

Home Parenteral Nutrition Patient Reported Outcome Questionnaire (HPN-PROQ)

For the Patient: This questionnaire is intended to help you identify areas of concern with your home TPN that may affect your quality of life. These patient-reported outcomes (PRO) may be used to prioritize what you would like to discuss with your physician, health care professional, or members of your home TPN team as well as set goals for your care.

For the Healthcare Professional: The responses on this questionnaire are intended to facilitate discussion between patient and practitioner regarding patient goals related to home TPN and lifestyle adaptation.

	How important are these things to you?	NOT AT ALL IMPORTANT	LOW IMPORTANCE	NEUTRAL	VERY IMPORTANT	EXTREMELY IMPORTANT
1.	Having one or more nights without TPN.					
2.	Having a shorter TPN infusion.					
3.	Being able to do what I want to do when I want to do it.					
	How well trained and prepared are you for TPN care?	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE
4.	I understand my need for being on TPN.					
5.	I understand how to care for my central line.					
6.	I understand how to use my pump.					
7.	I know the signs and symptoms of a central line infection.					
8.	I know the signs and symptoms of dehydration.					
9.	I know about my diet and what I should be eating.					
10.	I know whom to call when I have questions about my TPN therapy.					
11.	I am aware of local or national support groups for TPN therapy.					
12.	I am confident in my ability to perform TPN procedures on my own (or with my caregiver)					
	In the past 2 weeks how often have you experienced these things?	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS
13.	My health limited the things I want to do in my life.					
14.	My sleep was disrupted by the TPN pump.					
15.	My sleep was disrupted because I had to get up to urinate.					
16.	I had episodes of uncontrollable diarrhea (or ostomy output).					
17.	I had to rearrange my daily plans because of how much diarrhea (or ostomy output I had).					
	How do you feel about the challenges of coping with home TPN?	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE
18.	Being on TPN is difficult to cope with emotionally.					
19.	I feel supported by my home TPN team.					
20.	I feel relieved knowing my nutritional needs are being met by TPN therapy.					
		NO EFFECT	MINOR EFFECT	NEUTRAL EFFECT	MODERATE EFFECT	MAJOR EFFECT
21.	To what degree has your quality of life been affected by your underlying illness?					
22.	To what degree has your quality of life been affected by your home TPN?					
		POOR	FAIR	GOOD	VERY GOOD	EXCELLENT
23.	Overall, how has your quality of life been?					

Winkler MF, Machan JT, Xue Z, Compher C. Home Parenteral Nutrition-Patient Reported Outcome Questionnaire: Sensitive to quality of life differences among chronic and prolonged acute intestinal failure patients. JPEN J Parenter Enteral Nutr. 2021;45(7):1475-1483.

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