

# Health-related quality of life of patients with neuroendocrine tumor compared to the United States general population

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## BACKGROUND

- Health-related quality of life (HRQL) can be disrupted in patients with malignancies
- A recent Norwegian study has shown that patients with neuroendocrine tumor (NET) have significantly reduced HRQL compared to the general Norwegian population<sup>1</sup>

## OBJECTIVE

To evaluate the HRQL burden of patients with NET compared to the general United States population

## METHODS

- Individuals with NET were invited via email to participate in an online, anonymous survey
- Data collected:
  - Demographic and disease-related questions
  - RAND-36 health survey
  - PROMIS-29 health index
- Both standardized measures of HRQL (RAND-36, PROMIS-29) have US general population normative values available for comparison
- Norm-based scores were calculated for all subscales, such that a score of 50 represents the mean of the general population (standard deviation=10) and evaluated using one-sample t-tests
- On the anxiety, depression, fatigue, pain interference, and sleep disturbance subscales of the PROMIS, higher scores (> 50) represent worse outcome
- On the physical functioning and social role subscales of the PROMIS and all RAND-36 scales, lower scores (<50) represent worse outcome
- Clinically important difference is approximately 2.5 – 5 points (or 0.25 to 0.50 standard deviation units) on T-score metrics such as these
- HRQL scores of 3 subgroups were compared to the general population using t-tests:
  - Patients with no tumor currently present (e.g., been surgically removed)—no current NET;
  - Patients with tumor that has not been surgically removed or has come back after surgery—current NET, but without carcinoid syndrome;
  - Patients with current NET and carcinoid syndrome
- PROMIS scores for other chronic disease populations are presented for comparison (“Have you ever been told by a doctor that you have...”)<sup>2</sup>

## RESULTS

- Demographic and clinical characteristics of the sample are described in Table 1
- HRQL scores in patients with NET are significantly worse than the general US population (all  $p < 0.01$ ; Figures 1 and 2)
- Patients with no current NET had scores similar to the general population or better; patients with current NET but no carcinoid syndrome had slightly worse HRQL scores on some subscales; those with both NET and carcinoid syndrome reported much worse HRQL (Figures 3 and 4) particularly in the areas of fatigue, general health, & role limitations-physical
- Patients with current NET and carcinoid syndrome reported HRQL that is comparable to individuals with anxiety, depression, diabetes, or arthritis, but is worse than a mixed cancer population (patients/survivors) or individuals with hypertension (Table 2)

**Table 1. Demographic and clinical characteristics of sample (N=663)**

	N	%
<b>Male</b>	222	34%
<b>White</b>	604	91%
<b>Hispanic</b>	19	3%
<b>Median age</b>	50-55 years	
<b>Median years since diagnosis</b>	4 years (range: 0 – 34)	
<b>Tumor type</b>		
Carcinoid	536	81%
Islet cell	62	9%
Not sure what type	65	10%
<b>NET currently present</b>	443	68%
<b>NET spread to part of body other than lymph nodes</b>	309	47%
<b>Carcinoid syndrome</b>	422	65%
<b>Performance Status</b>		
Normal activity, without symptoms	176	27%
Some symptoms, do not require bed rest during the waking day	324	49%
Bed rest < 50% of day	129	20%
Bed rest > 50% of day, or unable to get out of bed	27	4%

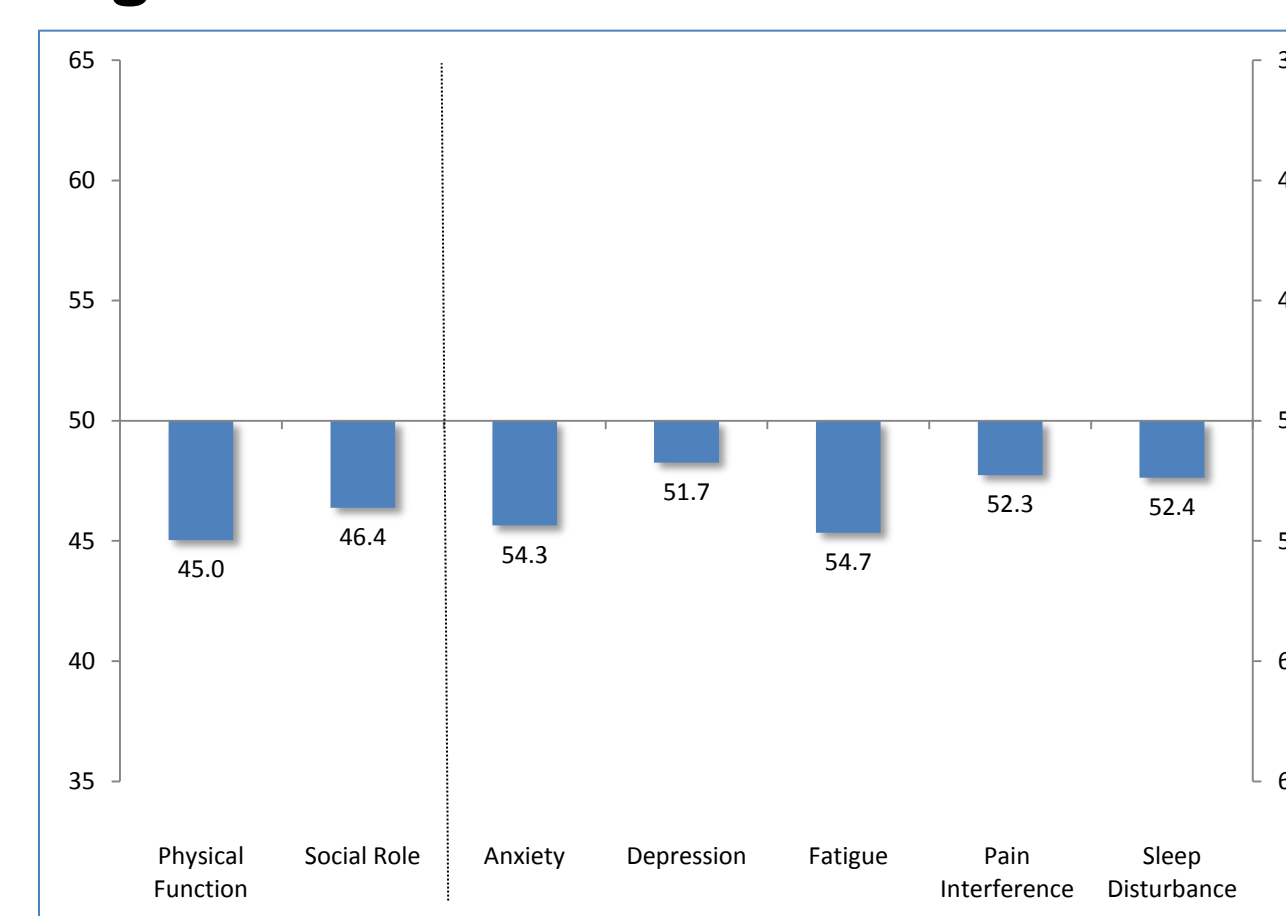
N < 663 for some questions, due to missing or “not sure” responses. Denominators for percentages are the number of non-missing responses for that item.

**Table 2. PROMIS scores relative to other chronic diseases**

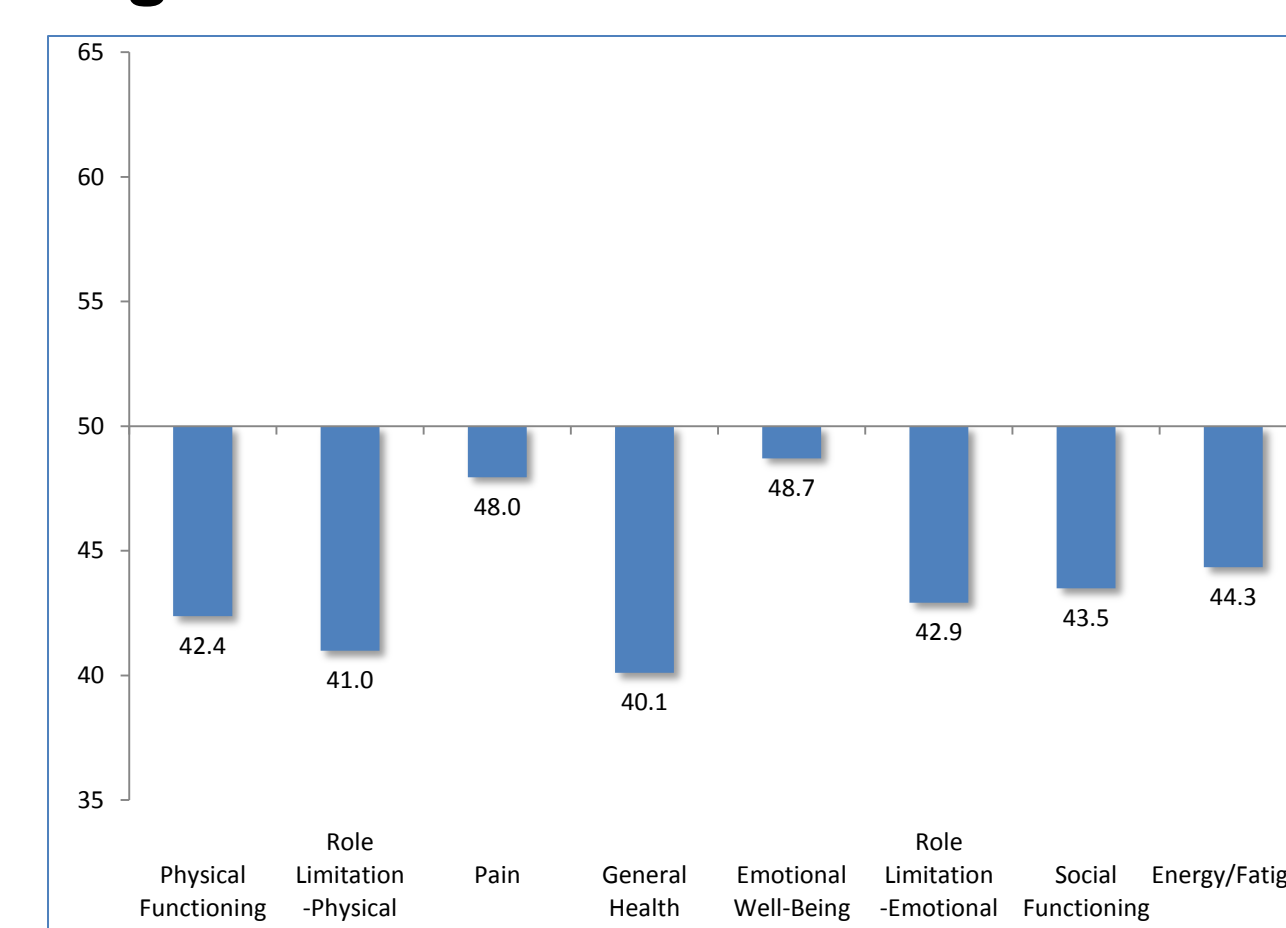
	All (n=663)	No current NET (n=83)	NET, no carcinoid syndrome (n=115)	NET + carcinoid syndrome (n=328)	Cancer	Hypertension	Anxiety	Depression	Diabetes	Arthritis
Physical Function	45.0	51.5	47.2	43.1	47.4	45.0	44.5	44.2	42.7	42.6
Social Role	46.4	53.1	47.8	44.6	50.7	48.6	46.0	45.8	48.1	48.3
Anxiety	54.3	51.3	53.0	55.0	48.6	50.3	57.6	56.2	51.3	51.3
Depression	51.7	48.0	50.2	52.7	48.5	50.4	56.8	56.8	51.6	51.4
Fatigue	54.7	47.9	51.8	56.8	49.3	51.6	57.5	57.3	53.5	53.5
Pain Interference	52.3	46.4	49.6	54.0	50.6	52.9	56.2	56.1	54.7	55.9

Notes: general US population score = 50; lower scores on Physical Function and Social Role indicate worse HRQL; Sleep Disturbance scores not available in comparison groups; subgroup sizes do not sum to total since some participants did not provide information on current presence of NET or carcinoid syndrome; chronic diseases = “Have you ever been told by a doctor that you have...?” asked of n=21,133 in PROMIS calibration sample

**Figure 1. PROMIS-29 Scores**

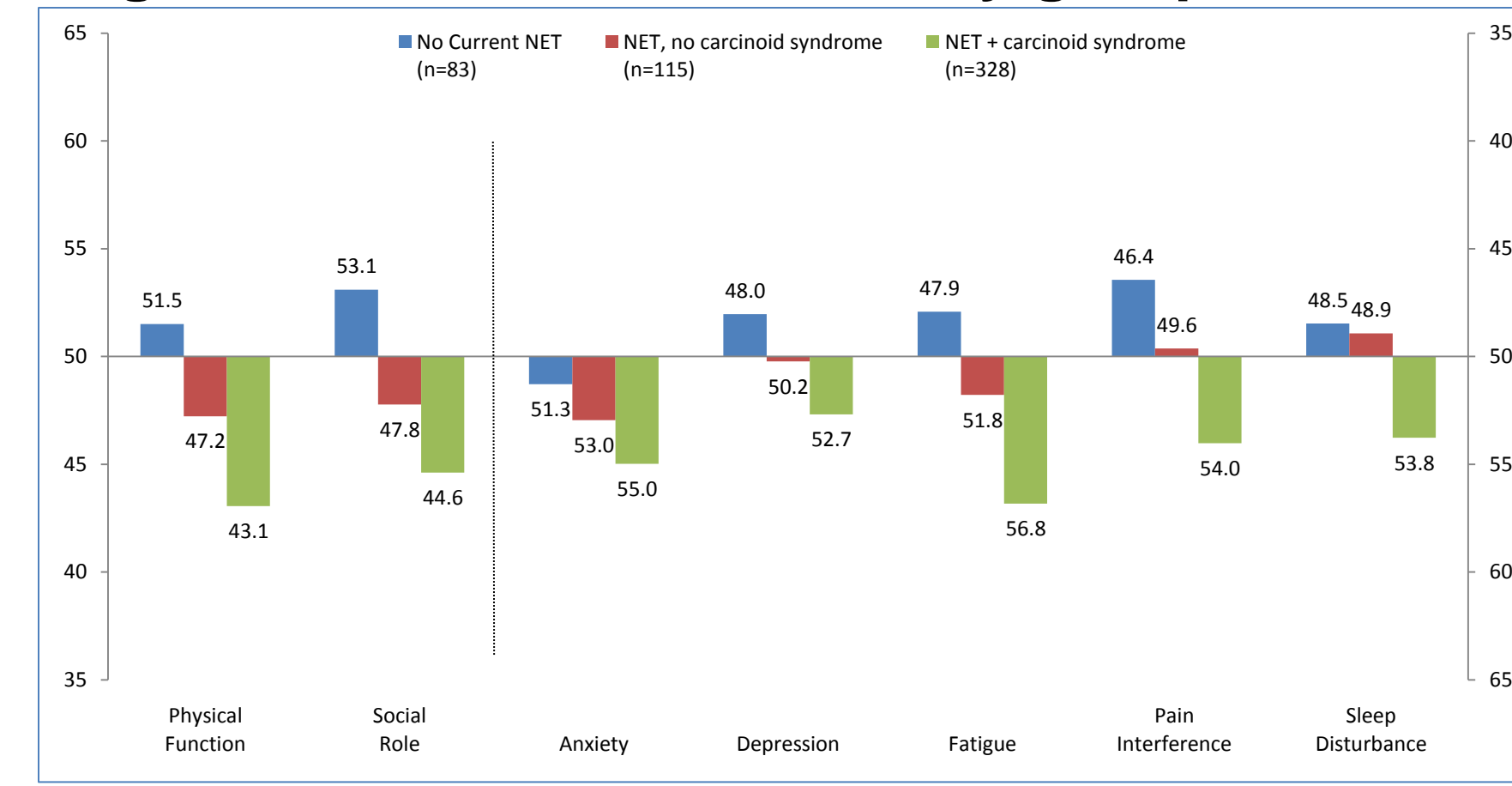


**Figure 2. RAND-36 Scores**

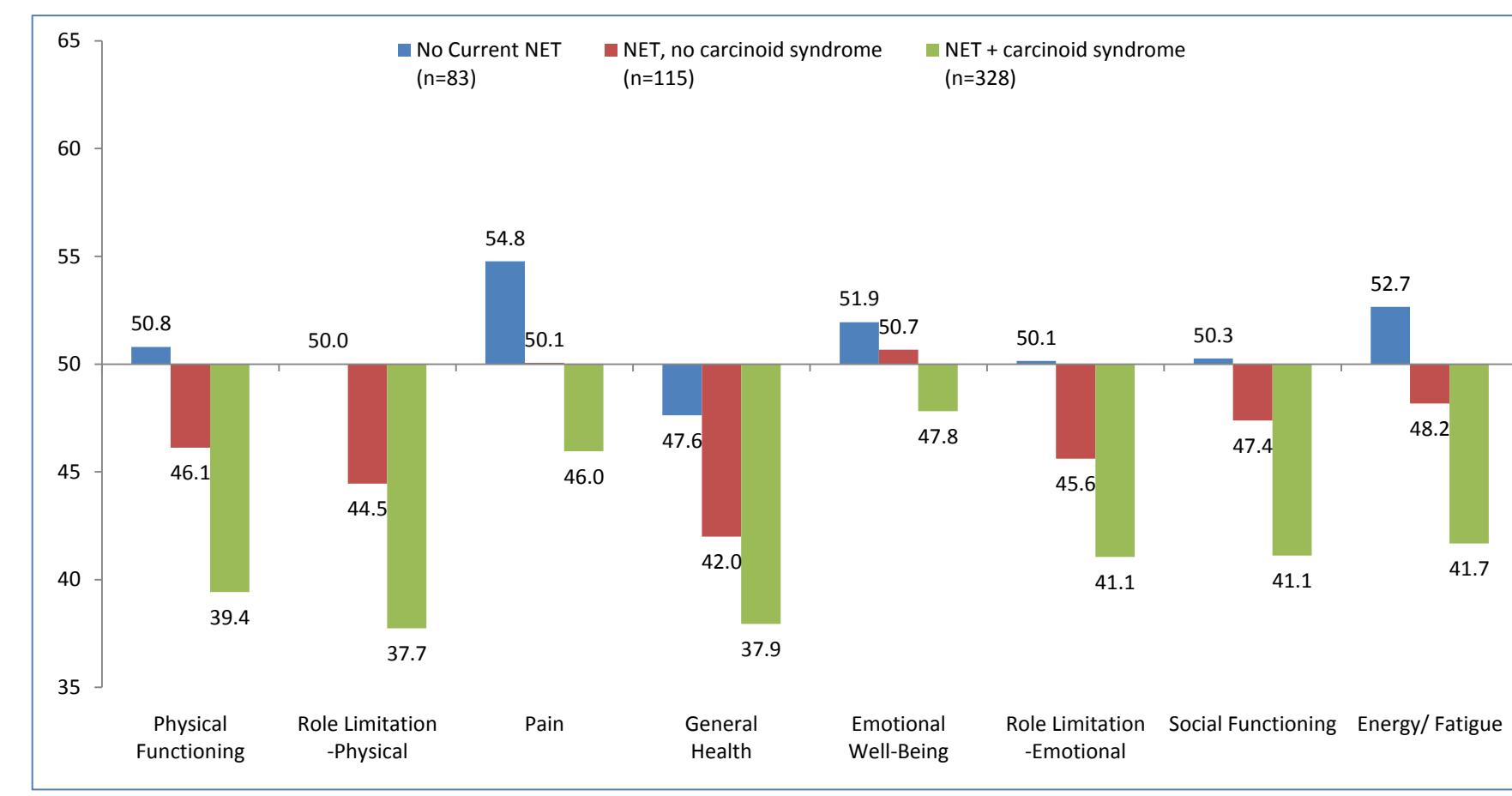


Bars below the 50 line represent worse HRQL

**Figure 3. PROMIS-29 Scores by group**



**Figure 4. RAND-36 Scores by group**



Bars below the 50 line represent worse HRQL

## CONCLUSIONS

- Patients with NET reported worse HRQL outcomes compared to the general population on all subscales of the RAND-36 and PROMIS-29
- HRQL burden is primarily due to the presence of carcinoid syndrome in over half of the sample, as this subgroup reported the greatest burden
- Symptom management and/or psychosocial interventions are needed to ease the HRQL burden experienced by patients with NETs
- A limitation of this study is that it is a cross-sectional, observational survey of a non-probability sample
- Further studies of treatment impact on HRQL are warranted