

A comprehensive evaluation on quality of life for persons living on enteral nutrition
and/or parenteral nutrition

By

Juliana Tamayo

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Approved By:

Major Professor

Dr. Linda Yarrow

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Abstract

Enteral and parenteral nutrition remain the two nutrition support therapies for those individuals that are unable to meet the nutritional needs orally. Enteral nutrition utilizes a feeding tube to deliver nutrition to the stomach or small intestine. Parenteral nutrition bypasses the gastrointestinal tract and uses the central vein to deliver a specialized formula for nutrition.

Because of the invasive nature of feeding tubes, central catheters, and peripherally inserted central catheter (PICC) lines, enteral nutrition (EN) and parenteral nutrition (PN) often result in physical and emotional problems for the individual. While there is evidence to suggest that both EN and PN are helpful in reducing malnutrition, there is limited data on the quality of life of persons undergoing EN and/or PN. This report explored the main themes that affect the quality of life of these individuals.

Study results show that persons undergoing EN and/or PN have mixed emotions regarding their feeding tubes, central catheters, or PICC lines, and what the nutrition support therapy may bring to their lives. While participants admitted to having regained some quality of life thanks to increased nutrition, there was a clear decrease to quality of life due to emotional, physical, and/or economic factors. The findings suggest that the emotional burden, physical discomfort, isolation, and economic costs of EN and/or PN are likely to impact the quality of life of the individual undergoing these nutritional support therapies.

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This report is dear to my heart because I am a person living on enteral nutrition and parenteral nutrition. I owe my life to nutrition support therapies, and I understand firsthand how difficult it can all be. This project is only the beginning of what I hope is a lifelong journey into helping persons, who like me, were once alone and scared.

Introduction

The purpose of this pilot study is to explore the emotional, physical, and economic impact that having a feeding tube, central line, or peripherally inserted central catheter (PICC) line has on patients and caregivers. To ascertain this, a general questionnaire was made available to nutrition support therapy patients and to health care providers. This report will address questionnaire findings and explore the general perceptions of enteral nutrition (EN) and parenteral nutrition (PN), current advances in EN and PN, side effects of EN and PN, and common misconceptions of both nutrition support therapies.

What is Enteral Nutrition?

EN is a type of nutrition support that feeds a person through the use of a tube; therefore, it is often referred to as “tube feeding.” EN is for individuals with a functioning gastrointestinal tract who are unable to meet their nutritional needs orally. A feeding tube may feed directly into the stomach or the small intestine, usually the jejunum (Wireko & Bowling, 2010).

Conditions that often result in the need for nutrition support therapy in the form of EN include impaired swallowing (dysphagia), severe pancreatitis, cystic fibrosis, burns, facial injury, HIV, inflammatory bowel disease, and gastroparesis.

Possible routes for an enteral feeding tube are nasogastric, nasojejunal, percutaneous endoscopic gastrostomy, or radiological/surgically inserted gastrostomy; and percutaneous endoscopic jejunostomy or radiological/surgically-inserted jejunostomy (Wireko & Bowling, 2010).

Enteral nutrition can be administered in different ways, either as a bolus feed with a syringe, gravity for intermittent feeds, or continuous feeds.

Common Problems of Enteral Nutrition

EN has been proven to be a safe and effective way to maintain nutrition levels in patients who are unable to orally ingest food. EN is a safe procedure with very few complications, which can often be avoided and managed. Some of the complications of EN arise from inadequate formula, delivery site issues, rate of feeding, and underlying disease.

Complications of EN can be classified as gastrointestinal, mechanical, metabolic, or a combination of factors. In some cases, these complications can be intertwined and result in economic and emotional stress for patients and caregivers.

Gastrointestinal Complications

Gastrointestinal complications as a result of EN include diarrhea, nausea and vomiting, and constipation (Bodoky & Kent-Smith, 2009).

Diarrhea

Diarrhea tends to be the most common complication in EN, occurring in up to 63% of individuals. Diarrhea is not necessarily a result of enteral nutrition, but may be a result of inadequate formula, rate of infusion, or repeated use of antibiotics (Bodoky & Kent-Smith, 2009).

Nausea and vomiting

Around 20% of patients on EN will experience nausea and vomiting, which increases the risk for aspiration. The most common cause of nausea and vomiting tends to be gastroparesis, which is delayed gastric emptying that can lead to early satiety, abdominal distention, and bloating (Bodoky & Kent-Smith, 2009).

Constipation

For patients undergoing EN, constipation may be a result of inactivity, decreased bowel movement, decreased fluid intake, a lack of dietary fiber, and impaction (Bodoky & Kent-Smith, 2009).

Mechanical Complications

Mechanical complications from EN include aspiration and feeding tube complications (Bodoky & Kent-Smith, 2009).

Aspiration

Pulmonary aspiration can be a dangerous complication of EN, with symptoms including dyspnea, wheezing, tachycardia, agitation, and cyanosis. Some patients who experience aspiration also may be febrile (Bodoky & Kent-Smith, 2009).

Feeding Tube Complications

Complications with feeding tube positioning include GI perforation, rotation, and ulceration. The insertion of a feeding tube may cause problems like airway complications, esophageal varices, necrotizing fasciitis, fistulas, and wound infections (Bodoky & Kent-Smith, 2009).

Other common problems include stoma site complications, such as leakage, infection, and incorrect size. Tube dysfunction can usually be resolved with tube replacement, but infection requires medication and tube removal (Bodoky & Kent-Smith, 2009).

Tube clogging is another common complication of EN. Most clogging is due to inadequate flushing of the tube after feeding or after medication administration. Clogging can occur more frequently with thick formulas and homemade blended products (Bodoky & Kent-Smith, 2009).

Metabolic Complications

Metabolic complications of EN are very similar to those for patients undergoing parenteral nutrition. Common metabolic complications include hyponatremia, hypernatremia, dehydration, hyperglycemia, hypokalemia, hyperkalemia, hypophosphataemia, and hyperphosphataemia (Bodoky & Kent-Smith, 2009).

What is Parenteral Nutrition?

PN is the intravenous administration of nutrition, which usually includes a formula containing protein, carbohydrates, fat, minerals, vitamins, and electrolytes. This type of feeding fully bypasses the gastrointestinal tract in cases where the person is unable to eat by mouth or receive nutrition through a feeding tube.

People of all ages—infants, children and adults—can receive PN. This type of nutrition can be used for as long as necessary, but it may often be a short-term solution to certain problems. To adequately receive PN, a chemical formula is administered in the bloodstream via catheter.

PN preparation and infusion require sterile techniques and may be prepared in standard formula or individualized formulas. Normally, a 2L/day of standard solution is needed, but the formula solutions can be modified to replenish specific nutrients and manage underlying disorders. Most calories in PN formulas come

from carbohydrates in the form of dextrose, but the amount and concentration may vary depending on caloric needs and metabolic factors (Thomas, 2020).

Central venous catheters must stay in place for a long time; therefore, strict protocols and sterile techniques are used during the time of placement and maintenance. External tubing must be changed every 24 hours and the dressing should be kept sterile. For persons receiving home PN, education on cleanliness and signs of infection is essential (Thomas, 2020).

A multidisciplinary team should follow patients undergoing PN. The patients require at least weekly monitoring of weight; blood count; electrolytes; and other lab values, such as blood urea nitrogen (Thomas, 2020).

Common Problems of Parenteral Nutrition

While efficient in nourishing certain individuals, PN is considered a high-risk therapy given the location of the central venous access. About 5% to 10% of PN patients experience complications related to the central venous access. Sepsis is a common complication; however, new sterilization techniques for catheter insertion and skin care have driven infection rates down (Maudar, 1995).

Catheter-Related Complications

Complications related to catheters for PN patients include catheter occlusion and glucose abnormalities.

Catheter Occlusion

Occlusion can take the form of a thrombotic or a nonthrombotic disorder. In these cases, the catheter may have a blood clot, which can often be resolved with a tissue plasminogen activator or a contrast study by an interventional radiologist (Buchman, 2007).

While thrombosis is rare, if it does occur, the patient should be fully anticoagulated. In some cases, including vitamin K in the PN formula may counteract the effects of warfarin or other anticoagulant drugs (Buchman, 2007).

Arterial embolism occurs in patients who have atrial fibrillation and necessitates anticoagulation. Around 11% of patients who develop thrombosis will also have catheter sepsis. Physicians should be aware of evaluating the absence of catheter tip malposition (Buchman, 2007).

In the instance of nonthrombotic catheter occlusion, many catheter occlusions are related to mechanical problems. In these cases, the physician should check the catheter position to make sure the tip is in the superior vena cava or the inferior vena cava. To properly avoid occlusions, medications must be compatible with a PN line (Buchman, 2007).

Glucose Abnormalities

Both hyperglycemia and hypoglycemia are common and can occur in more than 90% of patients on PN (Thomas, 2020). Monitoring plasma glucose, adjusting insulin dose, and giving subcutaneous insulin can help manage hyperglycemia.

Hypoglycemia can often occur because of a sudden stop in concentrated dextrose infusions (Thomas, 2020).

Capillary blood glucose monitoring remains the main tool in managing glucose abnormalities. However, it is difficult to assess the correct protocols and there is no real timeline on when to begin monitoring, implementing insulin infusion schedules, and stopping dextrose or insulin infusions. Hospitals and home PN centers tend to implement individualized plans depending on resources, patient comorbidities, and budgetary constrictions (Ratliff et al., 2018).

Hepatic Complications

Liver complications include liver dysfunction, painful hepatomegaly, and hyperammonemia.

Abnormalities in serum electrolytes and minerals

Vitamin and mineral deficiencies are rare when the PN solution is correct. However, if they do occur, these types of abnormalities can be corrected by modifying the infusion schedule or concentration. Elevated blood urea nitrogen can reflect dehydration and can be corrected with free water and 5% dextrose via peripheral vein (Thomas, 2020).

Metabolic Bone Disease

Also known as bone demineralization, either osteoporosis or osteomalacia can develop in some persons that are on parenteral nutrition for over 3 months (Thomas, 2020).

Allergic/ Adverse Reactions

Most allergic or adverse reactions occur as a result of lipid emulsion infusions, particularly if the infusions are given at a rate higher than $1.0\text{kcal} \cdot \text{kg} \cdot \text{hr}$. Most signs of allergic and adverse reactions include dyspnea, skin lesions, nausea, headache, back pain, sweating, and dizziness (Thomas, 2020).

Gallbladder Complications

Gallbladder complications include cholelithiasis, gallbladder sludge, and cholecystitis (Thomas, 2020).

The Eating-Mood Connection

Eating is an everyday activity for most people, but it can also be a tool for socializing, networking, establishing relationships, discovering new interests, and more. For those who rely on nutrition support therapy, eating may not be a possibility; and if it is, it may cause discomfort and pain.

A person's identity and self-worth tend to be centered on both internal and external factors. One of these external factors—food—can impact identity and

mood, and its role will not diminish even during times of illness. Nutrition support therapies provide individuals with adequate nutritional intake, but they fail to meet the social stimulation that food provides.

Eating and mood are often discussed in terms of eating disorders; however, people who are unable to eat orally also experience emotional turmoil. Those who restrict the amount of food they consume, whether by choice or not, tend to grow consumed with everything having to do with food (Ioakimidis et al., 2011).

The act of eating activates the neural network and results in positive emotions. This begins at infancy and continues through life into adulthood. However, when the act of chewing is no longer possible, be it temporary or not, there is a disconnection between the act of eating and emotional wellbeing (Ioakimidis et al., 2011).

Furthermore, food restrictions or food-related GI intolerance is not the same across the board and thus can result in very different symptoms. Patients who are unable to eat often attempt to eat orally anyway because of a strong desire or craving. The emotional toll of not eating can be too much, but the physical distress is also a consequence (Winkler et al., 2010).

Regardless of whether the individuals on EN or PN can eat solid food or not, the bulk of their nutrition comes through nutritional support therapies. In these cases, patients commonly report feeling social isolation and shame. Oftentimes, patients who can chew and swallow still eat, but they reportedly do so in smaller amounts and closely watch the types and amounts of foods they eat (Winkler et al., 2010).

Another factor people undergoing EN or PN must consider is the idea of accompanying others while they eat. Socialization can be difficult when social outings revolve around eating or meals. Many individuals undergoing nutrition support therapies are unable to eat orally, causing them to miss this entire part of the social process. However, many of these individuals still frequent restaurants and attend birthday celebrations, work gatherings, and other events that involve food and eating. In these scenarios, it is not uncommon for people with feeding tubes, central lines, or PICC lines to feel uncomfortable and to have to come up with an excuse for not eating. Alternatively, some individuals undergoing nutrition support therapies may choose not attend these events altogether and increase their risk of isolation (Winkler et al., 2010).

Saving Lives at What Cost?

Both EN and PN are prescribed for patients in critical care, in long-term facilities, and in nursing homes. Additionally, these nutrition support therapies are prescribed for people at home, and who are still very active. In both situations, nonetheless, added stress and costs accompany a feeding tube, central line, or PICC line.

A major cost of EN and PN therapies is the introduction of a foreign body into a patient. But economic costs are present as well. Many patients requiring these types of nutrition therapies are unable to work, relying instead on disability benefits, their families, and their savings. In some cases, these individuals are unable

to meet their health insurance costs and lose the ability to nourish themselves when their coverage is terminated. Furthermore, some types of medical insurance may not consider EN or PN to be a “necessary” therapy and may not cover all the supplies the therapy requires.

Home PN patients tend to have an increased amount of financial burden. For example, the numerous health services that home PN requires and the necessary professional care that is needed to manage maintenance and ensure success increases the financial strain on patients and their caregivers. According to Piamjariyakul et al. (2010), the added financial burden of home PN can be divided as follows:

- Physician office appointments: Patients on home PN typically see a wide range of specialists. Internists and gastroenterologists are the most common providers, but infectious disease doctors, surgeons, and other specialties are common as well. Some patients may have anywhere between two and 20 visits annually, some may have as many as 50, and others still may have closer to 100.
- In-home health visits: About 30% of patients on home PN require in-home services, with nurse visits being the primary service provided. Some patients require 15 minutes of nurse services per day, while others may require as many as 10 hours. Home deliveries are also included here, as home PN patients require delivery of medical equipment, supplies, medications, and other items.

- Complementary services: Patients on home PN may also seek complimentary services including visits with pharmacists, social workers, mental health providers, chiropractors, pain management specialists, massage therapists, and others.
- Hospital outpatient services: A majority of home PN patients report having to use outpatient services including laboratories, infusion clinics, emergency care facilities, and emergency rooms.
- Hospitalizations: these refer to hospital admissions that are greater than 23 hours. Annual hospital stays can range from two to 14, with some patients having up to four hospitalizations within six months. Average hospitalization lasts six days.

The costs that families and patients incur for these services vary based on the charges negotiated between insurance companies and providers. However, many families carry both public and private insurance. As of 2019, the average premium for single coverage was \$6,896 per year and the average premium for family coverage was \$19,616 per year (National Conference Of State Legislatures, 2018).

Even though patients and caregivers are not necessarily responsible for 100% of the charges of the services mentioned above, a percentage always falls to the patient. These services create conflict for both the providers and the patients and their families, particularly at the fear of economic burden. There is also the question of time spent organizing care, which can be costly for patients and their

caregivers, especially because it can negatively impact the quality of life of everyone involved.

While EN is in general less costly than PN, this is not to say that this type of nutrition support therapy goes without problems. Nutrition support via an enteral route tends to be less costly and have shorter average hospital stays. Unlike PN, EN can be administered safely and at a low cost in the home setting. In general, EN administered in the hospital tends to result in higher costs for both patients and insurance companies (National Alliance for Infusion Therapy and the American Society for Parenteral and Enteral Nutrition Public Policy Committee and Board of Directors, 2010).

Most enteral nutrition therapy costs are related to tube changes and supplies. Patients undergoing EN have lower incidence of infection or sepsis, but often have other reasons to go to the hospital at least four times a year. Persons with feeding tubes may also have complex chronic illnesses that require multiple provider visits a year. These patients also have added copays from medical supply companies and medications. According to National Alliance for Infusion Therapy and the American Society for Parenteral and Enteral Nutrition Public Policy Committee and Board of Directors, the following incur in EN patient overall financial costs:

- Hospitalizations: While not all EN patients are hospitalized, a vast majority of critical care patients have to remain in the hospital for a long period of time. The reasons for overnight stays vary, but they are likely due to tube complications.

- Supplies: Of the patients receiving EN, at least 30,000 were able to continue the nutrition support therapy at home. However, this therapy results in added costs for the patient when ordering supplies for tube feeding.
- Tube changes: One of the most common and costly procedures for EN patients is tube replacement, whether routine or emergent. In some cases, patients will need up to seven or more tube changes a year because of tube malfunction, perforation, infection, or obstruction. Depending on the severity of the case, this may result in hospitalization as well.

To Eat or Not To Eat?

To eat or not to eat is a common question for EN and PN patients, and it is what is referenced in “The Chicken Soup Paradigm and Nutrition Support: Rethinking Terminology as the Chicken Soup Paradigm” (Lipman, 2003). Lipman (2003) addressed how nutrition support, whether enteral or parenteral, is always preferred to starving. Still, because EN and PN are not associated with the pleasure of eating, what happens when the “chicken soup” that provides nutrition is no longer a positive, but instead a forced, invasive, artificial method of feeding? This raises the ethical questions of when and how nutrition support is an accepted—and thus positive—therapy. While many patients survive on PN and EN for short time periods, some may need either or even both nutrition support therapies for long-term periods or a lifetime. Nonetheless, there are cases where terminal illness, mental disabilities, and cerebrovascular accidents require nutrition

support therapies without having the patients' consent (Lipman, 2003). It is then important to remember that nonvolitional artificial feeding is not the same as eating, and thus should be treated ethically in these cases.

Ethically, the relationship between feeding necessity and feeding discomfort is always interdependent. This is particularly true for patients who are recovering from a cerebrovascular accident, a trauma, or a burn. These patients are often in acute care, and their recovery greatly depends on nutrition support. In a 2017 study by Green & Vandall-Walker, participants were asked to describe their experiences with tube feeding. Patients often used the words frustration, anger, depression, pain, and fear. Physical discomfort was also common, both because of feeding tube insertion and replacement, as well as side effects from EN including nausea, vomiting, abdominal distention, diarrhea, and high blood sugar.

Some patients see their feeding tubes as a necessity to heal, while others question their need during times of pain, stress, and discomfort. This same phenomenon applies to PN, which can be even more stressful because of the high-risk nature of this nutrition support therapy. Patients on PN often end up staying in the hospital longer and have a higher infection rate (Maudar ,1995).

When is nutritional support ethical? It is important to consider the patient's wishes first and foremost. But what happens when patients do not have a voice of their own? The "chicken soup" paradox is real and should be evaluated before it becomes evident that a person is being artificially fed without their consent. In some cases, patients may be ambivalent, and education and guidance are essential before making the decision to undergo EN or PN.

Emotional Support For Persons on Enteral and/or Parenteral Nutrition

Patients undergoing parenteral or enteral nutrition and their caregivers often express feelings of isolation and discomfort. Authors agree that the pathophysiology of persons in need of PN and EN varies, and thus does their quality of life (Winkler, et al., 2010; Piamjariyakul, et al., 2010; Lipman, 2003). Despite the perception that EN is remarkably less costly and less cumbersome than PN, some individuals on EN still feel restricted and experience physiological and emotional trouble. The same is true for patients on PN, with the additional emotional burden of economic uncertainty and added costs.

Furthermore, emotional support should be considered for caregivers, who are often asked to perform several duties—changing feeding tubes, administering medications, cleaning the site, and more—without much education or support. The care that a person on nutritional support therapy may receive from a caregiver correlates with the amount of support this individual obtains from health care providers. With home PN, home nursing is often expected, but the extent of the duties of the caregiver often do not surpass dressing changes and site cleaning. In some cases, nurses may be in contact with patients via phone. Unfortunately, these tools may not be available to all persons, and their availability often correlates with the type of health insurance and the level of coverage a patient receiving these therapies has (Piamjariyakul, et al., 2010).

When it comes to home EN, patients do not often have access to a nurse or health care facilitator because feeding tubes do not require sterilized care and can be washed normally. However, they do come with technical and functional issues. Tube-fed patients often have to go to the nearest emergency room to obtain care; depending on their geographic location, they may encounter different obstacles finding this care as well. In most cases, patients undergo emergency tube changes or overnight stays, but they are given no education or resources on preventing future problems or on what to expect at home (Roberge, et al., 2000).

The reasoning behind the lack of emotional support for home PN and home EN patients and their caregivers is simple: In most cases, physicians and health care providers themselves are not very educated on the matter. Even though registered dietitian nutritionist (RDN) visits are starting to be covered by a wider range of health insurance companies, sometimes the visit number is limited, and thus complete education is not possible.

Much of the misinformation or lack of information comes from the fact that hospitals do not have the resources to allocate to patient education, and hospitals may not be able to meet the individual cases of complex patients.

In addition to a lack of educational resources, patients on home PN and home EN often lack an emotional support network. This lack of support may become evident at some point during nutrition support therapy and can be difficult for patients to deal with. Many complex illnesses lead to problems that require multiple health care provider visits, hospitalizations, medications, and more. Still, patients may feel frustrated at the lack of coordination between health care providers, long

wait times, and the cost of care, among other things. These feelings can result in isolation, depression, and anxiety (Roberge, et al., 2000).

Perceptions on EN and PN Regarding Quality of Life

Most people who have not had to rely on home PN or EN often do not have a positive view of these nutrition support therapies until they are forced to use them. In most cases, home PN and EN are viewed as a last resource to prevent malnourishment and lower morbidity incidence. For the most part, many individuals begin home PN or home EN after having exhausted all other alternatives. This includes oral intake as a means of recovering weight and managing health, which often leads to gastrointestinal distress and further loss of appetite (King et al., 2019).

King et al. (2019) provided evidenced-based guidelines that recommend EN be considered when hospital patients cannot maintain greater than 50% of their recommended oral intake. In some cases, EN is not a viable option, and thus PN should be considered as a first line of treatment. The use of EN and PN often begins in the hospital setting, with some patients continuing therapies at home or in a long-term facility. This affects the perception that patients and caregivers may have regarding their nutrition support therapy.

Because both PN and EN have an invasive nature and require time to build tolerance, individuals and their caregivers may have a negative view of the therapy

itself. Personal experience—whether there is nausea, vomiting, glucose disorders, or pain—also factors into a person’s view on PN and EN.

Many patients describe their inability to eat as the primary reason for PN or EN therapy, and many described their desire to eat (Wrinkler, et al., 2010). This same perception could negatively impact the perception of nutrition support therapies. Once patients move past the hospital setting, they must adapt to being at home, which can be difficult without the support of the nursing staff and other health care providers to assist with EN and PN.

After a period of adjustment and trial and error, patients on nutrition therapies may start to see their feeding tubes, central line, or PICC lines as life-saving devices. For caregivers, the perception of these devices as a solution to weight loss, malnutrition, nausea, vomiting, and pain is often clear. Nonetheless, the same is not always true for individuals undergoing PN or EN. One clear example of negative perceptions regarding EN or PN is the time constraint it poses for the individual undergoing the therapy. In the study by Jordan et al. (2006), participants described negative feelings regarding their inability to participate in activities like shopping, eating out, special occasions, family mealtimes, and holidays. The same study found physical limitations contributed to negative perceptions because of patients’ association with physical immobility and restraint.

For most individuals undergoing EN or PN, infusions may take a large amount of their day, in some cases 24 hours at a time. This makes it difficult to attempt a normal daily routine. In the case of elderly persons, outside help may be needed to carry out the regular activities of daily living (ADLs). Furthermore,

individuals on EN and PN who require long infusion times may experience more gastrointestinal discomfort or glucose abnormalities, which negatively affect their perception of their nutrition support therapy (Huisman-de Waal, 2011).

A disruption of a daily routine is not the only area of conflict between EN and PN patients and their caregivers. While family mealtimes often disappear for individuals relying on these nutrition support therapies, patients come to see their feeding tubes, central line, or PICC lines as a necessity for nutritional purposes. Families and caregivers tend to remain hopeful about their loved one or patient regaining the ability to eat and drink orally. This conflict of views can result in feelings of frustration, despair, and stress (Huisman-de Waal et al., 2011; Ojo et al., 2019; Orrevall et al., 2004).

The question remains whether nutrition support therapy patients see EN or PN as superior. Scolapio et al. (2002) explained that for the most part, health care providers prefer EN because it remains somewhat natural and less costly. The opposite is true when it comes to how individuals who are about to undergo EN or PN feel (Scolapio et al., 2002). For the most part, IV nutrition is perceived as less invasive and more comfortable than tube feeding. Once provided with PN, the perception may change, as patients could experience infections, occlusions, or pain. Perceptions may also shift if patients have to alter their lives to ensure a sterile environment. When it comes to older users, however, the preference was for PN largely because of the physical discomfort of having to undergo a procedure for tube placement and replacement. Comfort remains the number one priority when it

comes to choosing PN or EN, but the perception may change once a person has begun one particular method of feeding.

The Future for Persons on PN and EN

Overall, people on EN or PN find support among their peers online and through organizations such as the Oley Foundation. The study by Chopy et al. (2015) shows the significance of patient advocacy, item exchanges, communication, and inspiration. In these instances, organizations like the Oley Foundation can help patients and caregivers retain a sense of normalcy, troubleshoot problems, and find advice regarding homemade remedies, new lines of treatment, physicians, hospitals, and more. According to this study, about 54% of participants found the Oley Foundation on their own when searching for answers. In about 46% of cases, health care providers, such as registered dietitian nutritionists (RDNs), introduced the foundation to their patients. In most cases, though, patients had only learned about the Oley Foundation and its resources after years of feeling isolated and alone (Chopy et al., 2015).

Organizations like the Oley Foundation, online communities like Inspire, social media groups on Facebook, and public profiles on Instagram prove to be transformational for persons undergoing PN or EN due to the sense of community they provide.

However, these resources are not always available to everyone, particularly elderly patients or caregivers. Still, the future of EN and PN and the improvement of

quality of life for persons undergoing these nutritional support therapies are highly dependent on health care providers including information regarding the aforementioned support groups when caring for patients.

It is important moving forward that patients feel supported and seen by their health care providers. In past studies by Wrinkler et al., 2010, Green, et. al., 2017, and King, et. al., 2019, regarding quality of life, the feeling of frustration remained palpable, but the health care system must find ways to do better.

Health care professionals working with individuals who are receiving enteral nutrition and PN also extends beyond assuring nutrition adequacy. We need to be aware of the social consequences of the loss of ability to eat. We need to recognize when patients' worries about eating cause social isolation and depression, and we need to help our patients develop effective coping strategies. Effective counseling should focus on both the relationship between food and physical health and the relationship between food and psychological well-being. (Winkler, 2007)

Winkler (2007) acknowledged what many health care providers fail to see: that the discomfort and pain is likely also associated with a lack of emotional support and the despair of being withdrawn from society. Many individuals associate food with the emotions of happiness and love, and many mourn the loss of new memories and good times, not necessarily just the food.

Understanding the social meaning food has for our patients can help in behavior modification and in preparing our patients for the loss and altered

identity that accompanies the absence of food, the inability to eat, or the dependency on nutrition support. (Winkler, 2007)

As mentioned in past sections, the social meaning of food and the loss of identity remains the biggest problem for people on EN and PN when it comes to quality of life (Winkler, 2007).

Advocacy for emotional support needs to occur at the local and national level. Agencies like the American Society of Parenteral and Enteral Nutrition and the Oley Foundation remain the leaders in these efforts. However, new smaller organizations like Gastroparesis Patient Association for Cures and Treatments (G-PACT) or Disautonomia International are setting a new example because they are run by patients and they put patients at the forefront of the fight for visibility and advocacy. It is also important to remember that for patients' quality of life to improve, doctors and health care providers must listen to the needs of persons undergoing EN or PN and their caregivers. Comfort goes beyond a functional feeding tube, central line, or PICC line, and it should be measured in terms of emotional wellbeing.

Interventions

This report consisted of the administration and review of a 25-question survey that reflected the concerns regarding the quality of life of persons living on EN and/or PN. The survey was finalized with the guidance of Dr. Linda Yarrow, PhD, RDN. The first set of questions was focused on relevant demographic and background information, including age, gender, geographic location, educational

attainment, work status, and living situation. The next 10 questions were yes or no with additional open-ended options. These questions focused on the social, emotional, and economic impact of nutrition support therapy on the participant's quality of life. The last seven questions used a rating-scale and were based on participant's feelings and perceptions toward their quality of life as persons on EN or PN. The Qualtrics program was used to create and distribute the survey (<https://qualtrics.com>). The survey was distributed among social media support groups, email listserv groups, and Internet forums. The data was retrieved via Qualtrics in order to make general observations regarding the quality of life of persons on these nutrition support therapies.

There were 123 final responses, which are included in the data analyzed. The main Facebook groups used for distribution included Adult Tube Feeding; Feeding Tube Support & Items Exchange; Feeding Tube Support and Friends; Feeding Tube Support; G-PACT; Support Group For EDS, POTS, Gastroparesis, TPN & Tubies; PICC Line Club 2.0; and TPN-Total Parenteral Nutrition. The survey was published in forums on Inspire.com mainly, in the G-PACT forum, and the Home IV and Tube Feeding Support Group & Forum. Finally, Dr. Linda Yarrow and Charmaine Jones, RDN shared the survey among a network of RDNs.

Participants in this survey remained 100% anonymous, but had the opportunity to enter their contact information at the end in order to be selected for one of 10 Amazon gift cards, each with a \$10 value.

Results

As mentioned, quality of life for persons living on EN or PN may be affected by lack of emotional and economic support. The participant population chosen in this report is undergoing either EN alone, EN and oral nutrition, PN alone, PN and oral nutrition, or both EN and PN. Using yes or no questions with the option to write-in thoughts and explanation, as well as a rank-based number of questions, insight into quality of life and how it affects this population was obtained. The survey focused on the elements of isolation, inability to work, economic burden, personal perception on quality of life, ability or inability to eat orally, feelings of shame, ability to perform ADLs, and feelings of anxiety or stress regarding medical procedures. These questions were designed to account for the common factors that affect a person's quality of life while on EN or PN based on the literature available and previous studies.

Of the respondents, 43.90% were on EN alone, 38.21% were on EN and oral nutrition, 6.50% were on PN alone, 2.44% were on PN and oral nutrition, and 8.94% were on EN and PN. The mean age was 39 years; the median age was 34 years; and the mode age was 25 years. The minimum age was 18 years; and the maximum age was 94 years.

One question addressed a loss of socialization: "Since you have been on nutrition support therapy, have you lost contact with family and/or friends due to not being able to eat socially with others?" Of participants, 43.90% responded that they had not lost contact with family or friends, and 56.10% responded that they

had lost contact with family or friends. The majority of persons on EN or PN expressed feelings of isolation at some point, which can sometimes be attributed to a loss of social interactions when the main activity involves food consumption (Ioakimidis et al., 2011; Jordan et al., 2006; Winkler et al., 2010). The majority of participants reported losing contact with family or friends, illustrating that EN and PN negatively affects one's social life, and therein, their feelings of belonging.

One question addressed work hours: "Since you have been on nutrition support therapy, did you have to cut your work hours or quit your job?" Of participants, 64.23% responded "No" and 35.77% responded "Yes" that they had to reduce work hours or quit their job. Participants were asked to elaborate if they selected "Yes." Some of the responses expressed sentiments of lack of energy and potential malnutrition through statements, such as "Tire very easily and don't have the energy I once had. Tube feedings need to be done as many hours a day as possible;" "cut back hours since my body couldn't handle;" "I just no longer have the energy to work, and I need to be running feeds, but I'm too self-conscious to run it at work;" and "I just can't manage what I used to—total fatigue." Other participants expressed their transition into disability after being on a nutrition support therapy with statements like, "On medical leave," "Became disabled," and "100% disabled not able to work at all." While some individuals begin PN or EN therapies during retirement, a number of respondents are forced to alter their lifestyle in order to accommodate the many hours necessary for nutrition support, hospital and doctor's visits, and physical restrictions. In many cases, survey participants may lose their pre-existing quality of life due to economic and physical constraints of having to quit

work. The results in this case show that a group of participants cannot hold a job due to disability and fatigue.

One question addressed insurance coverage for nutrition support therapy: “Are your feeding and nutrition support therapy supplies covered by insurance?” Of the participants, 55.28% responded “Yes, fully;” 25.20% responded “Yes, partly;” and 19.51% responded “No.” Participants were asked to elaborate if they selected “Yes” or “Yes, partly.” Some participants commented that they had to go through a complicated process of fighting for the correct supplies or they had to cover part of these supply costs out of pocket: “had to fight to get correct formula covered and often have to buy my own supplies,” “Medicare pays a portion of food and supplies,” “I have to meet deductible of \$2000 first, then pay 20% of everything until the out of pocket max is met for my policy.” These statements reveal the economic burden for persons receiving home EN or home PN. Now participants on home EN or home PN must worry about covering the cost of the monthly supplies needed for nutrition support therapy on top of the money they spend on insurance premiums, deductibles, copays, out-of-pocket expenses for hospital visits and doctor’s appointments, and tube and line changes (National Alliance For Infusion Therapy and the American Society for Parenteral and Enteral Nutrition Public Policy Committee and Board of Directors, 2010; Piamjariyakul et al., 2010). There is also clear disparity in terms of health care insurance in the United States. Factors influencing this disparity include age, socioeconomic status, and diagnosis. It is also relevant to explain that of the 123 participants, 2.48% (three) were in Asia, 0.81% (one) were in Africa, 8.94% (11) were in Europe, 2.44% (three) were in South

America, 6.50% (eight) were in Australia, and 78.86% (98) were in North America. Health care coverage varies depending on region, which could have affected the results based on anxiety of economic burden.

One question addressed quality of life: “Do you feel like your quality of life has changed since you have been on parenteral nutrition (PN) or enteral nutrition (EN)?” Of the participants, 13.82% responded “No;” 39.02% responded, “Yes, it has improved;” and 47.15% responded, “Yes, it has decreased.” Participants were asked to elaborate if they selected “Yes it has improved” or “Yes, it has decreased.” The mixed feelings regarding EN and PN are consistent with the ethical dilemma that most persons on EN or PN face: whether it is worth it to nourish themselves despite losing quality of life, or whether quality of life will improve despite the complications (Jordan et al., 2006; Orrevall et al., 2004; Scolapio et al., 2002; Winkler et al., 2010). Participants who noted an improved quality of life had mixed explanations for why their quality of life had improved. Responses ranged from “Improved my nutrition but makes everything else worse;” to “Mostly improved, but there should be a both option. I am no longer slowly starving to death and in a state of severe malnutrition, but it also impacts my daily life, activities I used to do, and my self-image;” and “More nutritionally stable, although socially excluded and hampered by feeding regime.” These statements reflect the complicated relationship between nourishment and living on nutritional support. Participants who noted a decrease in quality of life also had mixed explanations for why this was so. Comments included “I’ve lost the joy in eating and the social activities around eating. I don’t like to go on vacations anymore or gather anywhere where there’s food. The

grief is overwhelming;" "My health is better but my mental health is much much worse;" and "Lost self esteem and friends." Participants reported mourning the life they had before EN or PN, particularly because of the loss of social interaction, friendships, and relationships, even though nutrition improved. As one participant expressed, "My social life has become nonexistent. My identity through my work as a paramedic has been lost, my husband is not as affectionate and our relationship has strained since relying on nutritional support."

One question addressed feelings of isolation when patients experienced problems with EN or PN: "Do you feel alone when you have problems with your PN or feeding tube?" Of the participants, 34.15% responded, "Yes;" 28.46% responded, "Sometimes," and 37.40% responded "No." Participants were asked to elaborate if they selected "Yes" and "Sometimes," For those who expressed feeling alone when troubleshooting, the overwhelming majority felt left behind by their health care providers, family, or friends, as illustrated in the comments. "I don't feel comfortable talking about issues with family and friends and often it's the middle of the night and I am alone and have been sick and tube has displaced and I feel really ill;" "I struggle to find a doctor or nurse to listen and help with issue;" "Very little support and each time I ask to meet with the nutrition team I get voicemails and calls back days later." Similar feelings are expressed by those who feel alone sometimes, with comments including "Never know who to turn to or who I can vent to;" "My husband is very understanding. And I am in groups online. But it can be very isolating, yes. It's not a very 'normal thing;" and, "I have a Facebook group that is very helpful but most people don't understand the problems... not even all Drs get it." The majority

of participants on EN or PN reported feeling isolated and have turned to support groups, organizations, and social media to find advice, companionship, and solutions regarding any problems they may have. (Chopy et al., 2015; Huisman-de Waal et al., 2011; Ojo et al., 2019; Orrevall et al., 2004; Winker, 2007).

As mentioned previously, the loss of oral nutrition is one of the main concerns regarding the use of nutrition support therapies. This is particularly important when it comes to losing quality of life because of the inability to eat normally, whether it is the loss of social interactions or feelings of depression, anxiety, and isolation. (Green & Vandall-Walker, 2017; Ioakimidis et al., 2011; Lipman, 2003; Winkler et al., 2010). One question addressed this: "Are you able to eat for nutritional purpose or for enjoyment?" Of the participants, 44.72% responded "No;" 11.38% responded "Nutritional purposes;" 28.46% responded "Enjoyment;" and 15.44% responded "Both." The paradigm of artificial nutrition and enjoyment of food is evident in participants' statements: "I can't eat a lot. It takes too long and I still aspire. Mostly to eat socially and to enjoy flavors;" "Only on rare occasion for enjoyment ... a couple bites;" and "Some days it's less for nutrition more for enjoyment."

One question addressed the emotional distress and the feelings of shame and low self-esteem that often comes with not being able to eat orally: "Have you felt ashamed of not being able to eat normally?" Of the participants, 46.34% responded "No;" 42.28% responded, "Yes;" and 11.38% responded "Sometimes." Participants were asked to elaborate if they selected "Yes" and "Sometimes." For those who said that they felt shame, the overall feeling stemmed from the social experience of

eating and the expectations from others. Comments included “Most of the time especially when people tends to ask you reason on why I am on feeding tube;” “Eating normally is just what everyone expects and assumes everyone is capable of so it can be hard when that’s not your norm;” and “I feel awkward. Everyone feels awkward. I feel like I’m not part of normal society. I can’t take part in normal conversations about food and where to eat etc.” For those who said that they felt ashamed at times, the feeling came when in company of others and in the presence of food. Comments included “When I am in the company of others that are not aware of my G I Issues, I pick at food or say I am not hungry;” “Just feels weird when presented with food, but not able to eat it;” and “Its weird on holidays like Thanksgiving.”

One question addressed ADLs: “Does your PICC line, central catheter, or feeding tube interfere with your activities of daily living (driving, running errands, bathing, cleaning, etc.), and other leisure activities?” Of the participants, 39.02% responded “No;” 47.15% responded, “Yes;” and 13.82% responded “Sometimes.” Participants were asked to elaborate if they selected “Yes.” Quality of life is associated with ability to perform activities of daily living and being independent (Huisman-de Waal et al., 2011; Ojo et al., 2019; Orrevall et al., 2004; Pols & Limburg, 2015; Roberge et al., 2000). Those who expressed the inability to perform daily or leisure activities blamed physical constraint, lack of sleep, pain, and soreness. Comments included “Simply moving around the house tied to the pump makes everything harder;” “I have a feeding tube and port and my port interferes with showers and my FT is hard to run errands with;” “I am almost always uncomfortable

to some degree. It affects how I move and what exercise I can do. I feel embarrassed during sexual encounters. I do not feel safe swimming anymore, especially at lakes;" and "My j tube makes it impossible for me to hula-hoop, do gymnastics (bars, it gets caught) and hurts when I move in certain ways. It makes shopping more difficult as I have an extra backpack I have to wear now. Same issue with going to classes at school as I have to carry two backpacks."

One question addressed the potential constraint of nutrition support therapy: "Do you feel like your feeding tube, central catheter, or PICC line has become a burden despite being life-saving?" Of the participants, 34.15% responded "No;" 43.09% responded "Yes;" and 22.76% responded "Sometimes." Participants were asked to elaborate if they selected "Yes" and "Sometimes." For participants who felt like EN or PN is a burden, the feelings of life-saving nutrition versus the inability to eat, pain, isolation, and discomfort creates a greater burden (Green & Vandall-Walker, 2017; Huisman-de Waal et al., 2011; Jordan et al., 2006; Lipman, 2003; Orrevall et al., 2004; Roberge et al., 2000; Winkler et al., 2010). Patients cited feelings of shame, anxiety, and low self-esteem in their comments: "18 hours a day being tied to this pump is a burden;" "Can't do much due to the pain. Would rather have it out and have a few months doing what I want than spend most of my life trying not to move;" "I question several times a week whether it is worth it to continue living with a tube. I have lost a lot in my life so far because of it;" "It can crash on you mentally if not already physically;" and "I am forever thankful for it. But it does make me feel isolated. I miss being able to eat with friends and dinners. So much social life revolves around food."

One question addressed potential anxiety or stress regarding equipment: “Do you experience anxiety or stress when you think about tube changes, catheter changes, or PICC line exchanges?” Of the participants, 46.34% responded “No;” 43.53% responded “Yes;” and 8.13% responded “Sometimes.” Participants were asked to elaborate if they selected “Yes” and “Sometimes.” The burden of hospitalizations, procedures, check-ups, emergency room visits, and more is not just economical but also emotional (Bodoky & Kent-Smith, 2009; Buchman, 2007; Green & Vandall-Walker, 2017; King et al., 2019; Lipman, 2003; National Alliance for Infusion Therapy and the American Society for Parenteral and Enteral Nutrition Public Policy Committee and Board of Directors, 2010; Piamjariyakul et al., 2010; Winker et al., 2010). Participants explained feeling fear of pain, anxiety about mistreatment and misdiagnosis, and even PTSD from past medical experiences. Comments included “Have PTSD from cautious NJ tube placement and changes and now have to be sedated to get them. Started having panic attacks on the table;” “It is expensive and uncomfortable;” “During Covid, it is additional exposure. Most anxiety relates to the timing ...I can see and feel the tube getting weaker, but do I get it changed today, next week? Will insurance cover it today?” “I have medical trauma;” and “Tube changes are painful, so I hate doing them.”

The remaining questions were based on a rating scale; participants rated their feelings and perceptions of EN and PN on a scale from 1 to 7. The responses were mixed; however, some questions leaned more toward one end of the scale or the other.

The first ranked-choice statement addressed depression: “Over the past 30 days, I have felt depressed.” Of participants, 20.33% chose “Very Depressed,” 18.70% chose (option 3); and 10.57% chose “Never.” While a large number of participants felt very depressed (20.33%), almost the same amount felt neutral (18.70%) about the issue. This reflects the complex feelings involving persons who are on EN or PN and whether they feel at peace with their situation. From time to time, participants may experience periods of stress, anxiety, and depression, or they may feel rested, nourished, and fulfilled. The ever-changing nature of nutrition support therapy and the issues associated with having a feeding tube, central line, or PICC line can make individuals feel many emotions (Ang et al., 2019; Green & Vandall-Walker, 2017; Lipman, 2003; Roberge et al., 2000; Winkler, 2007; Winker et al., 2010).

Another ranked-choice statement addressed feeling understood: “Over the past 30 days, I felt those around me understood my chronic illness and life.” Of participants, 21.95% chose neutral by choosing a 4 in the scale; 13.01% chose “Not at all,” and 4.07% chose “Completely.” The responses to this question also show ambivalence, though it is clear that most participants (55.29%) gravitated toward the “Not at all” option, meaning that their loved ones do not understand their chronic illness and life (Ang et al., 2019; Chopy et al., 2015; Huisman-de Waal et al., 2011; Petitte et al., 2015). This is particularly relevant for the quality of life of persons living on EN or PN because it can cause distance between loved ones or feelings of anxiety, guilt, depression, and frustration. The use of outside support tools, such as the Oley Foundation, social media groups, YouTube channels, video

blogs, blogs, and forums, has become increasingly popular because of the instant communication those resources provide (Chopy et al., 2015; Huh et al., 2014; Merolli et al., 2015). Furthermore, persons on EN or PN feel closer to those in a similar position because they can share tips and advice, and they can exchange items regarding their nutrition support therapies.

Another ranked-option statement addressed depression: “Over the past 30 days, I have felt depressed about my future with PN or EN for the long-term.” Of participants, 19.51% chose “Neutral” (option 4), 16.26% chose “Not at all,” and 14.63% chose “Completely.” This statement measured whether depression is prevalent in persons with EN or PN. Responses regarding depression in the prior section of questions made it clear that some participants felt depressed, anxious, and insecure regarding their feeding tube, central line, and PICC line in the long term. However, this time participants felt more neutral. But at least 18 participants (14.63%) felt completely depressed (option 7), while 17 participants (13.82%) and 13 participants (10.57%) felt somewhat depressed. This data reflects the perceived lack of emotional support in the world of nutrition support therapy, home EN and home PN.

Another ranked-choice statement addressed how participants feel about regular eaters: “Over the past 30 days, I have resented my family and friends for their ability to eat.” Of participants, 39.02% chose “Not at all;” 8.94% chose “Completely;” and 12.20% chose “Neutral” (Option 3). This shows that persons on EN or PN are not prone to blame family members, friends, or loved ones for their own situation. Instead, many blame themselves or their bodies. Eating remains a

source of emotional distress, but many persons on EN or PN understand that those around them have to eat. In fact, many persons on these nutrition support therapies attempt to eat for enjoyment or simply for the social interaction that this implicates, as seen with response statements like, “I feel like I’m missing major family bonding time;” “Italian household food is medicine, socialization, and life itself;” “It’s hard watching other people eat when you can’t;” and “Some of my friends make it awkward when they are eating in front of me.”

The last ranked-choice statement of the survey addressed isolation: “Over the past 30 days, I have felt alone and lost when it comes to my illness and feeding tube.” Of participants, 18.70% chose “Neutral” (option 4), 17.26% chose “Completely” and 14.63% chose “Not at all.” This statement is similar to the one about depression, as feelings of isolation and loneliness are closely related to chronic illness and nutrition support therapies. Family support plays an essential role for many people on home EN or home PN, but patients still feel isolated when it comes to their inability to eat or work normally. Most individuals on EN or PN also lack the support from health care providers when it comes to common issues such as tube clogs, tube flips, line displacement, and infection, among others. It is important to acknowledge that feelings of isolation and lack of direction may change depending on where the patient is both emotionally and physically. Chronic illnesses are not linear, which may have a direct correlation with the selection of the neutral response. During disease flares, doctor’s visits, and hospitalizations, a person may feel more disheartened and more aware of a perceived lack of support from those in health care who are meant to guide them. While the support of family

and loved ones is important, these individuals may not be able to help an EN or PN patient in moments of distress, pain, illness, and more. Finally, it is important to acknowledge that social media, support groups, or forums can provide some relief when it comes to feeling lost or alone (Chopy et al., 2015; Garrett & Weisman, 2001; Huh et al., 2014; Merolli et al., 2015; Pettitte et al., 2015; Symister & Friend, 2003).

Discussion

The survey revealed two noticeable trends in the populations living on EN or PN. On one hand, 56.10% of the population surveyed felt they had lost contact with friends or family members because of their inability to eat socially. This phenomenon may also lead to feelings of isolation and depression, as revealed by the 34.15% who answered, “Yes” and 28.46% who answered “Sometimes” to the question “Do you feel alone when you have problems with your PN or feeding tube?” This is also true when it comes to routine procedures and emergency procedures related to feeding tubes, central lines, and PICC lines. Limitations on a patient’s ability to eat, perform daily activities, and carry out leisure activities may lead to lower quality of life, as shown by the 47.15% who said “Yes,” and 13.82% who said “Sometimes,” when it comes to performing these activities with feeding tubes, central lines, or PICC lines.

However, there were some notable discrepancies when it came to the ranked-choice section. In the multiple-choice and open-ended questions, participants felt more willing to explain their negative emotion toward their feeding

tubes, central lines, or PICC lines. The discrepancy is evident when it comes to the following statement, “Over the past 30 days, I felt those around understood my chronic illness and life.” Of participants, 24.39% chose option 2, 13.01% chose “Not at all;” and 4.07% chose “Completely.” This data contradicts some of the more evident feelings of isolation, loss of contact, and anxiety that participants expressed in the yes or no and open-ended survey questions.

When participants are given the option to choose a neutral response, instead of a more extreme one, it highlights the discrepancies between multiple choice and open-ended questions versus ranked-choice questions. It also shows the importance of having survey participants respond in more than one way. In most situations, participants are willing to explain why they chose “Yes” or “Sometimes.” But without the option to explain their choice, participants may feel more resistant to stating an extreme emotion or perception. However, it is important to restate that individuals on EN or PN also experience different situations in their daily living, which may be why they choose to remain neutral; they may feel one extreme or the other, depending on their situation. It is also relevant to note that persons on EN or PN may not feel as isolated once they find online support communities, and these resources were crucial in recruiting participants for this study.

The knowledge gained with this survey shows a decline in emotional wellbeing and perceptions on quality of life in part due to lack of emotional and physical support when it comes to issues with home EN and home PN, as well as the added economic costs that accompany these. At the same time, participants feel more willing to express their negative perceptions when given the opportunity to

explain them, as opposed to having to rank them. However, a statistical analysis is necessary to determine the significance of these results and to further support these observations.

Limitations

This report encountered certain limitations that could have affected the results. First, there was a time constraint for the survey to be distributed, which could have limited the number of responses. Respondent access was primarily through social media so results may not be representative of those who do not use social media technology. Future research should include multiple recruitment strategies. There is a need to determine a recommended sample size, with a test for statistical significance in order to further support these results and observation, though it is also noted that sample size is less relevant in qualitative research. Three-fourths of respondents were located in North America so results may not be generalizable to those outside North America. Additionally, because this was an international survey, responses regarding insurance coverage would be impacted by the structure of insurance in other countries. Another limitation of the survey was that there was not a question on length of time that respondents had been living with nutrition support. This question is important for future research. Finally, caution is required in the interpretation of the results as responses were self-reported and based on subjects' feelings and opinions. Self-reported data can contain sources of bias, one of which is selective memory. If respondents had a recent negative experience with nutrition support therapies, it could result in

respondents indicating a lower quality of life on numerous questions due to the impact of one particular experience. Future research should include recency of negative or positive experiences.

Conclusion

As the effort to treat malnutrition grows with new diagnoses of rare and chronic illnesses, so does the need for nutrition support therapies. EN and PN were believed to be only for the critically ill patients in hospital, hospice, or long-term care with the assumption that these patients tended to be of advanced age. However, as this survey shows, the median age for participants in this study was 34 years. While participants in this study may have been hospitalized at one time or another, home EN and home PN are prevalent. The literature on these two nutrition support therapies largely centers on functional issues, the quality of nutrition, and side effects. Little is known about the quality of life of the person undergoing such therapies.

The need for food is essential; not only do we need food to survive, but we also see food as a means of socialization and closeness to others. But what is an individual to do when eating food is no longer viable? Studies on the ethics behind EN and PN center on this issue. Calls to action on understanding the need for further education and empathy demonstrate there is still much more to be done regarding nutrition support therapies. As this study reveals, persons living on EN or PN feel left behind by the same medical entities and health care providers that once placed

them on the nutrition support therapy. Even within the dietetics field, the focus is often on quality of nutrition, weight gain, protein, and fiber (Winkler, 2007). However, many participants expressed feeling alone when they had questions regarding side effects to their formulas, as well as anxiety about the added costs of seeking care. This study reveals the overall feeling that despite receiving nourishment, quality of life for EN or PN patients may be compromised. Some participants described lacking energy, intimacy problems, depression, PTSD, chronic and acute pain, and more. For the most part, these problems may be common in complex and chronically ill persons, but EN or PN brings added stressors that may be difficult to manage for the individuals and their caregivers.

In conclusion, this study found several factors that decreased quality of life for patients on nutrition support therapies. These factors included the economic burden, isolation, the inability to eat, the inability to work or a decrease in work, and shame due to the need for artificial nutrition. Many participants of this study had to quit their job and alter their lives significantly, some perhaps even requiring help to perform daily and other activities. This is particularly relevant in the way these individuals may perceive their quality of life. Similarly, participants described feeling lonely as a byproduct of the physical and emotional distress that having a feeding tube, central line, or PICC line imparts. Nonetheless, participants found comfort within online communities and organizations that advocate for better quality of life, such as the Oley Foundation (Chopy et al., 2015; Huh et al., 2014; Merolli et al., 2015). These findings convey the important role that present and future health care providers have in understanding the weight of EN and PN for

those patients and how obtaining nutrition may not always signify improved quality of life for everyone. Further research should focus on what educational materials would be of benefit to health care providers and how individuals on EN and/or PN can receive the emotional support they need. There is also a need for advocacy in terms of policy changes so that nutrition support therapy patients receive adequate support when it comes to their EN or PN therapies. Change should be implemented in social work, psychology, community resources, and home care liaisons, among other areas.

The information collected and conclusions from this study are significant in showing how EN and PN may both increase and decrease a person's perception of their own quality of life. Factors identified in this study play a pivotal role in shaping an individual's perception and will need to be evaluated further in future research. There is also a need for statistical analysis to determine statistical significance that can further support these observations. This study may serve as a basis for further research on the quality of life of individuals living on EN and/or PN and can provide insight into what factors need to be explored in order to achieve better care for these persons.

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Appendix A - Evaluation on Quality of Life For Persons Living on Enteral and/or Parenteral Nutrition

Start of Block: Instructions

Hello, my name is Juliana and I'm Master's of Science candidate in the College of Health and Human Sciences at the Kansas State University. This survey's purpose is to gather information on the attitudes and perceptions on quality of life for persons undergoing enteral and/or parenteral nutrition support therapy. The objective of the research is to explore an area that has been under-researched in the past and that affects the standards of care for this population. Your participation in this survey is voluntary. By submitting this survey, you are indicating that you are 18 years or older. You can withdraw at any point in time without a penalty. The questionnaire will only begin after your informed consent to participate in the survey. Your identity will remain anonymous at all points. Participant's personal information is confidential and will not be identifiable in any of your answers. This survey will take approximately 15-20 minutes to complete and there are no foreseen risks. The Principal Investigator may terminate a subject's participation regardless of his or her consent if he or she does not follow procedure and guidance required for this survey. The anonymous survey results may be used for future research without the need for additional informed consent. Those who complete the survey will be eligible to enter a drawing to win one \$10 Amazon gift card (10

awarded). To be entered in the drawings you must complete the contact information requested at the end of the survey. The information you enter will not be linked to your survey responses. If you have questions about your participation or the survey, please contact the following investigators: Linda Yarrow, PhD, RDN (lyarrow@ksu.edu), Juliana Tamayo, MS Candidate (julitamayor@ksu.edu). If you have questions about your rights as a research participant, please call the Institutional Review Board representative: Rick Scheidt, Ph.D., 203 Fairchild Hall, Kansas State University, Manhattan, KS 66506, (785) 532-3224. Thank you for your participation.

End of Block: Instructions

Start of Block: Demographic Questions:

Q1 Gender

☐ Male (1)

☐ Female (2)

☐ Prefer not to identify (3)

Q2 What is your age?

Q3 Where do you live?

☐ Asia (1)

☐ Africa (2)

☐ Europe (3)

☐ North America (4)

☐ South America (5)

☐ Australia (6)

Q4 Do you work either in the workforce or self-employed?

☐ No (1)

☐ Less than 20 hrs/week (2)

☐ 20-30 hrs/week (3)

☐ 30-40 hrs/week (4)

☐ 40+ hrs/week (5)

Q5 Are you a current student?

☐ No (1)

☐ Yes, part-time (2)

☐ Yes, full-time (3)

Q6 Highest education level

☐ Some high school (1)

☐ High school/GED (2)

☐ Trade/Technical/Vocational training (3)

☐ College/University (4)

☐ Post-graduate Education (5)

Q7 Do you currently reside with anyone in your place of residence?

☐ No (1)

- ☐ Yes -- family members (2)
- ☐ Yes -- non-family members (3)
- ☐ Yes -- both family and non-family members (4)

Q8 Are you currently on enteral or parenteral nutrition?

- ☐ Enteral alone (1)
- ☐ Enteral and oral (2)
- ☐ Parenteral alone (3)
- ☐ Parenteral and oral (4)
- ☐ Parenteral and enteral (5)

End of Block: Demographic Questions:

Start of Block: Questions

Q9 Since you have been on nutrition support therapy, have you lost contact with family and/or friends due to not being able to eat socially with others?

☐ No (1)

☐ Yes (2)

Q10 Since you have been on nutrition support therapy, did you have to cut your work hours or quit your job?

☐ No (1)

☐ Yes (please describe) (2) _____

Q11 Are your feeding and nutrition support therapy supplies covered by insurance?

☐ Yes, fully (1)

☐ Yes, partly (please describe) (2) _____

☐ No (3)

Q12 Do you feel like your quality of life has changed since you have been on parenteral nutrition (PN) or enteral nutrition (EN)?

- ☐ No (1)
- ☐ Yes, it has improved (please describe) (2)
- _____
- ☐ Yes, it has decreased (please describe) (3)
- _____

Q13 Do you feel alone when you have problems with your PN or feeding tube?

- ☐ No (1)
- ☐ Yes (please describe) (2) _____
- ☐ Sometimes (please describe) (3) _____

Q14 Are you able to eat for nutritional purpose or for enjoyment?

- ☐ No (1)
- ☐ Nutritional purposes (2)
- ☐ Enjoyment (3)

☐ Both (please describe) (4) _____

Q15 Have you felt ashamed of not being able to eat normally?

☐ No (1)

☐ Yes (please describe) (2) _____

☐ Sometimes (please describe) (3) _____

Q16 Does your PICC line, central catheter, or feeding tube interfere with your activities of daily living (driving, running errands, bathing, cleaning, etc.) and other leisure activities?

☐ No (1)

☐ Yes (please describe) (2) _____

☐ Sometimes (please describe) (3) _____

Q17 Do you feel like your feeding tube, central catheter, or PICC line has become a burden despite being life-saving?

☐ No (1)

☐ Yes (please describe) (2) _____

☐ Sometimes (please describe) (3) _____

Q18 Do you experience anxiety or stress when you think about tube changes, catheter changes, or PICC line exchanges?

☐ No (1)

☐ Yes (please describe) (2) _____

☐ Sometimes (please describe) (3) _____

End of Block: Questions

Start of Block: Other format questions:

Q19 Over the past 30 days, I have felt depressed:

☐ Never (1)

☐ 1 (2)

☐ 2 (3)

☐ 3 (4)

☐ 4 (5)

☐ 5 (6)

☐ Very Depressed (7)

Q20 Over the past 30 days, I have felt anxious about covering the costs of my nutrition support therapy and supplies?

☐ Never (1)

☐ 1 (2)

☐ 2 (3)

☐ 3 (4)

☐ 4 (5)

☐ 5 (6)

☐ Very Anxious (7)

Q21 Over the past 30 days, when I thought about my catheter or tube, I felt:

☐ Dislike (1)

☐ 1 (2)

☐ 2 (3)

☐ 3 (4)

☐ 4 (5)

☐ 5 (6)

☐ Appreciation (7)

Q22 Over the past 30 days, I felt those around understood my chronic illness and life:

☐ Not at all (1)

☐ 1 (2)

☐ 2 (3)

☐ 3 (4)

☐ 4 (5)

☐ 5 (6)

☐ Completely (7)

Q23 Over the past 30 days, I have felt depressed about my future with PN or EN for the long-term:

- ☐ Not at all (1)
- ☐ 1 (2)
- ☐ 2 (3)
- ☐ 3 (4)
- ☐ 4 (5)
- ☐ 5 (6)
- ☐ Completely (7)

Q24 Over the past 30 days, I have resented my family and friends for their ability to eat:

- ☐ Not at all (1)
- ☐ 1 (2)
- ☐ 2 (3)
- ☐ 3 (4)

☐ 4 (5)

☐ 5 (6)

☐ Completely (7)

Q25 Over the past 30 days, I have felt alone and lost when it comes to my illness and feeding tube:

☐ Not at all (1)

☐ 1 (2)

☐ 2 (3)

☐ 3 (4)

☐ 4 (5)

☐ 5 (6)

☐ Completely (7)

End of Block: Other format questions:

Start of Block: Enter Prize Drawing

Q26 In order to be eligible to be selected for a \$10 Amazon Gift Card please provide the following contact information so that we may get in contact with you and deliver your gift card.

☐ Full Name: (1) _____

☐ Email Address: (2) _____

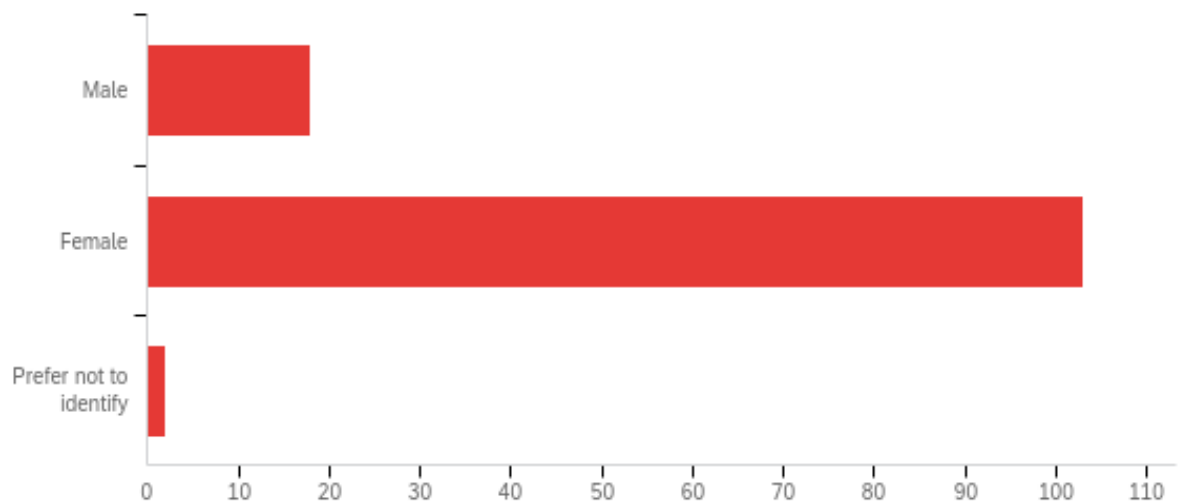
Q27 Your information will not be linked to your responses and it will only be used to enter the draw for this gift card.

End of Block: Enter Prize Drawing

Appendix B - A Comprehensive Evaluation on Quality of Life For Persons Living on Enteral and/or Parenteral Nutrition

Note: The values on the X-axis represent the number of respondents. A percentage and count breakdown is available in table form below the graphs.

Q1 - Gender



#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Gender	1.00	3.00	1.87	0.38	0.15	123

#	Answer	%	Count
1	Male	14.63%	18
2	Female	83.74%	103
3	Prefer not to identify	1.63%	2
	Total	100%	123

Q2 - What is your age?

What is your age?

52

37

31

30

29

52

70

46

46

41

24

65

21

30

37

65

25

65

34

25

27

19

66

19

69

85

18

18

26

23

35

49

47

30

74

76

40

70

32

64

37

69

40

33

34

27

44

63

64

25

25

30

40

30

41

28

31

19

21

39

74

59

31

27

25

54

58

43

18

38

24

34

36

54

21

25

20

20

22

43

46

40

94

23

24

28

20

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30

29

21

56

3

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33

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68

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37

18

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26

34

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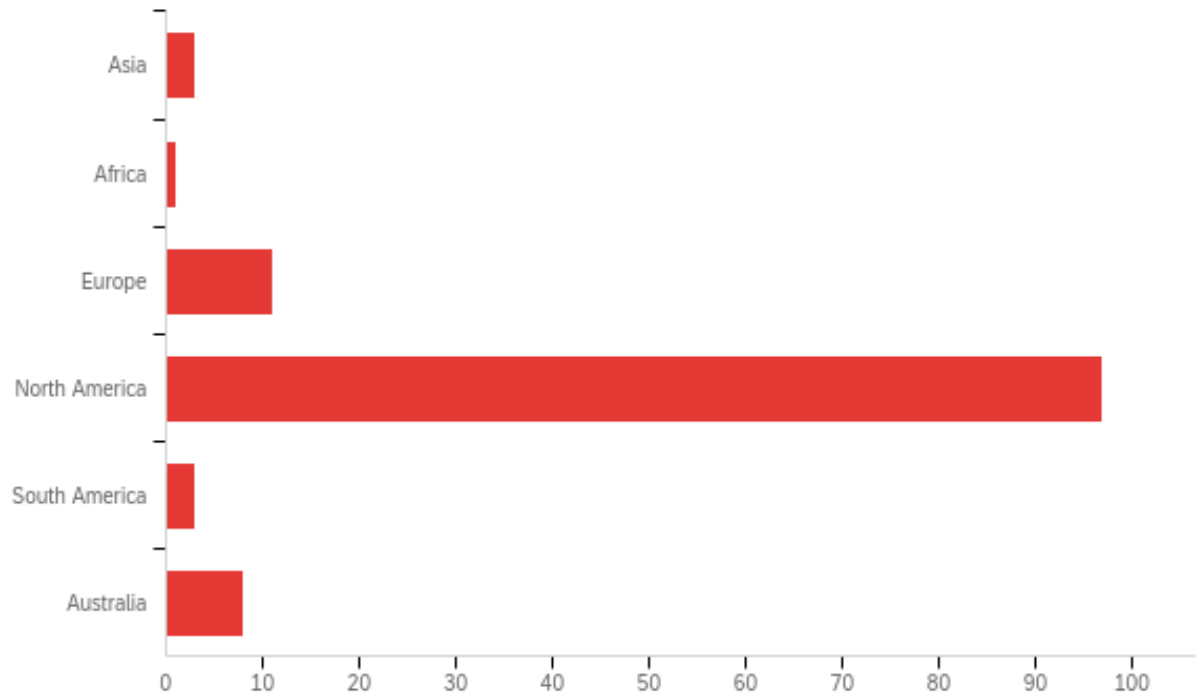
45

65

60

73

Q3 - Where do you live?

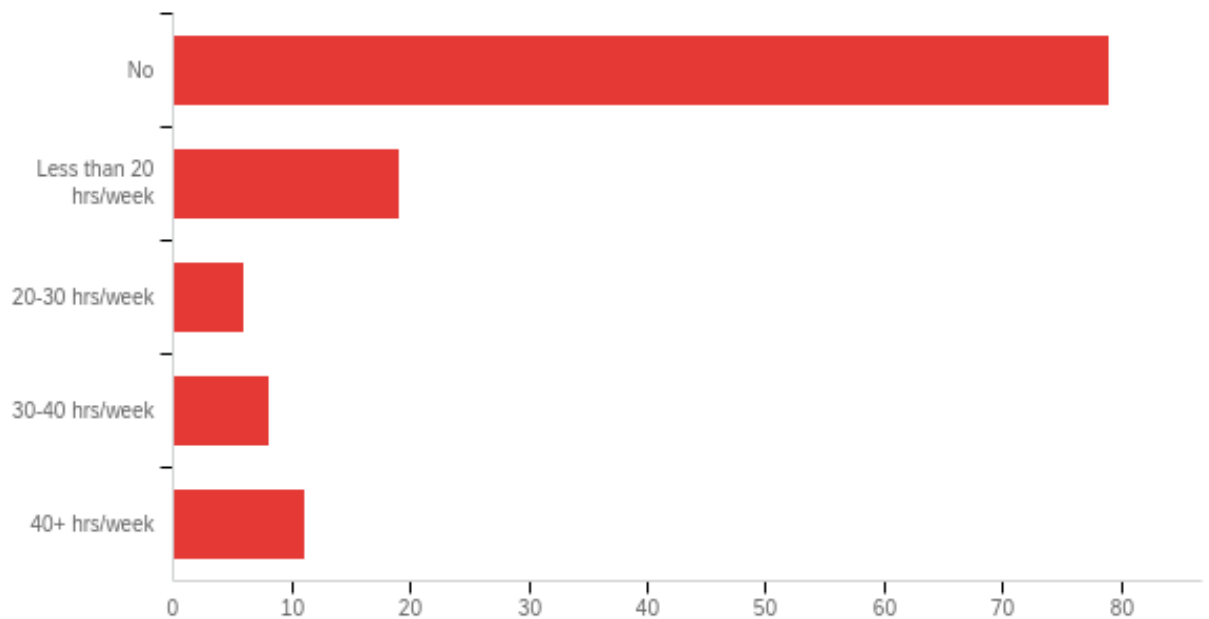


#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Where do you live?	1.00	6.00	3.98	0.79	0.63	123

#	Answer	%	Count
1	Asia	2.44%	3
2	Africa	0.81%	1

3	Europe	8.94%	11
4	North America	78.86%	97
5	South America	2.44%	3
6	Australia	6.50%	8
	Total	100%	123

Q4 - Do you work either in the workforce or self-employed?

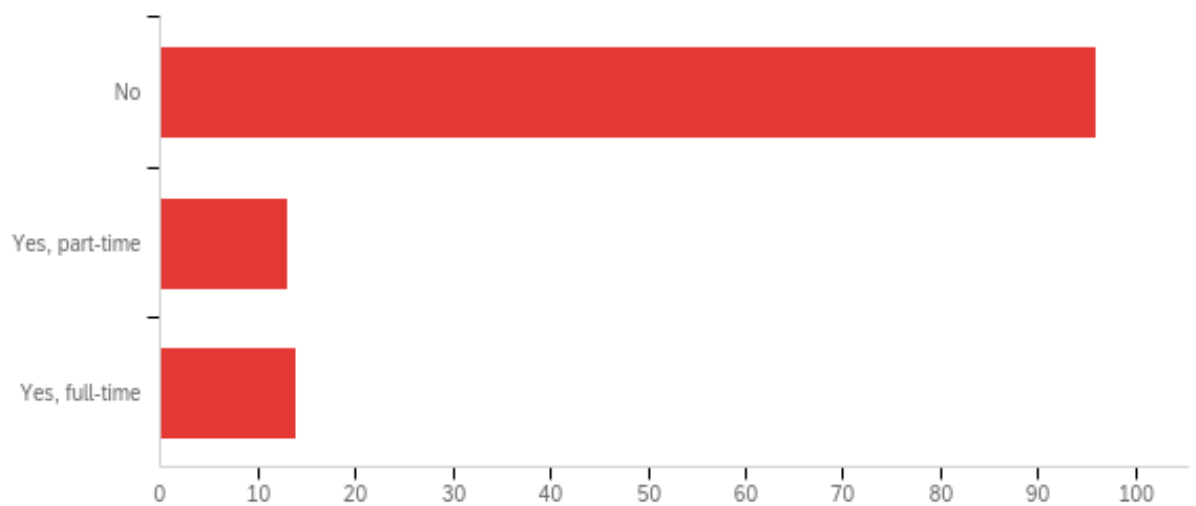


#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Do you work either in the workforce or	1.00	5.00	1.80	1.31	1.72	123

self-employed?

#	Answer	%	Count
1	No	64.23%	79
2	Less than 20 hrs/week	15.45%	19
3	20-30 hrs/week	4.88%	6
4	30-40 hrs/week	6.50%	8
5	40+ hrs/week	8.94%	11
	Total	100%	123

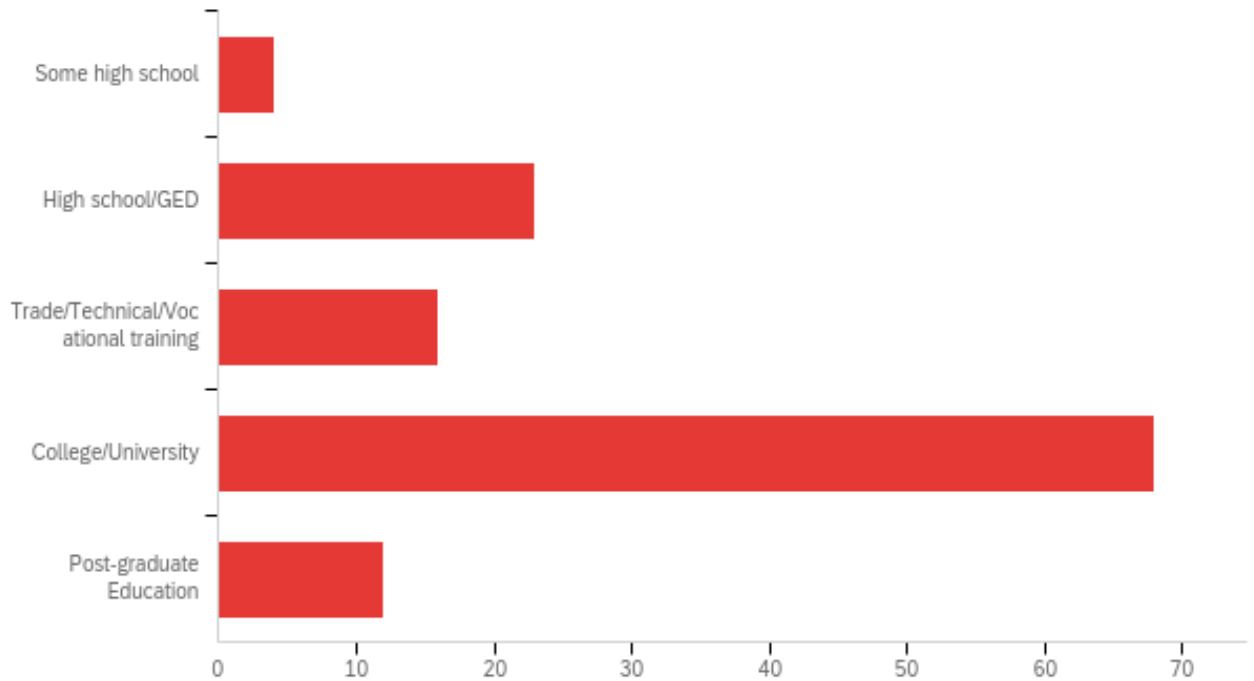
Q5 - Are you a current student?



#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Are you a current student?	1.00	3.00	1.33	0.67	0.45	123

#	Answer	%	Count
1	No	78.05%	96
2	Yes, part-time	10.57%	13
3	Yes, full-time	11.38%	14
	Total	100%	123

Q6 - Highest education level

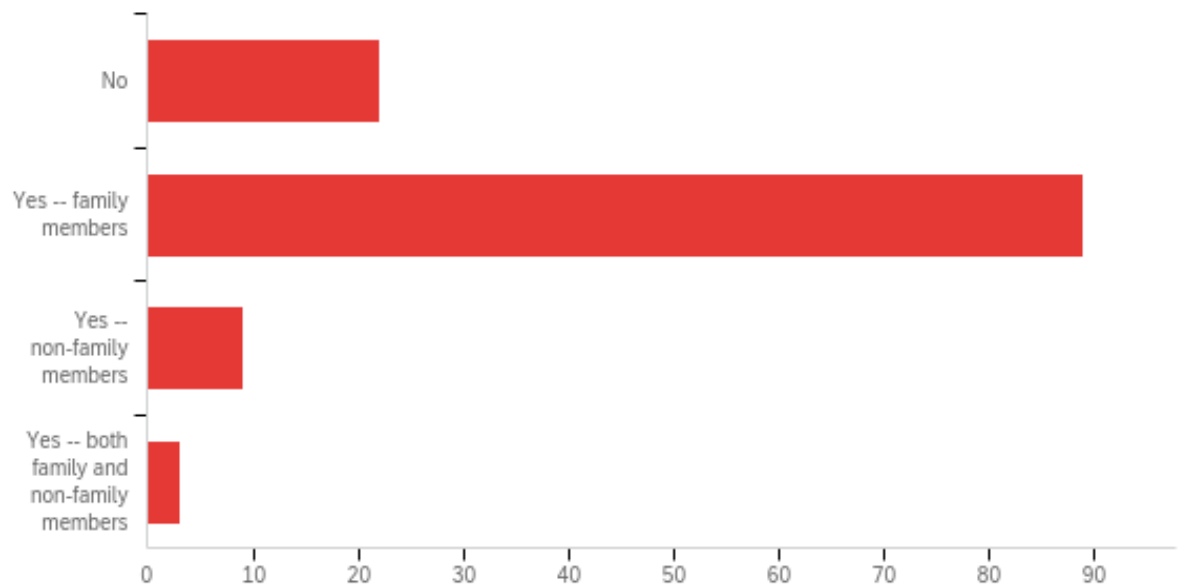


#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Highest education level	1.00	5.00	3.50	1.01	1.01	123

#	Answer	%	Count
1	Some high school	3.25%	4
2	High school/GED	18.70%	23

3	Trade/Technical/Vocational training	13.01%	16
4	College/University	55.28%	68
5	Post-graduate Education	9.76%	12
	Total	100%	123

Q7 - Do you currently reside with anyone in your place of residence?

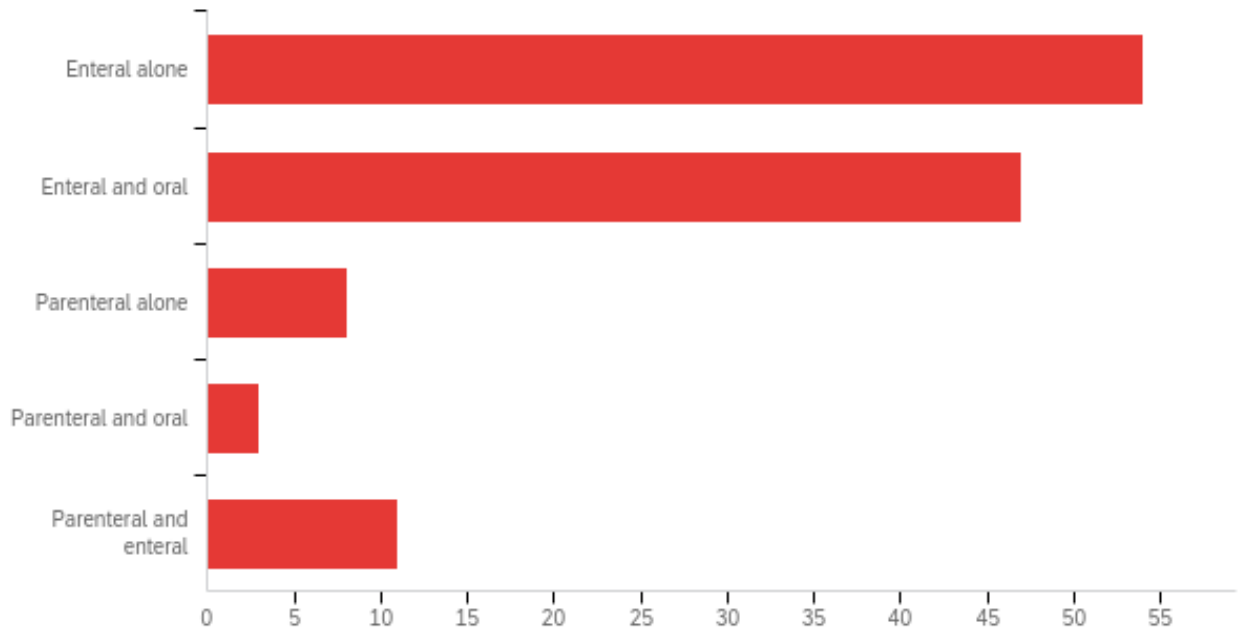


#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Do you currently reside with	1.00	4.00	1.94	0.59	0.35	123

anyone in your						
place of						
residence?						

#	Answer	%	Count
1	No	17.89%	22
2	Yes -- family members	72.36%	89
3	Yes -- non-family members	7.32%	9
4	Yes -- both family and non-family members	2.44%	3
	Total	100%	123

Q8 - Are you currently on enteral or parenteral nutrition?

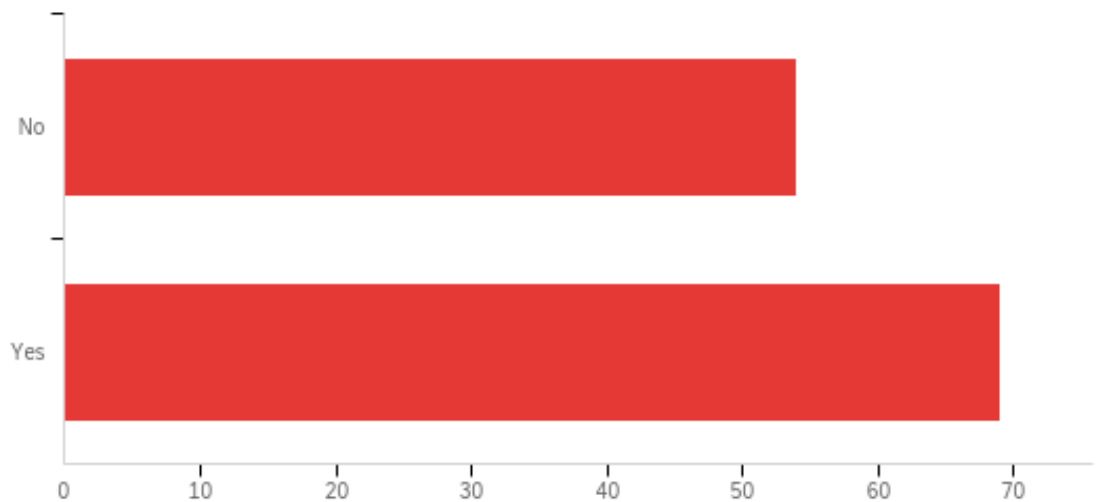


#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Are you currently on enteral or parenteral nutrition?	1.00	5.00	1.94	1.18	1.40	123

#	Answer	%	Count
1	Enteral alone	43.90%	54
2	Enteral and oral	38.21%	47

3	Parenteral alone	6.50%	8
4	Parenteral and oral	2.44%	3
5	Parenteral and enteral	8.94%	11
	Total	100%	123

Q9 - Since you have been on nutrition support therapy, have you lost contact with family and/or friends due to not being able to eat socially with others?

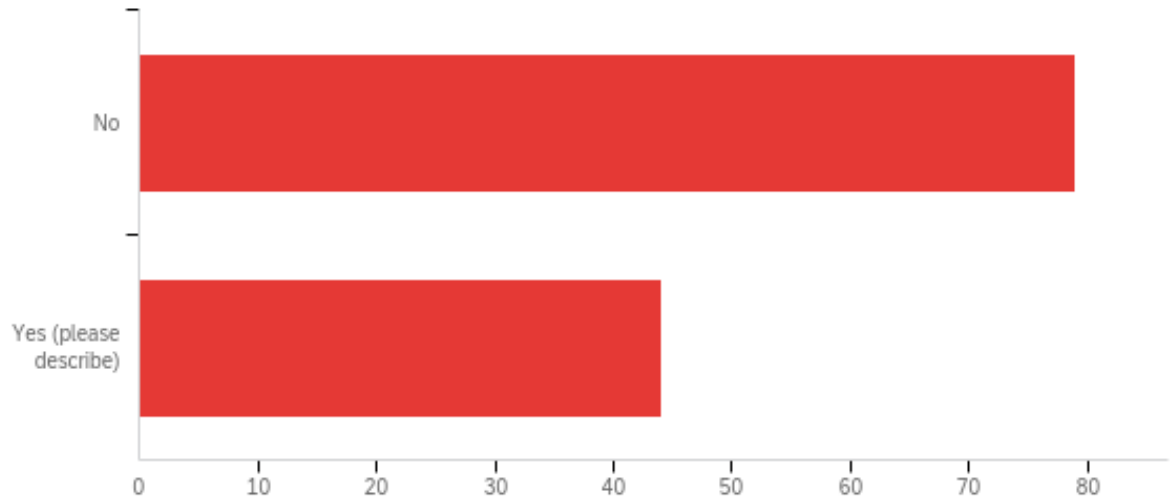


#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Since you have been on nutrition	1.00	2.00	1.56	0.50	0.25	123

support therapy, have you lost contact with family and/or friends due to not being able to eat socially with others?						
---	--	--	--	--	--	--

#	Answer	%	Count
1	No	43.90%	54
2	Yes	56.10%	69
	Total	100%	123

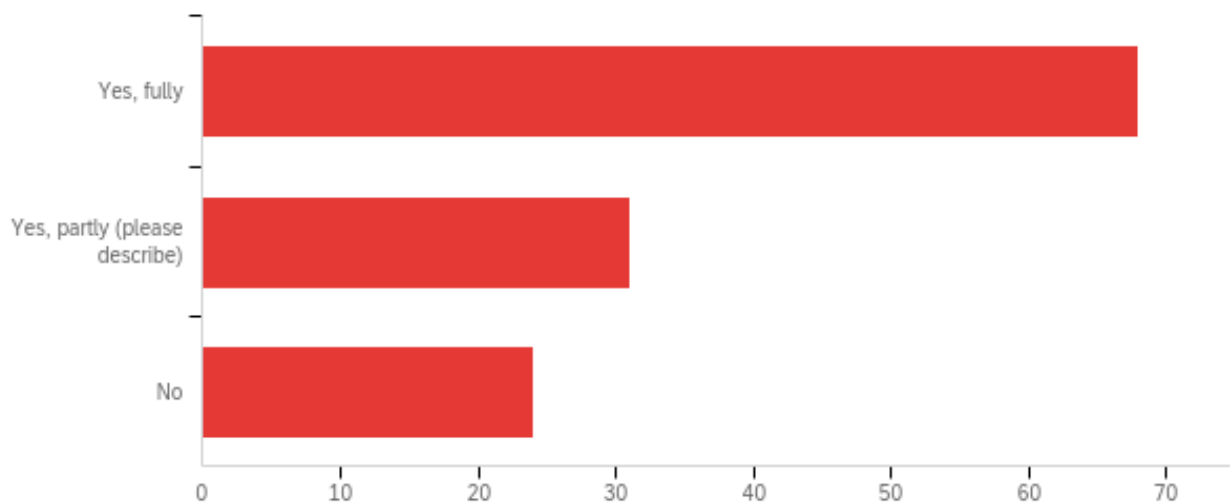
Q10 - Since you have been on nutrition support therapy, did you have to cut your work hours or quit your job?



#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Since you have been on nutrition support therapy, did you have to cut your work hours or quit your job? - Selected Choice	1.00	2.00	1.36	0.48	0.23	123

#	Answer	%	Count
1	No	64.23%	79
2	Yes (please describe)	35.77%	44
	Total	100%	123

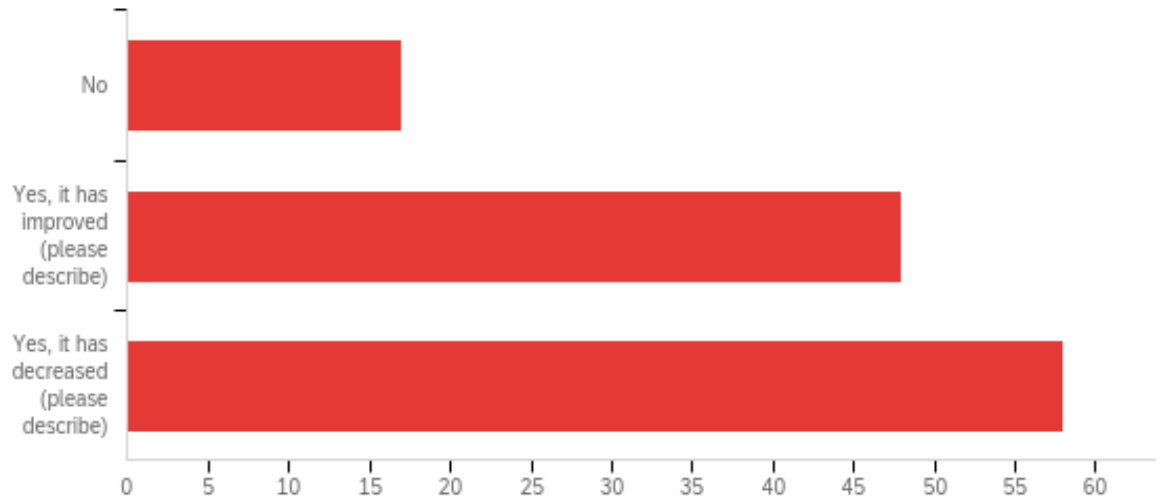
Q11 - Are your feeding and nutrition support therapy supplies covered by insurance?



#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Are your feeding and nutrition support therapy supplies covered by insurance? - Selected Choice	1.00	3.00	1.64	0.79	0.62	123

#	Answer	%	Count
1	Yes, fully	55.28%	68
2	Yes, partly (please describe)	25.20%	31
3	No	19.51%	24
	Total	100%	123

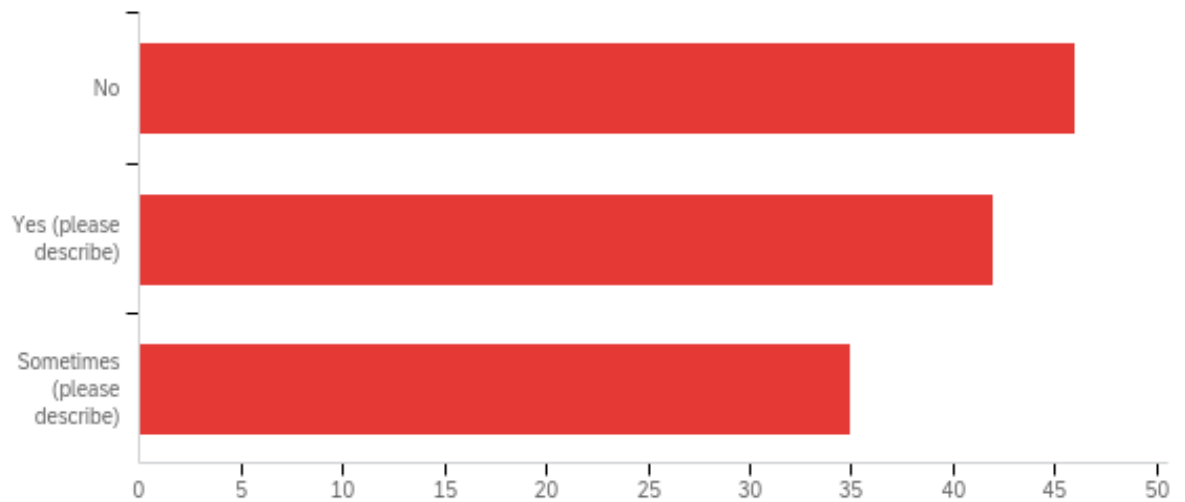
Q12 - Do you feel like your quality of life has changed since you have been on parenteral nutrition (PN) or enteral nutrition (EN)?



#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Do you feel like your quality of life has changed since you have been on parenteral nutrition (PN) or enteral nutrition (EN)? - Selected Choice	1.00	3.00	2.33	0.71	0.50	123

#	Answer	%	Count
1	No	13.82%	17
2	Yes, it has improved (please describe)	39.02%	48
3	Yes, it has decreased (please describe)	47.15%	58
	Total	100%	123

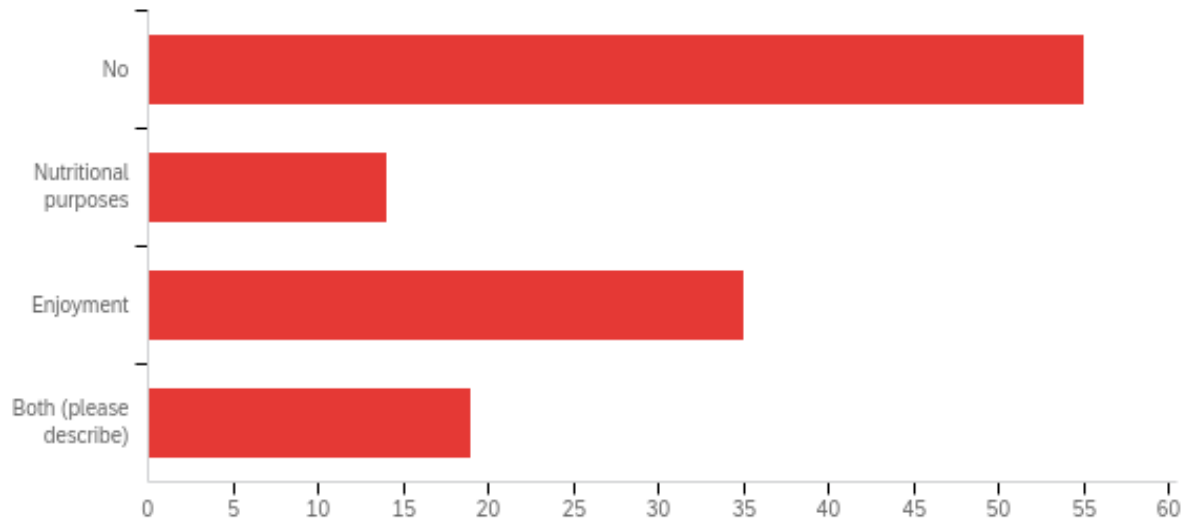
Q13 - Do you feel alone when you have problems with your PN or feeding tube?



#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Do you feel alone when you have problems with your PN or feeding tube? - Selected Choice	1.00	3.00	1.91	0.81	0.65	123

#	Answer	%	Count
1	No	37.40%	46
2	Yes (please describe)	34.15%	42
3	Sometimes (please describe)	28.46%	35
	Total	100%	123

Q14 - Are you able to eat for nutritional purpose or for enjoyment?

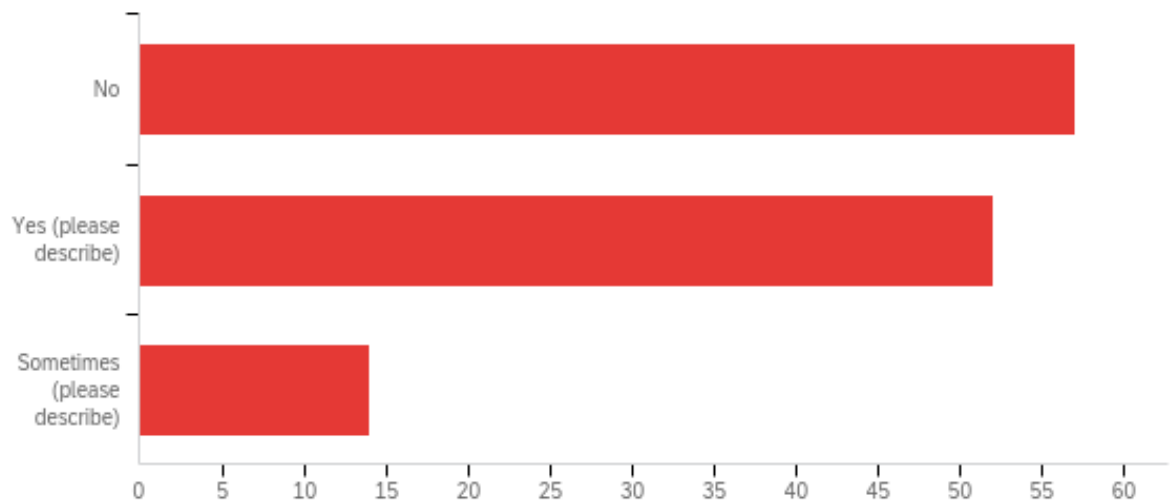


#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Are you able to eat for nutritional purpose or for enjoyment? - Selected Choice	1.00	4.00	2.15	1.15	1.33	123

#	Answer	%	Count
1	No	44.72%	55

2	Nutritional purposes	11.38%	14
3	Enjoyment	28.46%	35
4	Both (please describe)	15.45%	19
	Total	100%	123

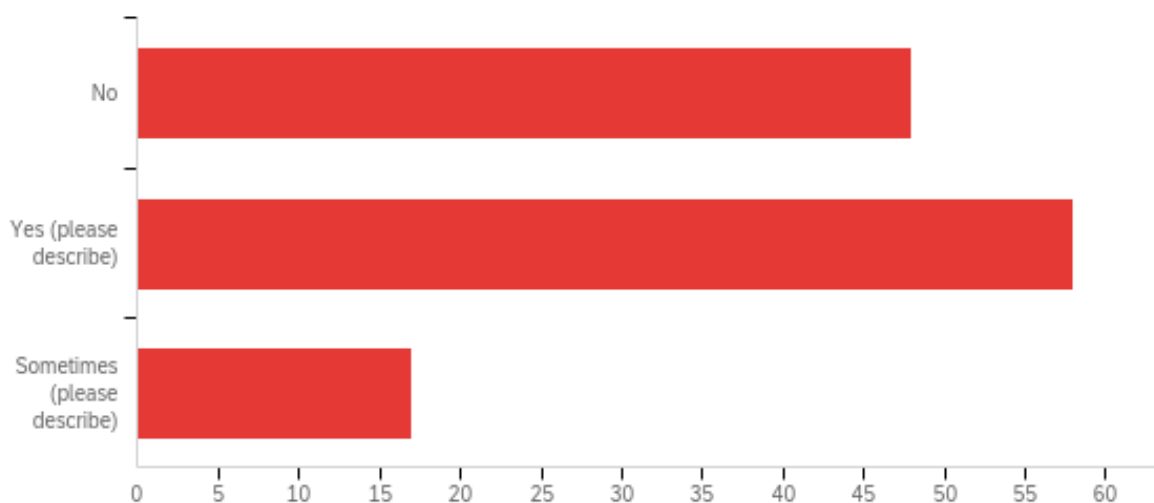
Q15 - Have you felt ashamed of not being able to eat normally?



#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Have you felt ashamed of not being able to eat normally? - Selected Choice	1.00	3.00	1.65	0.67	0.46	123

#	Answer	%	Count
1	No	46.34%	57
2	Yes (please describe)	42.28%	52
3	Sometimes (please describe)	11.38%	14
	Total	100%	123

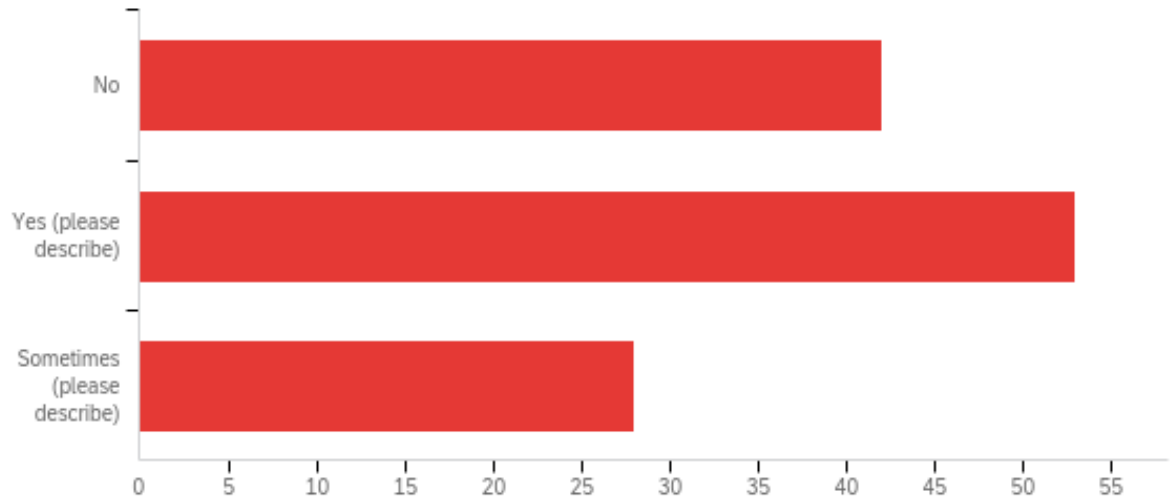
Q16 - Does your PICC line, central catheter, or feeding tube interfere with your activities of daily living (driving, running errands, bathing, cleaning, etc.) and other leisure activities?



#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Does your PICC line, central catheter, or feeding tube interfere with your activities of daily living (driving, running errands, bathing, cleaning, etc.) and other leisure activities? - Selected Choice	1.00	3.00	1.75	0.68	0.46	123

#	Answer	%	Count
1	No	39.02%	48
2	Yes (please describe)	47.15%	58
3	Sometimes (please describe)	13.82%	17
	Total	100%	123

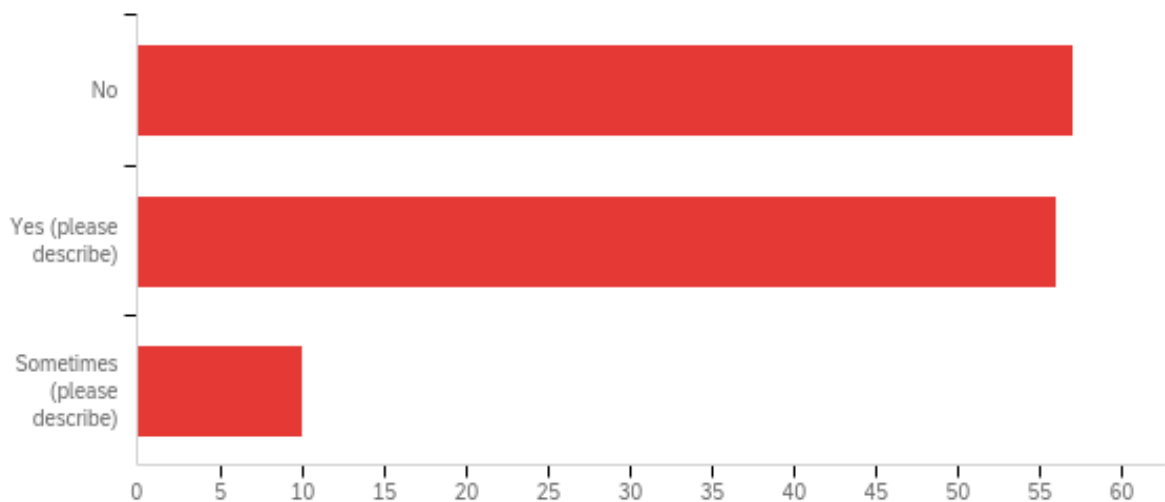
Q17 - Do you feel like your feeding tube, central catheter, or PICC line has become a burden despite being life-saving?



#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Do you feel like your feeding tube, central catheter, or PICC line has become a burden despite being life-saving? - Selected Choice	1.00	3.00	1.89	0.75	0.56	123

#	Answer	%	Count
1	No	34.15%	42
2	Yes (please describe)	43.09%	53
3	Sometimes (please describe)	22.76%	28
	Total	100%	123

Q18 - Do you experience anxiety or stress when you think about tube changes, catheter changes, or PICC line exchanges?

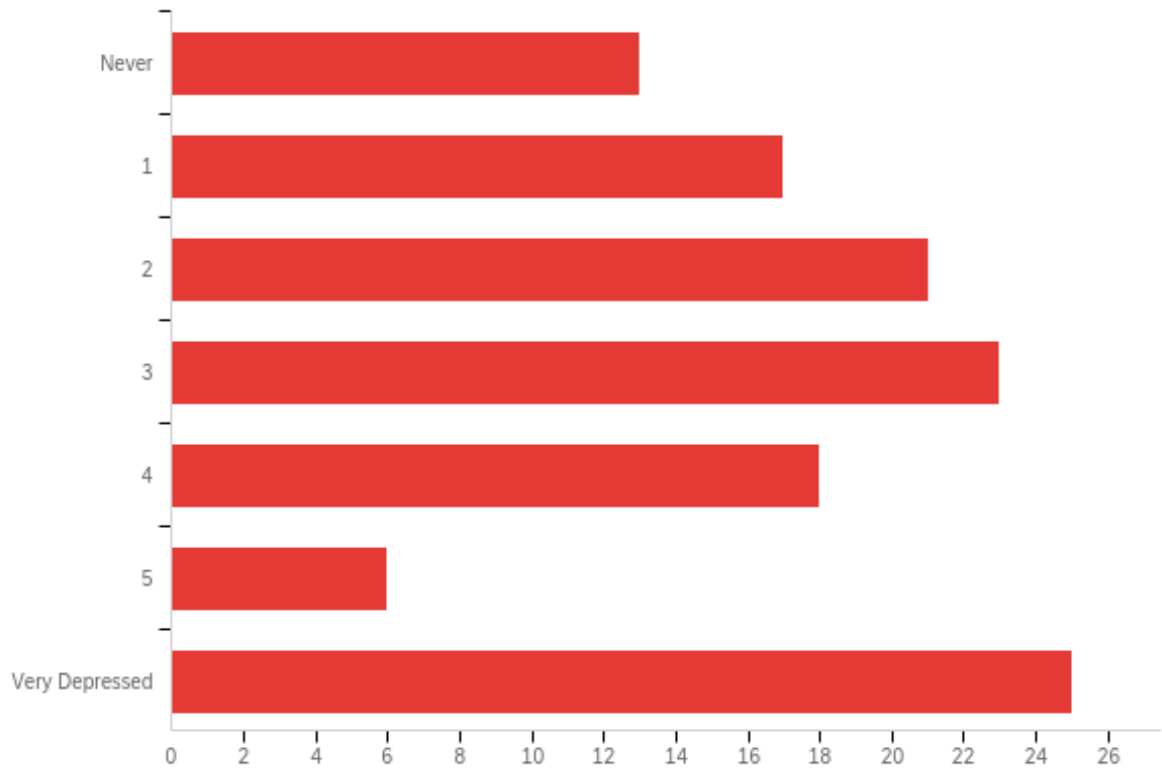


#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Do you	1.00	3.00	1.62	0.63	0.40	123

experience						
anxiety or stress						
when you think						
about tube						
changes, catheter						
changes, or PICC						
line exchanges? -						
Selected Choice						

#	Answer	%	Count
1	No	46.34%	57
2	Yes (please describe)	45.53%	56
3	Sometimes (please describe)	8.13%	10
	Total	100%	123

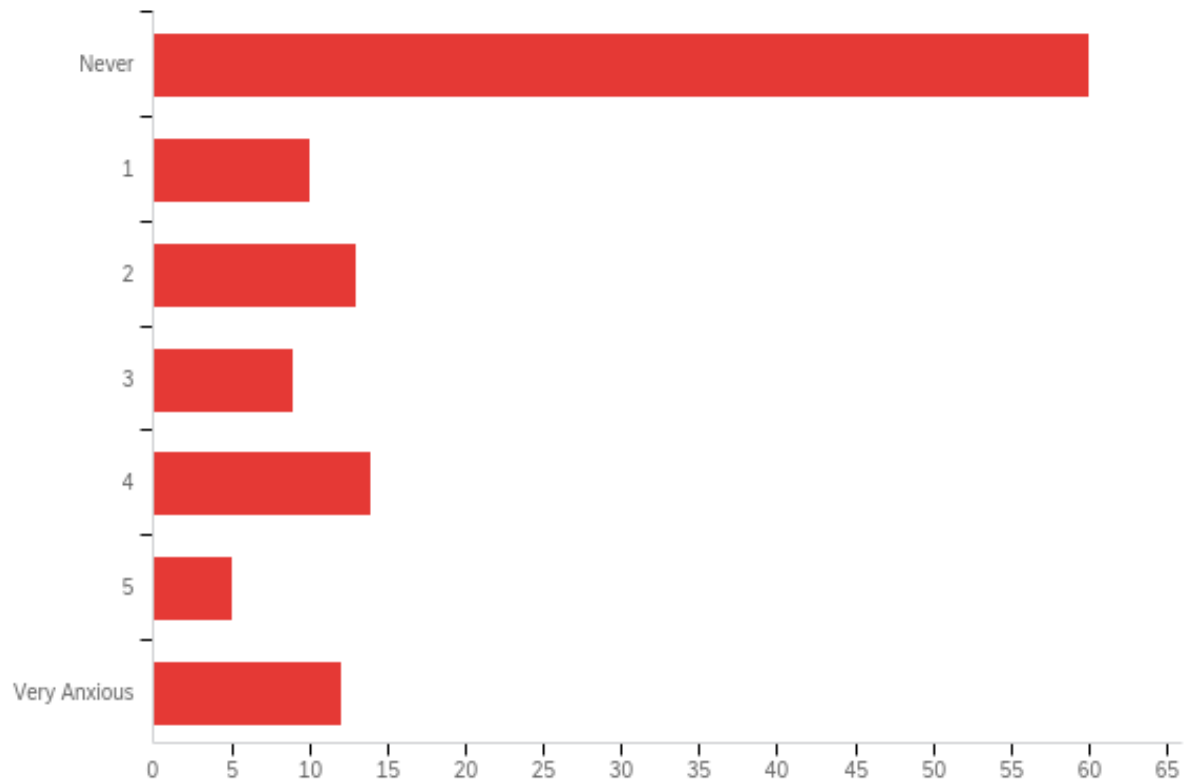
Q19 - Over the past 30 days, I have felt depressed:



#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Over the past 30 days, I have felt depressed:	1.00	7.00	4.09	1.96	3.84	123

#	Answer	%	Count
1	Never	10.57%	13
2	1	13.82%	17
3	2	17.07%	21
4	3	18.70%	23
5	4	14.63%	18
6	5	4.88%	6
7	Very Depressed	20.33%	25
	Total	100%	123

Q20 - Over the past 30 days, I have felt anxious about covering the costs of my nutrition support therapy and supplies?

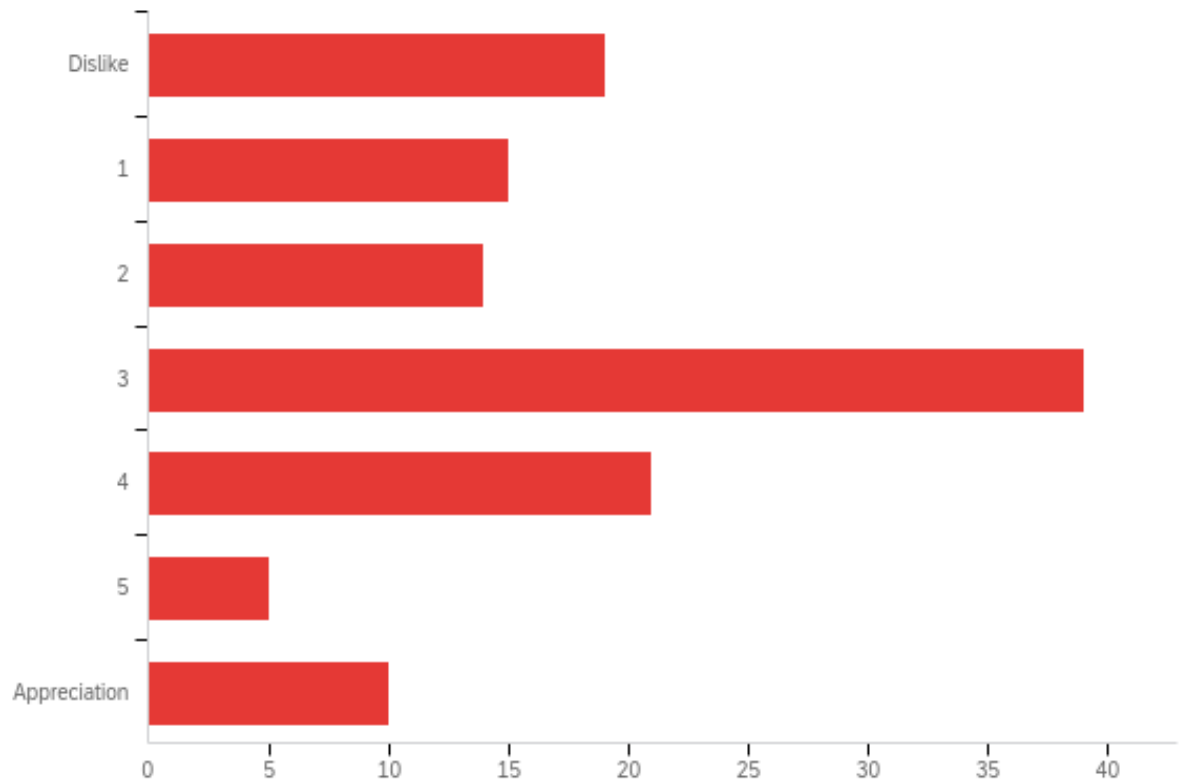


#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Over the past 30 days, I have felt anxious about covering the costs of my nutrition support therapy	1.00	7.00	2.76	2.10	4.43	123

and supplies?					
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#	Answer	%	Count
1	Never	48.78%	60
2	1	8.13%	10
3	2	10.57%	13
4	3	7.32%	9
5	4	11.38%	14
6	5	4.07%	5
7	Very Anxious	9.76%	12
	Total	100%	123

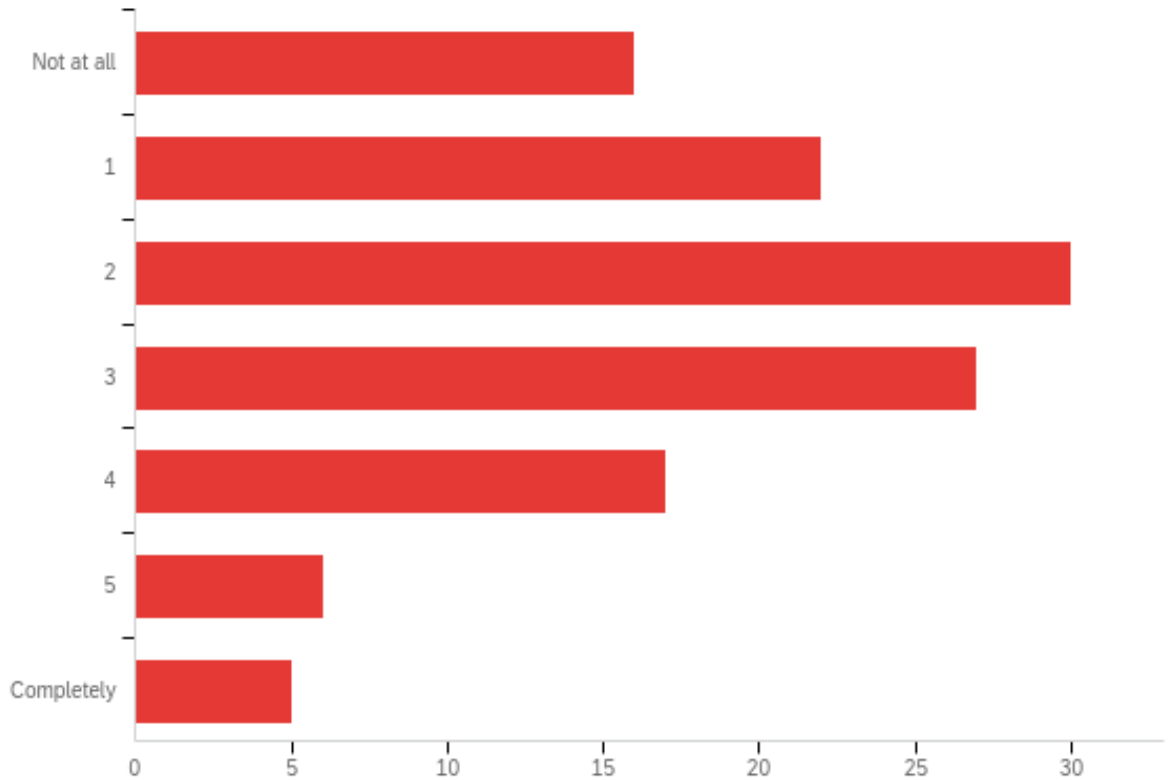
Q21 - Over the past 30 days, when I thought about my catheter or tube, I felt:



#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Over the past 30 days, when I thought about my catheter or tube, I felt:	1.00	7.00	3.67	1.72	2.95	123

#	Answer	%	Count
1	Dislike	15.45%	19
2	1	12.20%	15
3	2	11.38%	14
4	3	31.71%	39
5	4	17.07%	21
6	5	4.07%	5
7	Appreciation	8.13%	10
	Total	100%	123

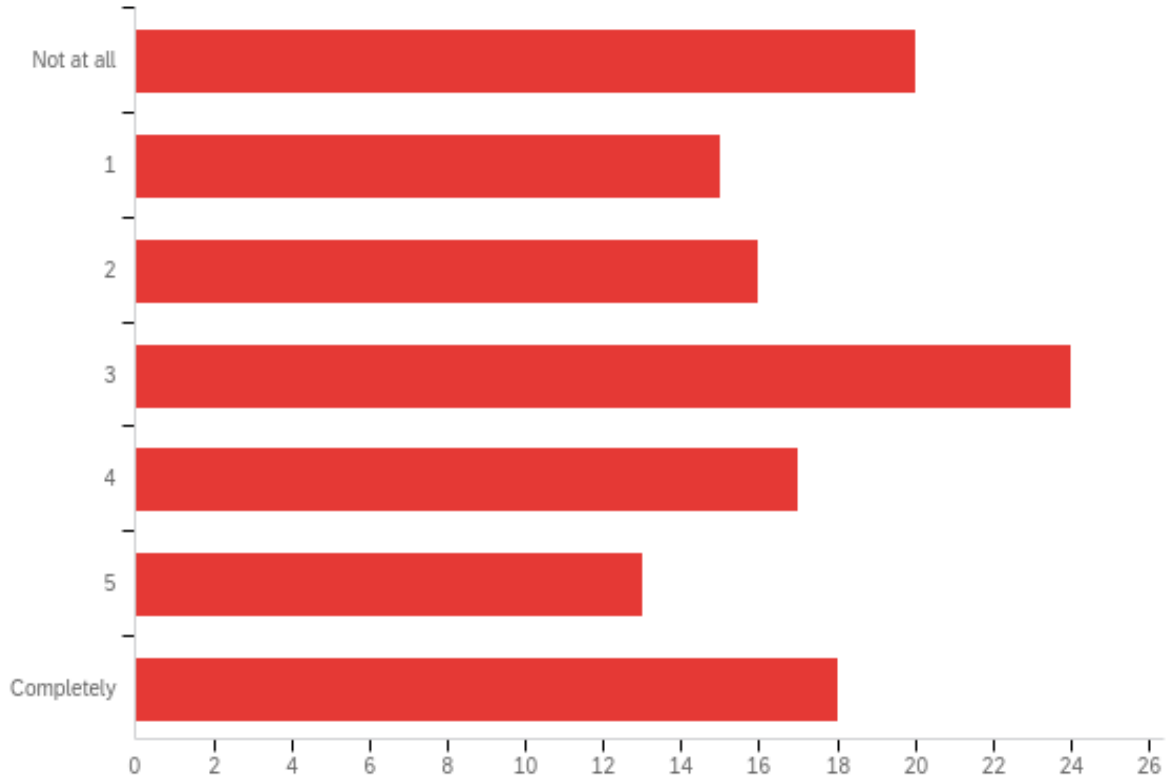
Q22 - Over the past 30 days, I felt those around understood my chronic illness and life:



#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Over the past 30 days, I felt those around understood my chronic illness and life:	1.00	7.00	3.37	1.56	2.43	123

#	Answer	%	Count
1	Not at all	13.01%	16
2	1	17.89%	22
3	2	24.39%	30
4	3	21.95%	27
5	4	13.82%	17
6	5	4.88%	6
7	Completely	4.07%	5
	Total	100%	123

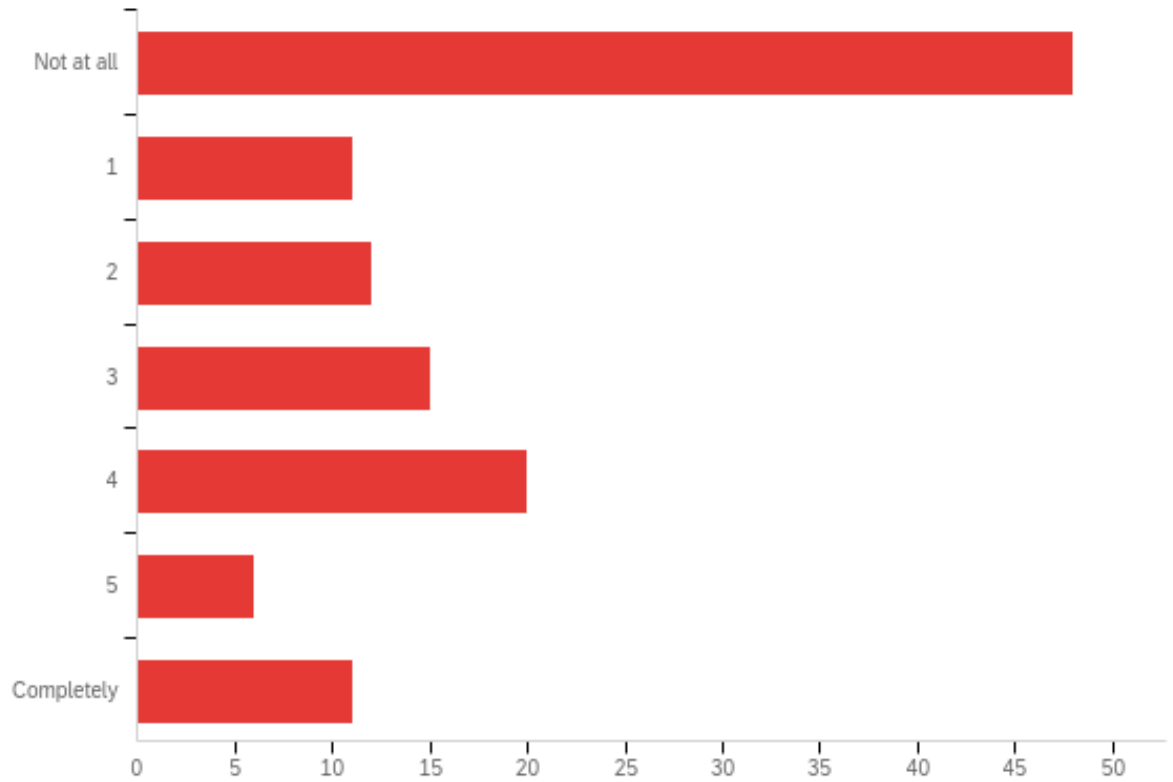
**Q23 - Over the past 30 days, I have felt depressed about my future
with PN or EN for the long-term:**



#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Over the past 30 days, I have felt depressed about my future with PN or EN for the long-term:	1.00	7.00	3.93	1.99	3.95	123

#	Answer	%	Count
1	Not at all	16.26%	20
2	1	12.20%	15
3	2	13.01%	16
4	3	19.51%	24
5	4	13.82%	17
6	5	10.57%	13
7	Completely	14.63%	18
	Total	100%	123

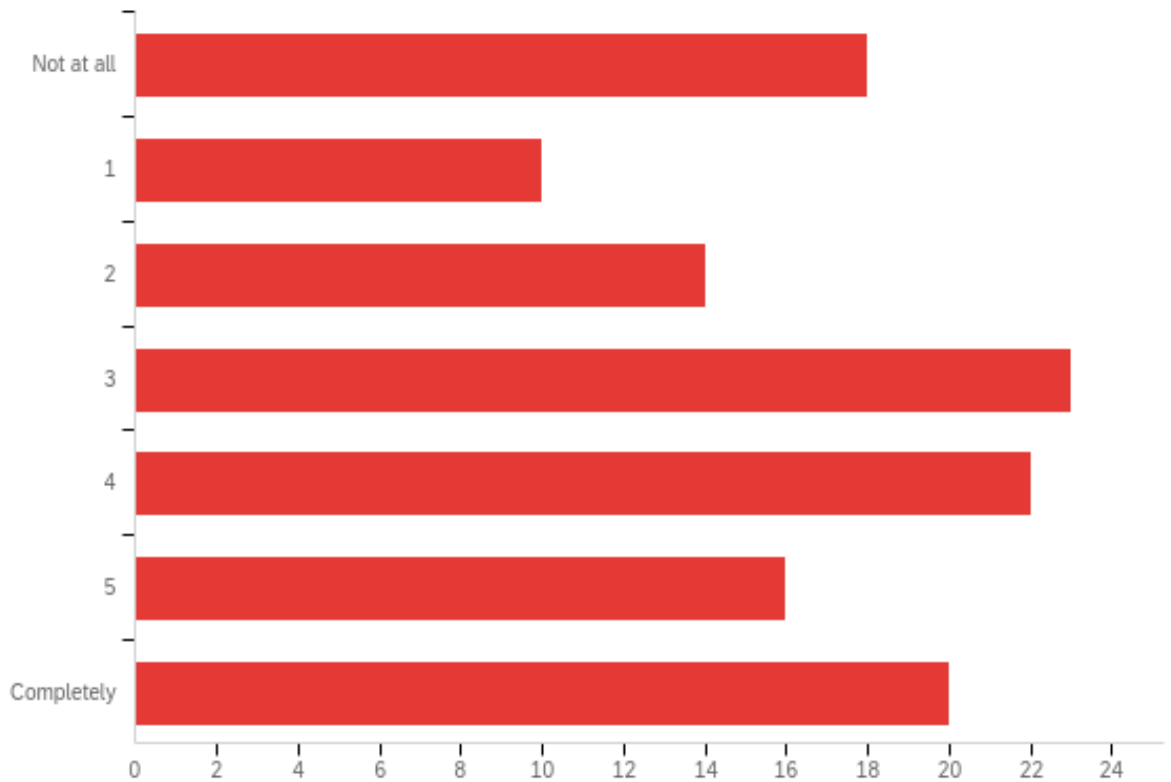
**Q24 - Over the past 30 days, I have resented my family and friends
for their ability to eat:**



#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Over the past 30 days, I have resented my family and friends for their ability to eat:	1.00	7.00	3.08	2.07	4.29	123

#	Answer	%	Count
1	Not at all	39.02%	48
2	1	8.94%	11
3	2	9.76%	12
4	3	12.20%	15
5	4	16.26%	20
6	5	4.88%	6
7	Completely	8.94%	11
	Total	100%	123

Q25 - Over the past 30 days, I have felt alone and lost when it comes to my illness and feeding tube:



#	Field	Minimum	Maximum	Mean	Std Deviation	Variance	Count
1	Over the past 30 days, I have felt alone and lost when it comes to my illness and feeding tube:	1.00	7.00	4.21	1.97	3.87	123

#	Answer	%	Count
1	Not at all	14.63%	18
2	1	8.13%	10
3	2	11.38%	14
4	3	18.70%	23
5	4	17.89%	22
6	5	13.01%	16
7	Completely	16.26%	20
	Total	100%	123

Appendix C - Relevant Text

Q10 - Since you have been on nutrition support therapy, did you have to cut your work hours or quit your job?

- Tire very easily and don't have the energy I once had. Tube feedings need to be done as many hours a day as possible.
- Cut back hours since my body couldn't handle.
- I just no longer have the energy to work, and I need to be running feeds, but I'm too self conscious to run it at work.
- I just can't manage what I used to - total fatigue.

Q11 - Are your feeding and nutrition support therapy supplies covered by insurance?

- Had to fight to get correct formula covered and often have to buy my own supplies.
- Medicare pays a portion of food and supplies.
- I have to meet deductible of \$2000 first, then pay 20% of everything until the out of pocket max is met for my policy.

Q12 - Do you feel like your quality of life has changed since you have been on parenteral nutrition (PN) or enteral nutrition (EN)?

- Improved my nutrition but makes everything else worse.
- Mostly improved, but there should be a both option. I am no longer slowly starving to death and in a state of severe malnutrition, but it also impacts my daily life, activities I used to do, and my self-image.
- More nutritionally stable, although socially excluded and hampered by feeding regime.
- I've lost the joy in eating and the social activities around eating. I don't like to go on vacations anymore or gather anywhere where there's food. The grief is overwhelming.
- My health is better but my mental health is much much worse.
- Lost self esteem and friends.

Q13 - Do you feel alone when you have problems with your PN or feeding tube?

- I don't feel comfortable talking about issues with family and friends and often it's the middle of the night and I am alone and have been sick and tube has displaced and I feel really ill.
- I struggle to find a doctor or nurse to listen and help with issues.
- Very little support and each time I ask to meet with the nutrition team I get voicemails and calls back days later.

- Never know who to turn to or who I can vent to.
- My husband is very understanding. And I am in groups online. But it can be very isolating, yes. It's not a very "normal thing."
- I have a Facebook group that is very helpful but most people don't understand the problems...not even all Drs get it.

Q14 - Are you able to eat for nutritional purpose or for enjoyment?

- I can't eat a lot. It takes too long and I still aspirate. Mostly to eat socially and to enjoy flavors.
- Only on rare occasion for enjoyment...a couple bites.
- Some days it's less for nutrition more for enjoyment.

Q15 - Have you felt ashamed of not being able to eat normally?

- Most of the time especially when people tends to ask you reason on why I am on feeding tube.
- Eating normally is just what everyone expects and assumes everyone is capable of so it can be hard when that's not your norm.
- I feel awkward. Everyone feels awkward. I feel like I'm not part of normal society. I can't take part in normal conversations about food and where to eat etc.

- When I am in the company of others that are not aware of my G I Issues, I pick at food or say I am not hungry.
- Just feels weird when presented with food, but not able to eat it.
- Its weird on holidays like Thanksgiving.

Q16 - Does your PICC line, central catheter, or feeding tube interfere with your activities of daily living (driving, running errands, bathing, cleaning, etc.) and other leisure activities?

- Simply moving around the house tied to the pump makes everything harder.
- I have a feeding tube and port and my port interferes with showers and my FT is hard to run errands with.
- I am almost always uncomfortable to some degree. It affects how I move and what exercise I can do. I feel embarrassed during sexual encounters. I do not feel safe swimming anymore, especially at lakes.
- My j tube makes it impossible for me to hula-hoop, do gymnastics (bars, it gets caught) and hurts when I move in certain ways. It makes shopping more difficult as I have an extra backpack I have to wear now. Same issue with going to classes at school as I have to carry two backpacks.

Q17 - Do you feel like your feeding tube, central catheter, or PICC line has become a burden despite being life-saving?

- 18 hours a day being tied to this pump is a burden.
- Can't do much due to the pain. Would rather have it out and have a few months doing what I want than spend most of my life trying not to move.
- I question several times a week whether it is worth it to continue living with a tube. I have lost a lot in my life so far because of it.
- It can crash on you mentally if not already physically.
- I am forever thankful for it. But it does make me feel isolated. I miss being able to eat with friends and dinners. So much social life revolves around food.

Q18 - Do you experience anxiety or stress when you think about tube changes, catheter changes, or PICC line exchanges?

- Have PTSD from cautious NJ tube placement and changes and now have to be sedated to get them. Started having panic attacks on the table.
- It is expensive and uncomfortable.
- During Covid, it is additional exposure. Most anxiety relates to the timing...I can see and feel the tube getting weaker, but do I get it changed today, next week? Will insurance cover it today?
- I have medical trauma.
- Tube changes are painful, so I hate doing them.

Appendix D - IRB Approval Form



TO: Linda Yarrow
Food, Nutrition, Dietetics, and Health
206 Justin Hall

Proposal Number: 10318

FROM: Rick Scheidt, Chair

A handwritten signature in black ink, appearing to be "Rick Scheidt", is written over a horizontal line.

Committee on
Research Involving Human Subjects

DATE: 11/25/2020

RE: Proposal Entitled, "A Comprehensive Evaluation on Quality of Life For Persons Living on Enteral Nutritional and/or Parenteral Nutrition."

The Committee on Research Involving Human Subjects / Institutional Review Board (IRB) for Kansas State University has reviewed the proposal identified above and has determined that it is EXEMPT from further IRB review. This exemption applies only to the proposal - as written – and currently on file with the IRB. Any change potentially affecting human subjects must be approved by the IRB prior to implementation and may disqualify the proposal from exemption.

Based upon information provided to the IRB, this activity is exempt under the criteria set forth in the Federal Policy for the Protection of Human Subjects, **45 CFR §104(d), category: 2, subsection:ii.**

Certain research is exempt from the requirements of HHS/OHRP regulations. A determination that research is exempt does not imply that investigators have no ethical responsibilities to subjects in such research; it means only that the regulatory requirements related to IRB review, informed consent, and assurance of compliance do not apply to the research.

Any unanticipated problems involving risk to subjects or to others must be reported immediately to the Chair of the Committee on Research Involving Human Subjects, the University Research Compliance Office, and if the subjects are KSU students, to the Director of the Student Health Center.