Introduction

A person's identity and the self-image they construct are based on everyday interactions and life experiences. Part of this identity involves how people think of themselves, how they see others, and how they view the world around them. This includes aspects such as illness, treatment, and quality of life. People's experiences of being ill, either in childhood or adulthood, can shape their individual identities and self-perceptions. This study aimed to explore these meanings 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 and try to get as many calories in as I could, but I wasn't making it."

Methods

Recruitment: Self-referral via announcements to HPN programs, home infusion providers, and The Oley Foundation.

Purpose Sampling Strategy: Adults 18 + years receiving HPN because of intestinal failure excluding adults with depression or receiving palliative care.

Participants: Enrolled until achievement of data saturation.

Verbal consent; informed and assured confidentiality and anonymity.

Audio taped telephone interviews

Semi-structured interview (open-ended questionnaire; cognitively reviewed and pilot tested).

Open-ended communication and extensive probing.

Verbatim transcription and analysis.

Computer assisted data management (NVivo).

Current and interpretable phenomenological analysis.

Simultaneous independent review by RN Clinician; strong inter-rater agreement (Cohen's Kappa = 0.850).

Factors Influencing Eating and Food Enjoyment

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Themes and Representative Quotations

Pleasure Outweighs Expense

"I used to feel … like it's a wasted expense to eat out, but now I just figure if I get a couple of meals out of it, sometimes I even get three meals that isn't too bad."

"I can take the food. It feels good going down. Just mentally thinking and eating myself, what a waste of money."

"I still go to a restaurant, sit down and eat, and then excuse myself, go to the bathroom and upchuck."

"There are some days I am absolutely ravenous and then a day or two will go by and I can care less."

"About once a day I will have a period of time that only lasts about an hour or two at the most where I get really hungry and I always try to act on it if I can."

"I think you have to feed your mind, your spirit, and your body. If you go out and have a blast at a restaurant with good friends or family and you eat food, and you relax and I get that emptiness... and I feel better from it."

"It [TPN] gives you great security because I know that the TPN is doing everything that needs to be done. I rely on that and relax and eat what I want."

"If I eat, it's more just because I know I'm supposed to eat or should eat…"

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"I walk a fine line. My body has walked a very fine line since I've started TPN, of feeling slightly dehydrated and comfortably hydrated."

"If I eat, it's more just because I know I'm supposed to eat or should eat…"

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Eating Because of Hunger or Time to Eat

"At one time I was eating about 100 calories an hour or so before I would go to sleep and then again after I got up in the morning."

"I tend to eat before I go to bed and then I have my intermittent fasts."

"I can take the food. It feels good going down. Just mentally thinking and eating myself, what a waste of money."

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Eating Being Thirsty or Hungry

"Some people say I eat too much. It bothers me a little because a dry mouth is pretty much the only way it is."

"I tend to eat before I go to bed and then I have my intermittent fasts."

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Strategies for Restaurant Eating

"I order appetizers instead of an entree, wine with a spouse or friend."

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Conclusions

1. Being able to eat and enjoy food is an important component of QOL.

2. Parenteral nutrition was viewed as a “nutritional safety net” and helped participants maintain weight and strength without the pressure of having to eat to survive.

3. The burden of eating to survive was pronounced in individuals who had short bowel syndrome due to Crohn’s disease and radiation enteritis. This burden should be considered in the decision making process of initiating and weaning PN.

4. Diarrhea had no “rhyme or reason” despite pharmacological and nutritional management.

5. Cooking provided a sense of control and was a source of pleasure.

6. Nutritional counseling should focus on the social and emotional aspects of food and eating as well as fulfilling nutritional requirements and management of GI symptoms with restrictive diets.

7. A home parenteral nutrition-specific QOL instrument should include a domain to address the importance of food and eating.

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1 Rhode Island Hospital, 2 Alpert Medical School of Brown University, 3 University of Kansas, and 4 University of Medicine and Dentistry of New Jersey.