

Relationships Among Home Parenteral Nutrition, Food and Eating, and Quality of Life

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Introduction: The value of food and eating on social patterns, self-esteem, pleasure, and nutritional status is not considered in most generic quality of life (QOL) tools. Similarly, none of the QOL instruments used in prior studies of home parenteral nutrition (HPN) specifically address the importance of food and eating. While HPN provides the basic need for nutrients, its impact on other human needs associated with food requires further investigation. The aim of this research was to explore the meaning of food and eating from the perspective of adults receiving HPN as their primary form of nourishment and to describe how living with HPN and the ability to eat influences QOL.

Methods: The research design was qualitative using content and interpretative phenomenological analysis. A purposeful sampling strategy was used to enroll adults with intestinal failure and HPN dependency. Sampling continued until data saturation was achieved. Semi-structured interviews were conducted by telephone, transcribed verbatim, and uploaded into a computerized assisted program (NVIVO). A second reviewer coded a sub-sample of narratives. Intercoder agreement was >80%.

Results: The sample included 24 adults with short bowel syndrome (95%) and pseudo-obstruction (4%). The length of remnant small bowel was 56.6 ± 40.3 cm. The length of HPN dependency was 8.1 ± 8.2 years. HPN was viewed as a lifeline and nutritional safety net. Most participants experienced reduced pressure to eat once beginning HPN and expressed relief knowing HPN was meeting their nutrition and hydration needs. Participants defined good quality as "being able to eat what I want, when I want". All participants were able to eat. Factors interfering with eating and food enjoyment included pain, intractable diarrhea, physician orders not to eat, restrictive diets, a perception of wasting money, and poor health. Participants described being thirsty as far worse than being hungry. Three themes emerged from the data analysis: (1) eating for survival, (2) eating for health benefits, and (3) eating for socialization. Participants described how eating prior to HPN was a desperate and futile attempt to sustain themselves with oral food and fluid resulting in weight loss and poor QOL. While receiving HPN, participants chose healthy foods with an expectation of receiving immune benefits, promoting intestinal adaptation, and sustaining hope and optimism that HPN could eventually be discontinued. Participants described strategies for restaurant eating and creating positive social experiences with family and friends whether they were eating or not.

Conclusions: Being able to eat and enjoy food was an important component of good QOL. HPN helped participants maintain weight and strength without the pressure of having to eat to survive. Eating strategies were employed to minimize gastrointestinal pain and diarrhea. A healthier orientation around food was adopted. Satisfaction was

achieved from cooking, providing food for others, and participating in family events. Social isolation was not evident as participants recognized the importance of being together regardless of whether or not they ate a “normal” meal. Nutritional counseling should include not only the nutrient content of food and management of diarrhea, but the social and emotional aspects of food and eating.

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