Enhancing Quality of Life in the Intestinal Failure Patient

Marion Winkler, PhD, RD, LDN, CNSC
Professor of Surgery, Alpert Medical School of Brown University
Surgical Nutrition Specialist, Department of Surgery and Nutritional Support Service at Rhode Island Hospital

Maria Karimbakas, RD, CNSC
Optum Intestinal Rehab Program Manager
Financial Disclosures

Marion Winkler
• Takeda Pharmaceuticals, Nutrition Consultant
• VectivBio, Nutrition Consultant

Maria Karimbakas
• Optum Infusion Pharmacy, Employee
• VectivBio, Patient Leadership Council
Learning Objectives

1st Learning Objective: To understand the factors that impact the IF consumer’s quality of life

2nd Learning Objective: To discuss modifications in parenteral support to enhance quality of life

3rd Learning Objective: To review consumer-based actions to improve quality of life
QoL Practical Applications
Infusions and QoL

- Infusion Hook-up Time - did you choose it?
- Time of Day of infusion - daytime vs. overnight?
- Infusion Hours - can it be any shorter?
- Number of days - has any weaning been discussed?
- Independence - ability to connect/disconnect infusions on your own?
- Mobility - are you using a pump and backpack with your infusions?
- Hydration - compounded vs. shelf-stable?
- Lab frequency - parameters for reducing?
Medications and QoL

- Do you know the condition/symptom that each oral and IV medication has been prescribed for?
- Has the maximal dose been prescribed (i.e. anti-diarrheals)?
- Are there medications you are struggling to take (i.e. due to pill size, taste, side effect, cost)?
- Have you been instructed on the most ideal time to take medication/supplements and those that need to be separated to avoid interactions?
- IV Medications - are pre-filled syringes an option and can any be added by pharmacy?
Diet and QoL

• Have you been instructed on the most appropriate food and beverages for your underlying condition?

• Could making diet changes positively impact your GI output, volume and frequency?

• Are you being overly restrictive with your diet which might be negatively impacting your QoL?

• Have you considered keeping intake and output records?
Did You Know?

• Using an insulated cup can help you stay hydrated
• Oral nutrition supplements are not required
• Certain fast foods can be eaten “on the go”
• Learning how to read food labels can be very helpful
• Always having non-perishable snacks helps you to more easily meet your calorie needs
Are you prepared?

✓ Snacks & ORS stick packs
✓ Anti-diarrheals—bring them!
✓ Store extra clothes and supplies in car
✓ Keep toilet paper, plastic bags, containers in car
✓ Do you know how to travel with your supplies?
Helpful Resources

• HPN-PRO-Q
• Oley bathroom card
• Oley restaurant card
• Save My Line poster
• SBS support groups
• Connect with an Oley Ambassador
Next Steps

For the Consumer

• Take the HPN Pro-Q
• Make a list of topics to discuss with your team and rank them
• Begin addressing 1 topic at a time

For the Clinician

• Ask your patient about their QoL and what changes would be most impactful
• Spend time understanding the “why” behind the decisions they make
Thank you to VectivBio for sponsoring Oley for this session.