

Quality of life measurements over 24 months in patients receiving Home Parenteral Nutrition

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Background

Quality of life (QOL) is often an underrepresented outcome measure in studies of patients receiving home parenteral nutrition (HPN), despite recommendations of its importance from professional organizations and societies. Additionally, many QOL studies are small, and involve a single-center or single-provider experience, therefore much remains unknown regarding the experience and QOL of those receiving HPN.

Purpose

The purpose of this study was to evaluate Short Form-36 (SF-36) QOL scores over a 24-month period in patients enrolled in the Health Evaluation and Learning for Total Parenteral Nutrition at Home (HEALTH) Registry.

Methods

Analysis of data from the HEALTH Registry:

- Longitudinal, prospective registry designed to establish and track therapy utilization and outcomes of patients receiving HPN
- Patients in the registry complete SF-36 QOL surveys every 6 months
- Scoring ranges 0-100; higher scores represent better QOL

Inclusion criteria:

- Patients of any age, gender and HPN indication enrolled in HEALTH Registry with completion of at least one SF-36 survey

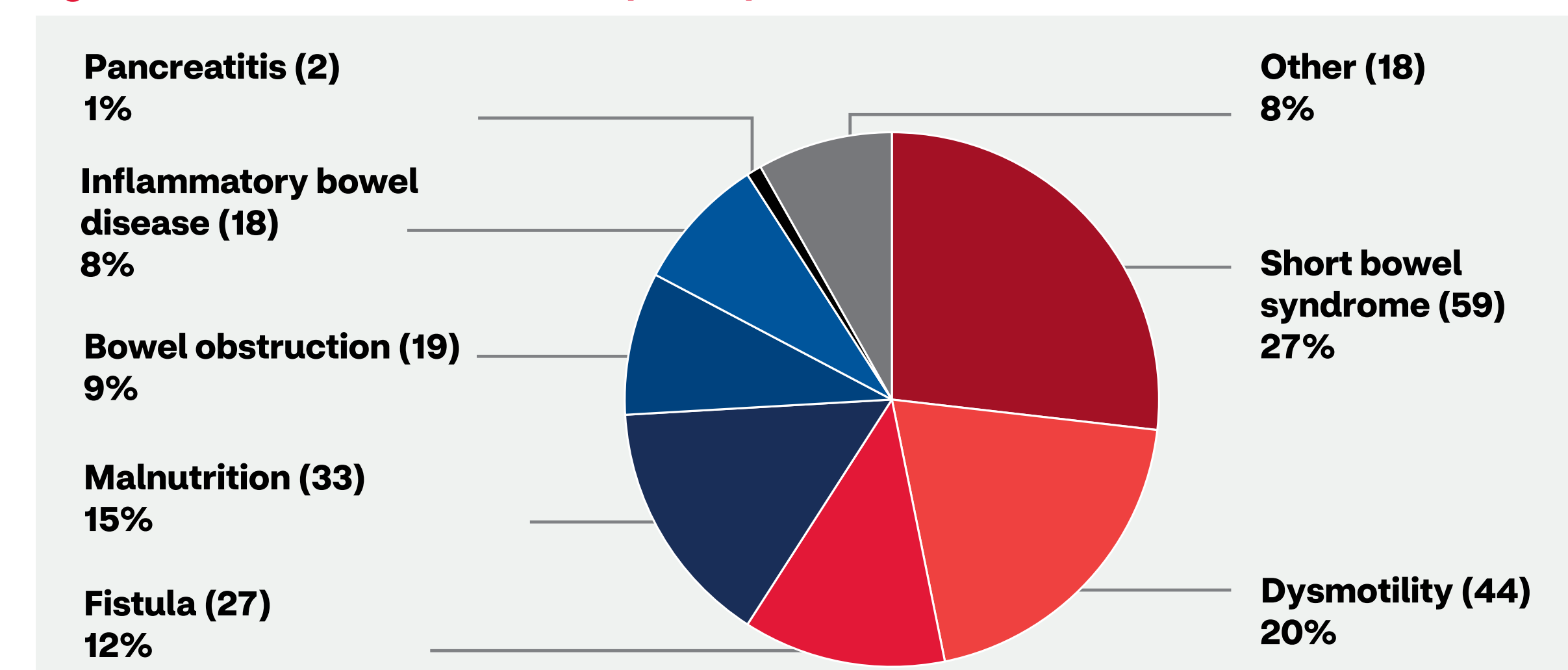
Primary outcome measures:

- Difference in SF-36 scores by timepoint:
 - Baseline, 6 Months, 12 Months, 18 Months, 24 Months

Results

- A total of 220 patients met inclusion criteria for the analysis
 - 184 unique HPN prescribers in 32 states
- SF-36 scores increased at each timepoint for seven of the eight SF-36 domains and both summary scores, representing an improvement in QOL over time, although the changes were not statistically significant

Figure 1. HPN indication at baseline (N=220)



Conclusions

Quality of life scores increased in patients receiving Home Parenteral Nutrition (HPN) over 24 month

- Results suggest that QOL continues to incrementally improve over time in those receiving long-term HPN.
- Further studies are needed to determine causative factors and interventions leading to improved QOL.



Table 1. Clinical and demographic characteristics of patients at each timepoint

	Baseline (N=220)	6 Month (N=81)	12 Months (N=50)	18 Months (N=37)	24 Months (N=14)	P value
Sex						
Female	155(70.5)	59(72.8)	38(76.0)	28(75.7)	7(50.0)	0.16
Male	63(28.6)	22(27.2)	12(24.0)	9(24.3)	7(50.0)	0.40
Missing	2(0.9)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	
Indication for HPN						
Short bowel syndrome	59(26.8)	31(38.3)	24(48.0)	20(54.1)	6(42.9)	0.002
Dysmotility	44(20.0)	19(23.5)	13(26.0)	9(24.3)	5(35.7)	0.62
Fistula	27(12.3)	10(12.4)	3(6.0)	3(8.1)	0(0.0)	0.42
Malnutrition	33(15.0)	7(8.6)	4(8.0)	1(2.7)	1(7.1)	0.14
Bowel obstruction	19(8.6)	4(4.9)	2(4.0)	1(2.7)	1(7.1)	0.52
Inflammatory bowel disease	18(8.2)	7(8.6)	3(6.0)	2(5.4)	1(7.1)	0.96
Pancreatitis	2(0.9)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0.80
Other	18(8.2)	3(3.7)	1(2.0)	1(2.7)	0(0.0)	0.21
Body mass index (kg/m ²) ^a	23.8 ± 5.4	23.8 ± 5.4	22.8 ± 4.6	22.8 ± 4.6	22.4 ± 2.5	0.79
HPN duration (d) ^b	159 (540.5)	612 (988.0)	974 (1244.5)	1340 (1981.0)	2835 (1830.3)	
HPN formula frequency (d) ^c	6.7 ± 0.96	6.45 ± 1.2	6.2 ± 1.6	6.4 ± 1.5	6.4 ± 1.8	0.55
Length (hr) ^d	14.2 ± 4.3	12.5 ± 2.9	12.1 ± 2.5	12.0 ± 1.6	12.4 ± 2.0	0.09
Volume (mL) ^e	1874.7 ± 652.1	1936.6 ± 696.3	1841.0 ± 711.3	1980.2 ± 607.2	2032.9 ± 689.0	<0.001
Dextrose (g) ^f	229.1 ± 79.7	204.0 ± 92.3	211.0 ± 98.7	199.8 ± 95.3	207.1 ± 129.6	0.54
Amino acids (g) ^g	79.4 ± 25.6	76.6 ± 27.7	64.8 ± 25.7	70.6 ± 26.1	69.3 ± 33.2	0.12
Lipids (g) ^h	34.4 ± 18.7	26.8 ± 17.7	24.2 ± 15.2	28.7 ± 21.0	29.1 ± 17.0	0.10
Total kcal ⁱ	1433.3 ± 445.4	1274.0 ± 477.3	1222.1 ± 480.3	1252.9 ± 527.2	1252.3 ± 632.6	0.16

Categorical data presented as n(%); Chi square test used to analyze differences between timepoints
 Continuous data presented as mean ± standard deviation (HPN duration presented as median [interquartile range])
 Repeated measures ANOVA used to analyze differences between timepoints
^aBaseline: n=214, 6 Months: n=80, 12 Months: n=49, 18 Months: n=35; ^bBaseline: n=214; ^cBaseline: n=215, 6 Months: n=80; ^dBaseline: n=215, 6 Months: n=78, 6 Months: n=49, 18 Months: n=36; ^eBaseline: n=210, 6 Months: n=77, 12 Months: n=36; ^fBaseline: n=210, 6 Months: n=77, 12 Months: n=49, 18 Months: n=35; ^gBaseline: n=210, 6 Months: n=78, 18 Months: n=36; ^hBaseline: n=210, 6 Months: n=77, 12 Months: n=48, 18 Months: n=35; ⁱBaseline: n=209, 6 Months: n=78, 12 Months: n=36

Figure 2. SF-36 Physical domain and summary score at each timepoint

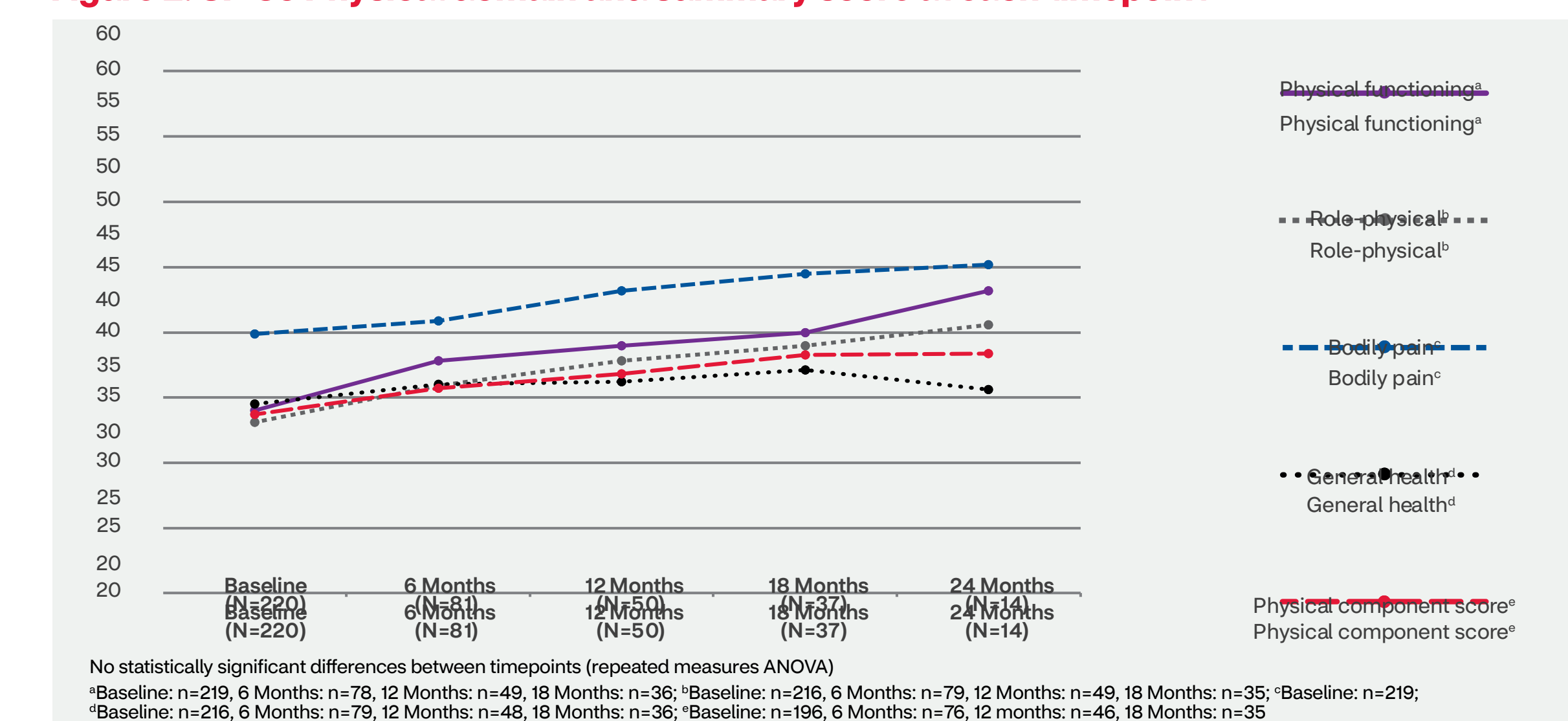


Figure 3. SF-36 Mental domain and summary score at each timepoint

