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*JPEN J Parenter Enteral Nutr* published online 17 March 2014

DOI: 10.1177/0148607114527134

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# A Qualitative Study of the Perceived Value of Membership in The Oley Foundation by Home Parenteral and Enteral Nutrition Consumers

Journal of Parenteral and Enteral  
Nutrition  
Volume XX Number X  
Month 201X 1–8  
© 2014 American Society  
for Parenteral and Enteral Nutrition  
DOI: 10.1177/0148607114527134  
jpen.sagepub.com  
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## Abstract

**Background:** Support and educational organizations have been shown to improve quality of life of consumers of home nutrition support. One such organization, The Oley Foundation, offers resources for the home parenteral and enteral nutrition (HPEN) consumer. While research has shown proven benefits to HPEN consumers affiliated with The Oley Foundation, no studies have investigated the perceived value of membership to the consumer or the way in which consumers are introduced to the organization. **Methods:** Qualitative methodology was used to gain a deeper understanding of the perceived value of membership in The Oley Foundation. Audiotaped, in-depth, semistructured telephone interviews were conducted to explore participants' experiences with The Oley Foundation and HPEN. Inductive content analysis was used to analyze data and identify themes associated with membership value. **Results:** The value of The Oley Foundation lies in programs and resources and the competency, inspiration, normalcy, and advocacy gained from membership, helping individuals adjust to life with HPEN dependency. More than half of participants found the organization through self-initiated Internet searches, but all participants clearly expressed the desire "I wish I knew about it sooner." **Conclusion:** This study identifies the value of membership in The Oley Foundation and the important role the organization has in the lives of HPEN-dependent consumers. Nutrition support clinicians should introduce the organization to patients when the need for HPEN is established and prior to hospital discharge. (*JPEN J Parenter Enteral Nutr.* XXXX;xx:xx-xx)

## Keywords

home parenteral nutrition; home enteral nutrition; quality of life; qualitative research

## Clinical Relevancy Statement

This research provides a deeper understanding of the value gained through membership in The Oley Foundation for home parenteral and enteral nutrition (HPEN) consumers. The competency, inspiration, normalcy, and advocacy attained assist consumers in overcoming many challenges associated with HPEN. Nutrition support clinicians could play a key role in introducing their patients to educational and support organizations, such as The Oley Foundation, to help them adjust to this complex therapy.

## Background

Individuals receiving home parenteral nutrition (HPN) and home enteral nutrition (HEN) face many physical and psychological challenges in coping with their disease state as well as challenges in their continual reliance on nutrition support. Physical complications such as infections, metabolic abnormalities, and intolerance issues affect consumers of home parenteral and enteral nutrition (HPEN).<sup>1,2</sup> Psychosocial factors include coping with medical diagnoses, being dependent on technology, the loss of

the eating experience, reliance on others for care, low self-esteem, interference with sexual function, and the financial burden of nutrition support.<sup>2,3</sup> All of these factors present potential challenges to the HPEN consumer. While the technology and associated burdens may make life difficult for the HPEN consumer, there are resources available to help cope with these obstacles.

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Financial disclosure: None declared.

M. W. serves on the board of trustees of The Oley Foundation as a volunteer. K. C. conducted this study in partial fulfillment of the degree of Master of Science at the University of Rhode Island.

Received for publication September 10, 2013; accepted for publication February 13, 2014.

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Organizations that provide information and social support offer resources that may help to improve quality of life (QOL) for the HPEN consumer. While there are several social media sites for this type of support, many HPEN consumers participate in the activities of The Oley Foundation. The Oley Foundation is a nonprofit organization that provides up-to-date educational materials and social support for consumers of HPEN. The use of *consumer* is the preferred terminology of members of The Oley Foundation since these individuals do not view themselves as patients and believe they have choice with respect to their nutrition and health care. The Oley Foundation currently has 12,500 members, including clinicians and families of HPEN consumers.<sup>3</sup> By “informing, connecting and supporting,” The Oley Foundation hopes to improve QOL for all consumers of HEN and HPN.<sup>3</sup>

Support and educational organizations have been shown to improve QOL in consumers of HPEN, but little is known about the perceived value of these services.<sup>2,4,5</sup> The aim of this study was to gain a greater understanding of the perceived value of membership in The Oley Foundation and to learn more about consumers’ introductions to the organization.

## Methods

This study used qualitative methodology to explore how HPEN consumers value membership in The Oley Foundation. The Oley Foundation was selected because it is a nonprofit organization for HPEN consumers, families, caregivers, and clinicians, and to our knowledge, after an extensive review of the Department of Health and Human Services healthfinder.gov website, it is the only consumer/patient organization dedicated to HPEN in the United States. Meaning was derived from the data through inductive content analysis. This analysis is based on the development of categories designed to capture dominant themes from each interview.<sup>6,7</sup> Semistructured, audio-recorded telephone interviews were used to elucidate perceptions and emotions participants have toward their Oley Foundation membership and their experiences with HPEN.<sup>8</sup> In-depth telephone interviews previously have been used to document experiences in similar populations.<sup>2,5</sup> The interview questions were developed after an extensive literature review and were revised after evaluation by colleagues with expertise in qualitative research and home nutrition support. A pilot interview was conducted to evaluate the purpose, intent, and clarity of each question. The data from this pilot interview were not included in the results of the study.

By using a structured interview guide, questions and probes prompted the participants to give a verbal summation of their experiences with HPEN, their involvement in The Oley Foundation, and how best to introduce this organization to new consumers. Demographic information was collected prior to concluding each interview if not previously disclosed and included type of nutrition support therapy, medical diagnosis, length of time dependent on HEN or HPN, age, sex, number of

people in the household, geographic location, employment status, school enrollment, and highest education level achieved. Excel (2007; Microsoft, Redmond, WA) was used for descriptive statistical analysis.

Recordings of each interview were transcribed verbatim, deidentified, and saved as Word documents and uploaded into a computer-assisted data management program (Nvivo, QSR International PTY Ltd, 2012, Melbourne, Australia). Transcripts were read several times and analyzed with an open coding scheme in which words and phrases were organized into groups and categorized to identify similar concepts and emerging themes to conceptualize the value of membership in The Oley Foundation. A theme reflected ideas repeatedly heard across many or all interviews. Relevant quotations pertaining to each theme are presented in the Results section. An ellipsis (. . .) is used to indicate omitted words or phrases, and brackets [ ] are used to designate words added for clarity.

Trustworthiness and credibility of the data were established by seeking negative or contradictory examples with probes and by providing supporting examples for conclusions drawn (ie, direct quotations).<sup>9</sup> Five interviews were coded by 2 study investigators (K.C. and M.W.); substantial intercoder agreement was established with Cohen’s  $\kappa$  coefficient of 0.842.<sup>10</sup> The  $\kappa$  coefficient was calculated using SPSS version 20 (SPSS, Inc, an IBM Company, Chicago, IL). Based on the high level of agreement determined by the  $\kappa$  coefficient, the remaining interviews were coded by a single investigator (K.C.). A written summary of each transcript was emailed to each participant as an initial member check and was discussed during a follow-up call. A member check allows the participant to review the data provided by their interview to ensure accuracy and to illuminate any nuances overlooked or misinterpreted by the interviewer.<sup>6</sup>

## Sampling Strategy

This study used a purposive homogeneous sampling method to recruit participants.<sup>11</sup> Announcements were made on The Oley Foundation’s website and through email blast to members. Study candidates self-selected to participate by contacting the study’s email address. Eligibility criteria included English-speaking adults older than 18 years who were dependent on HPEN and had joined the organization within the past 2 years. The criterion that the participants had joined within the past 2 years was set so that they would better recall their introduction. Sample size was determined based on previous qualitative studies using in-depth interviews with HPEN consumers.<sup>4,5,12</sup> The target sample was established at 6–10 HPN consumers and 6–10 HEN consumers. Participants gave verbal informed consent by telephone. The institutional review boards of Rhode Island Hospital and the University of Rhode Island as well as the research committee of The Oley Foundation approved all procedures and materials.

**Table 1.** Demographic Characteristics of Study Participants.

Demographic Characteristics	Home Enteral Nutrition (n = 7)	Home Parenteral Nutrition (n = 7)
Years on HPEN, mean $\pm$ SD (range)	5.3 $\pm$ 8.8 (0.83–25)	11.1 $\pm$ 12.2 (0.75–31)
Female sex, %	57.1	57.1
White race, %	85.7	100
Age, mean $\pm$ SD (range), y	36.7 $\pm$ 13.3 (22–61)	39.9 $\pm$ 10.2 (27–58)
Employed, %	28.6	42.9
Enrolled in school, %	14.3	14.3
Highest level of education (n)	Some college (2) Associate's degree (1) Bachelor's degree (3)	Bachelor's degree (3) Master's degree (1) Doctoral degree (1) Not reported (2)
Geographic location (n)	Maine (1) Massachusetts (1) New York (1) Ohio (2) Virginia (1)	Florida (1) Iowa (1) New Jersey (1) New York (1) Ohio (2) Utah (1)
Medical diagnosis <sup>a</sup> (n)	Amyotrophic lateral sclerosis (1) Crohn's disease (1) Gastrointestinal dysmotility (1) Gastroparesis (3) Parkinson plus syndrome (1)	Chronic intestinal pseudo-obstruction (2) Crohn's disease (1) Gastrointestinal dysmotility (1) Gastroparesis (1) Intestinal failure (2)
People in the home, mean $\pm$ SD (range)	1.7 $\pm$ 1.8 (0–5)	2.1 $\pm$ 1.2 (1–4)

HPEN, home parenteral and enteral nutrition.

<sup>a</sup>There are 7 diagnoses for both home enteral nutrition and home parenteral nutrition because 1 participant received both therapies.

## Results

A total of 22 participants responded to recruitment emails and 13 were selected to participate. The remainder was excluded because they were not HPEN dependent or data saturation occurred. The study sample included 1 HPEN, 6 HPN, and 6 HEN consumers receiving therapy for  $6.9 \pm 9.9$  years (range, 0.75–31 years). The most frequent medical diagnosis of participants receiving HEN was gastroparesis (50%), while participants receiving HPN most frequently had chronic intestinal pseudo-obstruction (33.3%) or intestinal failure (33.3%). Study participants were not under the care of any of the investigators and lived in 9 different states. Demographic characteristics of the study sample are shown in Table 1. The average length of time of the interviews was  $29 \pm 9.6$  minutes (range, 16–47 minutes).

### Valuable Programs and Resources

Study participants identified a wide range of programs and resources that were described as helpful, important, or valuable (Table 2). HPN and HEN participants were very similar in the way in which they talked about their experience with The Oley Foundation, and most appreciated the wealth of available resources and networking. Examples of the frequency in which

participants connected with the organization included bookmarking the website, visiting the site regularly, and checking email daily. The primary sentiment expressed was that The Oley Foundation should be the “go-to source” for HPN and HEN information. More than half of the participants (59%) belonged to at least one other group. These groups included Inspire or Facebook (n = 4) and disease-specific organizations such as the Gastroparesis Patient Association for Cures and Treatments, the Association of Gastrointestinal Motility Disorders, and the Crohn's and Colitis Foundation of America (n = 4).

### Perceived Value of Membership

Four main themes (competency, inspiration, normalcy, and advocacy) and 10 subthemes related to the value of membership in The Oley Foundation emerged from the data analysis (Table 3). Participants described a feeling of competence, that they had adequate knowledge, skills, or experience to manage their lives on HPEN. It was common for participants to describe how they used materials from The Oley Foundation to educate themselves, especially when they believed they did not receive adequate discharge education. HEN consumers more commonly discussed the lack of discharge education. For example, one participant explained, “We literally did a crash

**Table 2.** Perceived Value of Oley Foundation Programs and Resources by Home Parenteral and Enteral Nutrition Consumers.

Program/Resource	Representative Quotation
Newsletter	“They have articles, they have a bimonthly newsletter . . . where you get to see that you’re not the only person that has this problem.”
Educational material	“The educational materials, how to clean your feeding tube, how to take care of it, little tricks, gimmicks that you can use to . . . have a better life with your feeding tube.”
Email	“I kind of get excited every time I get an email from them. I know that sounds corny but it’s something that kind of helps me through the process more or less.”
Restaurant card	“They sent me some cards that I can carry with me so that when I go out in public with my family to a restaurant . . . I can give the waitress a card and let them know that I’m not eating and why I’m not eating.”
Social media	“It’s been really helpful getting information and knowing that other people are on tube feeds . . . I mean I’ve never personally met anyone else on tube feeds but . . . just getting information through the forum.”
Social support	“As a network, to meet other people who I could call and meet, people who have a central line, and see what life’s like with that.”
Equipment and supply exchange	“The supply exchange, that’s helped me because I was going on a formula trial and my supply company would only send me a couple to try.” “I had this formula but I couldn’t send it back so . . . I was able to send it to people that needed it, who didn’t have insurance coverage.”
Conference	“[If I attend], I’ll be hearing things, and . . . just being able to go and seeing all these people with backpacks and tubes coming out and things like that. . . . It’s kind of just a normal thing and to meet different people.”

**Table 3.** Value of Membership in The Oley Foundation.

Theme	Subthemes
1. Competency	1. Providing tools to manage care 2. Making personal medical decisions 3. The consumer as an educator
2. Inspiration	4. Sharing experiences 5. Seeing that others can do it
3. Normalcy	6. Sense of community 7. Helping others 8. “I am not alone” 9. HPEN does not need to impede life
4. Advocacy	10. Consumer advocate

HPEN, home parenteral and enteral nutrition.

course on Oley that night . . . if it wasn’t for Oley we wouldn’t have known what to do.” Similarly, participants described finding helpful instructions specific to brand-name catheters and tubes as well as equipment and supplies. This new knowledge helped consumers build competency in providing self-care for HEN and HPN.

In describing problem solving, several participants stated that receiving information from their peers was beneficial, noting that when healthcare professionals “don’t always have the answer to a question,” what they liked about The Oley Foundation was how they can “pull together kind of the wisdom of just the common folk” (ie, sharing personal experiences about HPN and HEN). Others appreciated reading scientific and health-related materials that were “technical

enough to be helpful and simple enough to be understandable.” Participants discussed sharing information from The Oley Foundation with others, including children, family and friends, and clinicians. They described using materials to better help them explain the technical aspects of HPN and HEN to “people who do not have tubes and central lines.”

A common sentiment expressed by both HPN and HEN participants was that “seeing other people living life” with HPEN was inspirational, encouraging, and instrumental in helping them make their own decisions related to home nutrition therapy and accepting their own need for HPN or HEN. For example, one participant explained that after seeing pictures of children with feeding tubes, backpacks, and pumps, he came to the conclusion that “surely a grown man who was in the army could tackle it too.” From the stories of others, participants also recognized that the need for HPEN was not an “end-of-life decision”; rather, it was a means for children and adults of all ages to “carry on a decent life as long as their disability allows.”

Study participants strongly expressed the sentiment “I am not alone” and shared many ways they gained a sense of normalcy from the knowledge that there were other people in similar situations. A common theme throughout the interviews was that membership in The Oley Foundation provided a sense of normalcy by being part of an HPEN community, knowing that there are similar people experiencing HPEN therapy, and the realization that HPEN does not need to impede daily life. Representative quotes demonstrating this sense of community and belonging are shown in Table 4. Specifically, study

**Table 4.** Community and Sense of Belonging Gained From Oley Foundation Membership.

## Representative Quotations From Home Parenteral and Enteral Nutrition Consumers

“It basically makes me feel like I’m not the only one.”

“It’s helped me not feel so isolated or alone. I felt like I was the only one in the world dealing with this.”

“Before . . . there was nobody, there was no support group for me, there’s no one around me. Everybody here where I live, they’ve never seen this before, so to be able to gravitate towards a group of people that . . . are there for people who really don’t have anywhere to go.”

“I try to make life normal. We talk about normal school things. It’s nice to have an outlet to discuss that with, knowing that other people my age [are] dealing with that.”

“They basically show you that there are people all over the world. We’re not just talking about here in the States. I talk to people all the way in Australia that have dealt with [home parenteral nutrition]. It is just that added confirmation and that added reassurance that you are not the only one out there.”

participants enjoyed the “support network,” meeting others who are “going through the same or similar things,” and seeing others “thriving.” Study participants also described examples of altruistic behavior when they spoke about how The Oley Foundation provided them with an opportunity to participate in research and to help others. Many participants explained, “To know that I can, this is going to help not just me but other people is important to me as well.”

HEN-dependent participants spoke about their attitudes toward feeding tubes more frequently than did HPN-dependent participants spoke about having a central line. There was, however, a repeatedly stated misconception by HPN and HEN study participants that they might not have been able to live a “normal” life with HPEN. Membership in The Oley Foundation dispelled this myth. It was common to hear study participants reveal that “I just go about life with it [HPEN],” “it’s normal for me now,” “I am less fearful,” and “I think Oley helped a lot with that attitude.”

The theme of advocacy was expressed in two distinct ways. Study participants viewed The Oley Foundation as an advocate providing a voice for HPEN consumers and by empowering consumers to advocate for themselves. With regard to consumer advocacy, common sentiments were “they are patient advocates,” “they have my back,” and “someone is there standing up for me.” Empowerment was evident in the stories of some participants who shared personal experiences through lobbying and writing letters to congressional leaders for better healthcare coverage and improved access to parenteral nutrition (PN) additives in short supply. The advocacy issues for HPEN consumers appeared to differ by type of nutrition therapy.

Half of the HEN participants expressed concern about insurance coverage. One participant stated, “My biggest problem right now is that my insurance won’t cover me for a nutritionist consult.” In contrast, nearly all of the HPN participants brought up the topic of drug shortages and product recalls, including how the nationwide shortage of lipids and other PN additives “impacted me directly” and noting that The Oley Foundation kept them up to date through emails and website announcements.

### *Learning About The Oley Foundation*

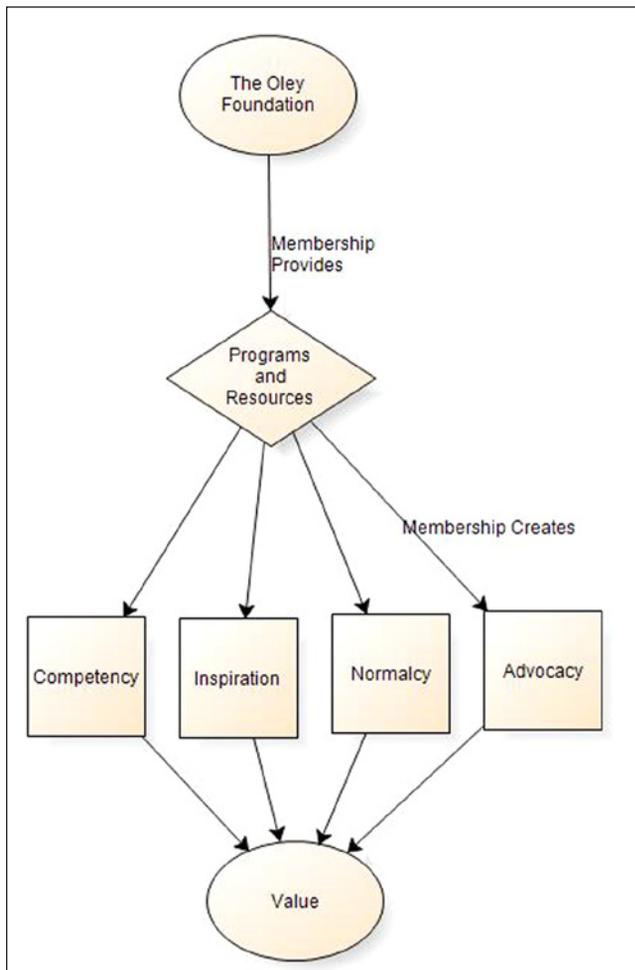
Most study participants (54%) became aware of The Oley Foundation on their own, either through search engines or by links from other education or support organizations. It was common to hear study participants state, “I found them by myself actually” or “I think I Googled something.” Healthcare professionals, including nutrition support team members, a wound care nurse, and dietitians, introduced 46% of study participants to The Oley Foundation often in response to therapy-related problems.

Introductions to The Oley Foundation occurred at very different time points in relation to a participant’s experience with HPEN. Some participants found the organization while doing research before starting HPEN, while others were introduced to the organization soon after beginning HPEN. Regardless of how they learned about The Oley Foundation, a dominant theme that emerged from discussions about how and when participants were introduced to Oley was, “I wish I would have known about it sooner.” For example, one long-term (30 year) HPN participant explained, “I just kind of wish I knew about it sooner just to have that kind of insight that other people are dealing with . . . to help me out on my road, on my little journey if you will.” Similarly, other participants wished they learned much sooner about “how to deal with leaking from the tube site,” “getting tips for hanging with friends,” “knowing that you can travel or go swimming,” and the “social aspect” of HPEN. Furthermore, the recognition that information and peer support available through The Oley Foundation “would have helped me emotionally and physically” was evident in the stories shared by many participants.

Study participants repeatedly emphasized their desire to learn “as soon as possible.” Most participants also believed their physicians or HPEN clinicians should provide information and introduction to The Oley Foundation “beforehand” in order to “have a heads up about what is involved.” Participants had the desire to understand the HPEN experience from the patient perspective prior to making decisions about their own care.

### **Discussion**

The results of this study suggest that the value of The Oley Foundation lies in the competency, inspiration, normalcy, and



**Figure 1.** A conceptual model of value in membership in The Oley Foundation.

advocacy gained from membership and programs and services. Figure 1 shows an illustration of this perceived value. The information and resources provided by The Oley Foundation through membership create competency among members. Educational resources give members the tools and confidence they need to manage their complex therapy. Consumers feel inspired by other people who are successfully integrating HPEN into their lives and are able to achieve normalcy in their own lives. Members appreciate the Foundation's advocacy on their behalf and use its resources to advocate for themselves and other consumers. Collectively, these important themes relate to the perceived value of membership in The Oley Foundation.

Current literature has explored challenges that are experienced by HPEN consumers.<sup>1,12,13</sup> The impact of these challenges and other burdens on QOL in HPEN consumers has been shown to be related to complications, isolation, need for lifestyle adaptations, and discrepancies between expectations

and reality.<sup>2,4,5,14</sup> Studies have shown that HPEN consumers have unmet needs and may perceive things differently than clinicians. Education of consumers has been shown to improve patient outcomes and competence in managing self-care, although physicians are not always comfortable providing this education.<sup>15-17</sup> Studies by Smith et al<sup>4</sup> have demonstrated that affiliation with The Oley Foundation has an effect on health outcomes for HPEN consumers. Thompson et al<sup>5</sup> have reported that providing support, education, and mentors helps foster coping skills. Other support organizations have been shown to be valuable to participants by increasing knowledge and confidence, as well as providing peer support and empathy.<sup>18,19</sup>

Programs and resources provided by The Oley Foundation serve a wide variety of functions. Participants took advantage of resources, including print materials, such as the restaurant cards, online forums for discussion, and the equipment and supply exchange program. Educational resources have been shown to be valuable to members. Lasker et al<sup>18</sup> found that in a group of people with biliary cirrhosis, patients primarily looked for biomedical information. While the assessment of what people search for in online educational and support organizations is important, it does not uncover the intangible, potentially unvoiced benefits seen from our study. This search for knowledge along with "the wisdom of the common folk" gained through membership in The Oley Foundation is important in gaining competency.

Munn-Giddings and McVicar<sup>19</sup> found that members of a support organization for caregivers also gained a sense of competence from membership, which allowed them to communicate more effectively with healthcare professionals. This competence, combined with improved communication, may allow participants to manage their own care. Fex et al<sup>17</sup> found that education, support, and planning were important factors for people medically dependent on technology to have in order to manage their own care. Their analysis also showed that the importance of living is an important factor in self-care.

White and Dorman<sup>20</sup> reviewed several comprehensive online support organizations for smoking cessation, cancer, AIDS, Alzheimer disease, and caregiving. A common attribute of each organization was that they provided support and encouragement. Participants in our study received support and encouragement and felt inspired by others who were thriving on HPEN, subsequently inspiring them to look at their own life with a new attitude. Normalcy gained from the participation in The Oley Foundation was important to most study participants. The subtheme "I am not alone" is similar to previous research findings that describe support organizations for HEN consumers as providing a feeling of universality.<sup>5</sup> Research conducted with groups dedicated to patients who have amyotrophic lateral sclerosis and hemophilia found that advocacy was an important function of a support organization.<sup>21,22</sup> Similarly, participants in this study described The Oley Foundation as one that is "really there for the patient."

Study participants learned about The Oley Foundation at a variety of points in time, some prior to the need for HPEN and others well into their HPEN dependency. More than half of the study participants located The Oley Foundation by themselves, but nearly all participants strongly expressed the sentiment, “I wish I knew about it sooner.” These findings are important because it deepens our understanding of how and why participants become involved in The Oley Foundation or similar education and support groups, as well as what ways the services could benefit patients who are newly receiving HPEN. No previous research has investigated when members learn about organizations. Madigan et al<sup>16</sup> conducted a study with general practitioners in the United Kingdom and found them to believe that patients were not prepared for discharge from the hospital with feeding tubes and that they themselves were not well educated or prepared to address the topic. While this was a small study in the United Kingdom and does not represent healthcare in the United States, several participants in this study described using information from The Oley Foundation to educate their clinicians.

Similarly, no research exists on how and when to introduce patients to support and educational groups such as The Oley Foundation. Most participants in this study located the organization on their own. More research is needed to determine if this is representative of Oley Foundation members as whole. The results from this study suggest that clinicians and discharge planners need further education about The Oley Foundation and similar organizations to provide patients with a range of resources regarding HPEN.

## Strengths and Limitations

Strengths of this study include the in-depth telephone interview, which allowed for confidentiality for study participants and the opportunity for them to speak freely and honestly about their experiences with The Oley Foundation. The member check provided data credibility, although only 8 of 13 participants took part in the follow-up calls. The high interrater agreement demonstrated good reliability of the coding scheme.

The sampling for this study, by design, does not represent all members of The Oley Foundation. The participants were all HPEN-dependent adults who had joined within the past 2 years. Results, therefore, do not necessarily reflect what would be valuable to a child or adolescent, parents, families, caregivers, clinician members, or those who have been members for many years. Participants were predominately white and college educated; different ethnic groups or those who are less educated may perceive value differently. Only participants with Internet and telephone access were eligible to participate, which also provided selection bias for higher socioeconomic status, although this demographic was not collected.

Selection bias may have occurred, since participants self-selected and were interested in and willing to participate. On one hand, those with a complaint to voice may have been more

motivated to participate; on the other hand, members with higher levels of satisfaction may have been more likely to choose to participate. Investigators’ biases, values, and knowledge of The Oley Foundation may have influenced the interview process or analysis. Despite these limitations, participants discussed their experiences with The Oley Foundation; both negative and positive sentiments were expressed. The results of this study are representative only of The Oley Foundation. More research is needed to determine if the results can be generalized to other education and support organizations.

Future research is needed to address if other groups value the same aspects of membership in The Oley Foundation. Parents of children, teens who are transitioning to adult care, and long-term members (since our study focused on <2 years) would be priority areas for more in-depth study. Furthermore, it may be interesting to explore whether HPEN consumers obtain similar or different benefits from organizations such as The Oley Foundation based on the type of program (academic medical center vs community hospital; nutrition support team vs private practitioner). The application of these results to other online or in-person education and support organizations could also be investigated.

## Call to Action for Clinicians

This study aimed to gain a deeper understanding of membership value in The Oley Foundation. The themes that represent value to the participants are competency, inspiration, normalcy, and advocacy. Overall, participants learned through their Oley Foundation involvement that “I am not alone.” Participants in this study wished they had learned about the organization sooner, indicating that more could be done to introduce new HPEN-dependent patients to the organization prior to starting therapy or hospital discharge—for example, educating clinicians, case managers, and home care agencies about The Oley Foundation or providing resources for HPEN as part of the discharge education packet. A greater focus on what is valuable to consumers could improve clinician-patient relationships and facilitate a positive transition to HPEN.

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