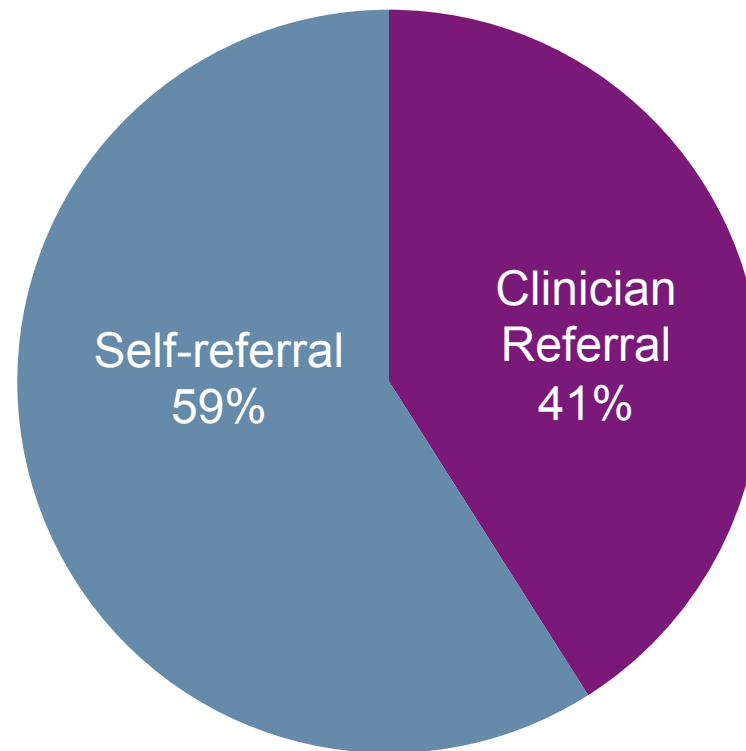
ThriveRx Online Survey, 2014.

Did you seek professional help for these symptoms?



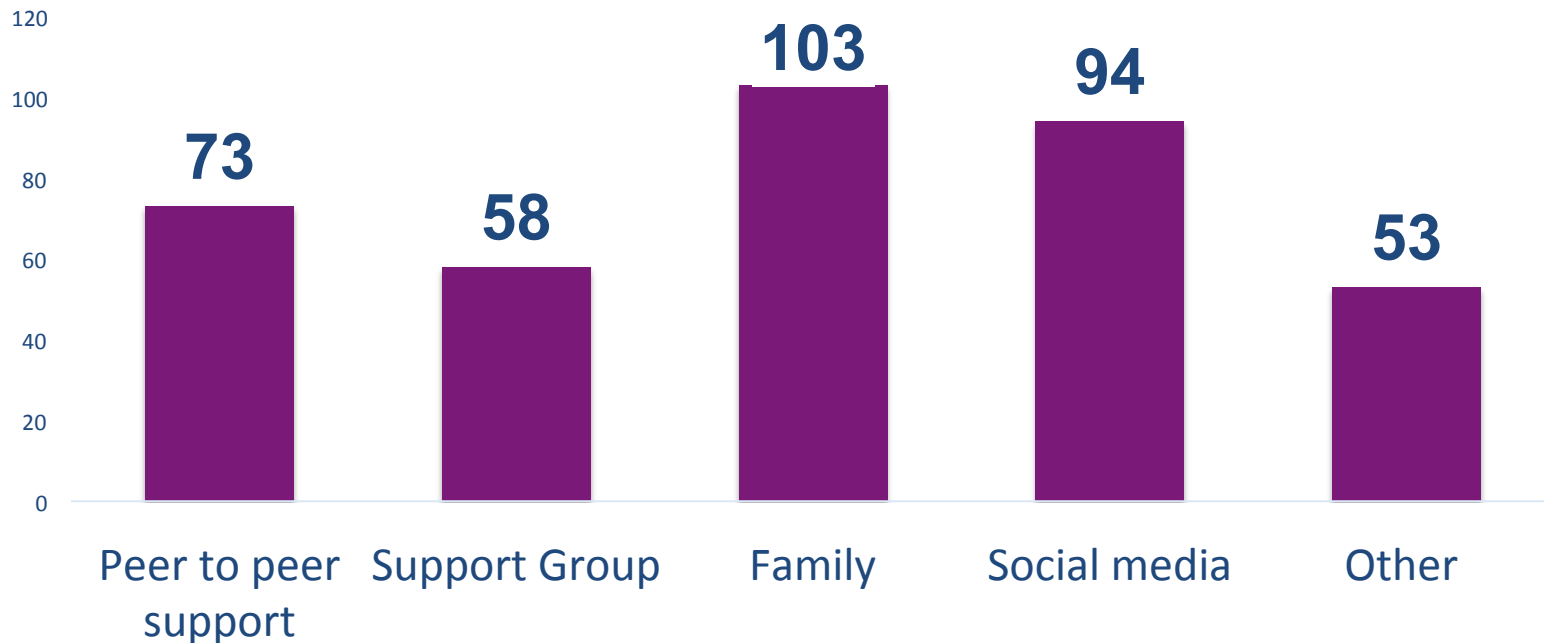
ThriveRx Online Survey, 2014.

Sought mental health support: type of referral



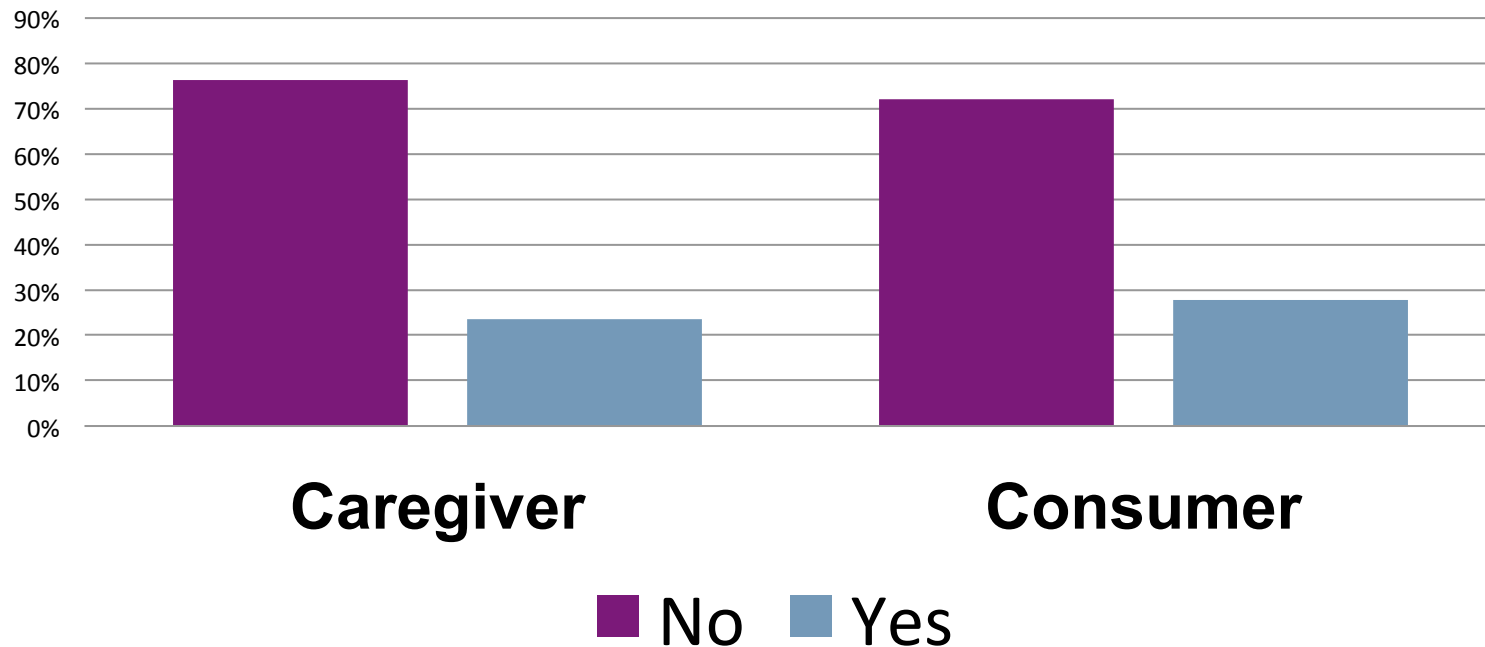
ThriveRx Online Survey, 2014.

Did not seek professional help: How did you cope?



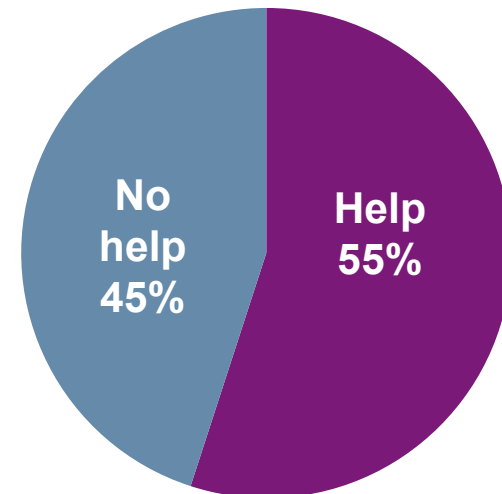
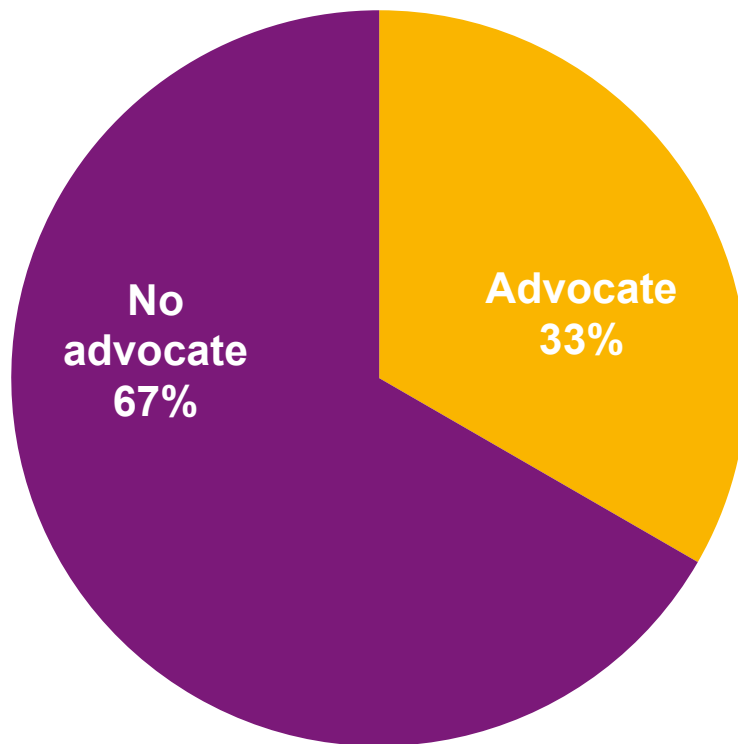
ThriveRx Online Survey, 2014.

Did your practitioner or clinical team provide any type of mental/emotional support?



ThriveRx Online Survey, 2014.

Did you have a consumer advocate?



ThriveRx Online Survey, 2014.

A man with a beard and short hair, wearing a light blue button-down shirt over a white t-shirt, is sitting in a workshop. He is holding a large black tire in front of him. The workshop background is filled with shelves of tools, a pegboard with various tools, and a workbench. The lighting is warm and slightly dim.

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.

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.

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