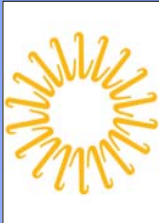




Relationships Among Home Parenteral Nutrition, Food and Eating, and Quality of Life

Marion F. Winkler PhD RD^{1,2}, Terrie Wetle PhD², Carol Smith RN PhD³, Julie O'Sullivan Maillet PhD RD⁴
and Riva Touger-Decker PhD RD⁴

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



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 construct life experiences around food. Social roles individuals assume in life, such as mother (nurturer) and spouse (caregiver and/or wage earner) are connected to food. Food not only has physical dimensions but psychological and emotional attributes as well. Eating involves more than food intake and fulfilling nutritional requirements; it evokes pleasurable phenomena such as taste, smell, and socialization. The meaning of food for individuals who receive home parenteral nutrition (HPN) has not been extensively explored. Similarly, 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 used in studies of HPN. We previously reported the definition of QOL perceived by adults receiving HPN as, "enjoying life", "being happy and satisfied with life", and "being able to do what you want to do when you want to do it". The description of "good" QOL by these same individuals included "being able to eat what I want, when I want". While HPN provides the basic need for nutrients, its impact on other human needs associated with food requires further investigation.

Purpose

The purpose 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

- Recruitment: Self-referral via announcements to HPN programs, home infusion providers, and the Oley Foundation.
- Purposeful 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 obtained; confidentiality and anonymity assured.
- Audio taped telephone interviews
- Semi-structured interview template; cognitively reviewed and pilot tested.
- Open-ended communication and extensive probing.
- Verbatim transcription of interviews.
- Computer assisted data management (NVIVO).
- Content and interpretative phenomenological analysis.
- Simultaneous independent review by RN Clinician; strong inter-rater agreement (Cohen's Kappa = 0.684)
- Participant feedback and expert clinician review of themes and findings.
- Research journal and study audit trail maintained.
- IRB approval: Rhode Island Hospital and the University of Medicine & Dentistry of New Jersey, Newark.

Example of Coding Process

Word, Phrase, Passage	Code(s)	Category	Theme
"I don't feel pressure to eat to live because I know that the TPN is doing everything that needs to be done. I rely on that and relax and eat if I want to or not." "You know for sure you're getting all your vitamins..." "It [TPN] gives you great security"	Security	Meaning of home parenteral nutrition	Nutritional safety net

Interview Questions

1. Tell me your story of what it is like to be on PN at home?
2. What does the term quality of life mean to you? How would you describe your own quality of life?
3. Tell me about memories you have of food and eating events from childhood or adulthood.
4. Tell me about the community where you live(d). Did you have any cultural, ethnic, or religious rituals or customs that involve food?
5. Tell me about a time in your life that a particular food or meal gave you a source of pleasure.
6. What is your role in the family in relation to food and meal preparation?
7. What can you tell me about your experience with eating since your diagnosis and need for PN?
8. Tell me about your experiences eating out in restaurants or in other social situations.

Results

Study Participants (n=24)

	n	%		n	%
Diagnosis					
Pseudo-Obstruction	1	4.2	Education	6	25.0
Short Bowel Syndrome	23	95.8	High School & Some College	4	16.7
Crohn's or IBD	8	34.8	Associate Degree	1	4.2
Extensive Bowel Resection	5	21.7	Bachelor Degree	7	29.2
Trauma or Ischemia	5	21.7	Graduate Degree	4	16.7
Radiation Enteritis	5	21.7	Medical School	2	8.3
Ostomy Present	12	50.0	Employment		
Gender			Part Time	4	16.7
Female	18	75.0	Full Time	3	12.5
Male	6	25.0	Retired	5	20.8
Race			Disability	11	45.8
White	22	91.7	Medical Leave of Absence	1	4.2
Other	2	8.3	Geographic Distribution		
Marital Status			Midwest	10	41.7
Married	18	75.0	Northeast	8	33.3
Not Married	6	25.0	South	4	16.7
Oley Foundation Involvement	13	54.2	West	2	8.3

	Mean ± SD	Range
Age (years)	54.3 ± 10.9	28 – 68
Residual Small Bowel (cm)	56.6 ± 40.3	20 – 137
HPN Dependency (years)	8.1 ± 8.2	0.25 – 26
PN Daily Volume (ml)	2322 ± 714	1200 – 4000
PN Infusion (days)	6.3 ± 1.3	2 – 7
PN Infusion (hours)	12.3 ± 3.5	9 – 24
Interview Length (minutes)	66.2 ± 14.0	38 – 90

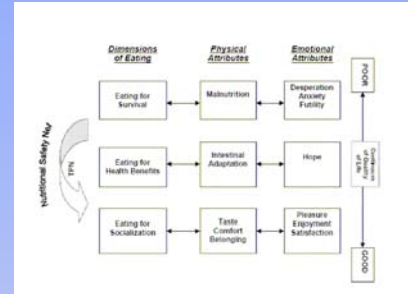
Factors Influencing Eating and Food Enjoyment

- ~ abdominal pain – intractable diarrhea – physician orders not to eat ~
- ~ restrictive diet – poor health – sensory pleasure from cooking ~

Themes and Representative Quotations

Perceived Wasted Expense of Eating	<p>Expense Outweighs Benefit</p> <p>"Just to go out and spend dollars for a giant portion of food that I'll only eat half of at most, to me just doesn't make sense." "I can taste the foods. It tastes good going down. I just mentally keep thinking and telling myself, what a waste of money." "When I feel like I'm not getting my money is when part way through the meal I have to go throw up. That's when I feel like it's been a real waste of money." Pleasure Outweighs Expense</p> <p>"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 ... then that's not so bad." "Sometimes we go out and eat a nice meal and I think in about 2 hours that was foolish because it's all gone. But it satisfies my palate ... and my husband says don't worry about it, you enjoyed it while you [were] eating." "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 happen to lose what you just ate, you only lost the food, and hopefully not too much electrolytes, but what you gained ... [is] a good time with your friends." "I still go to a restaurant, sit down and eat, and then excuse myself, go to the bathroom and urchback."</p>
Eating Because of Hunger or Time to Eat	<p>Hunger</p> <p>"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 get hungry. There are times when I'm just starving and I [have to] eat something." Time to Eat</p> <p>"It's not that I'm really starved or anything, it's just time to eat, so I'd better eat something." "First of all you soon learn that meals punctuate the day and if you don't eat you don't have that punctuation any more to mark the passage of events or time." "If I eat, it's more just because I know I'm supposed to eat or should eat..."</p>
Being Thirsty is Worse than Being Hungry	<p>"Sometimes my eyeballs get dry. That bothers me a lot but having a dry mouth is pretty much the way it is..." "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." "I would get thirsty and I would really guzzle, but it's the fluid that goes through you, so sometimes ... in the car I always have a bottle of water. It try to do it, take a nice big sip and savor it instead of just guzzling, guzzling."</p>
Strategies for Restaurant Eating	<ul style="list-style-type: none"> • Eat at buffets or smorgasbords because "you get a little of everything." • Order an appetizer instead of an entrée; share with a spouse or friend. • Request a doggy bag. • Bring half home and eat the next day.

A Model of the Relationship between Food, Eating, and Quality of Life



This figure, based on themes emerging from the data analysis, illustrates the meaning of food as perceived by home PN dependent adults. The curved arrow on the far left depicts the overarching theme, how participants perceived home PN as a "lifeline and nutritional safety net". The dimensions of eating in the first column on the left side of the figure portray: (1) Eating for Survival, (2) Eating for Health Benefits, and (3) Eating for Socialization. The next two columns depict physical attributes of eating and emotional attributes experienced by participants. Moving from left to right, the physical aspect of eating for survival was linked to malnutrition and feelings of desperation, anxiety, and futility. Healthy eating was linked to an expectation of promoting intestinal adaptation with the hope that PN dependency could be reduced. Eating for socialization was linked to belonging and taking part in social gatherings and was reported by participants as important, even if they were only eating for taste. The continuum of QOL, spanning from poor to good QOL, is depicted on the far right. Eating for survival was strongly expressed with poor QOL because of the inability to work or participate in desirable activities due to diminished strength, weight loss, and malnutrition. Eating for socialization was reported together with improved QOL because of the ability to participate in family, holiday, and community gatherings.

Eating for Survival

"I could never catch up and of course I was never absorbing anything. I was losing weight and I was thirsty all the time, and if I tried to drink something I was desperate. You can only be thirsty for so long ... it's brutal and you're exhausted ... The whole thing was an absolute nightmare."

"When I was off TPN I was trying to force-feed myself [because] it was survival and then I was not hungry all the time. I'd make eggs and throw cheese in it and try to get as many calories in as I could, but I wasn't making it."

"I was still having the output. I still wasn't able to eat enough during the day. I could reduce my TPN [to] 3 days a week but it was still always running in a deficit, and then I would have to play catch-up ... we could never quite find that middle road [because] I'd lose so much."

Eating for Health Benefits

"Eat whatever goes down good because whatever you eat keeps your immune system good and healthy."

"Just putting something in your stomach, it helps for everything down there. It may not make you always feel the best but I've made a conscious effort to try."

"I try to stay on some sort of reasonable diet in terms of trying to get nutrition out of food ... I never know how much of anything I'm going to absorb ... I love vegetables and so I attempt them more than anything else and salads and I pay dearly for those ... but there are times when I want something green."

Eating for Socialization

"I host Christmas for both sides of the family and I don't eat much but that's fine, it's just having everyone together and they all enjoy it."

"When you take food out of the equation of a social event you really appreciate the social interactions more."

"Being together, it's part of the ambience of being together, the social part of it, not just the food per se but the whole social part of it."

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 "rhyne or reason" despite pharmacological and nutritional management. Achieving pleasure and satisfaction from small amounts of food and hope for intestinal adaptation was more important to participants than trying to control diarrhea and GI symptoms with restrictive diets.
5. Cooking provided sensory pleasure and satisfaction even when food was not consumed.
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.
7. A home parenteral nutrition-specific QOL instrument should include a domain to address the importance of food and eating.

Acknowledgements

- Financial disclosures: none
- Supported by the Department of Surgery, Rhode Island Hospital, Providence RI.
- This work was conducted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Health Sciences, University of Medicine and Dentistry of New Jersey, School of Health Related Professions.