



The Quality of Life of Adult Patients on Home Parenteral Nutrition in Northeast England & Cumbria

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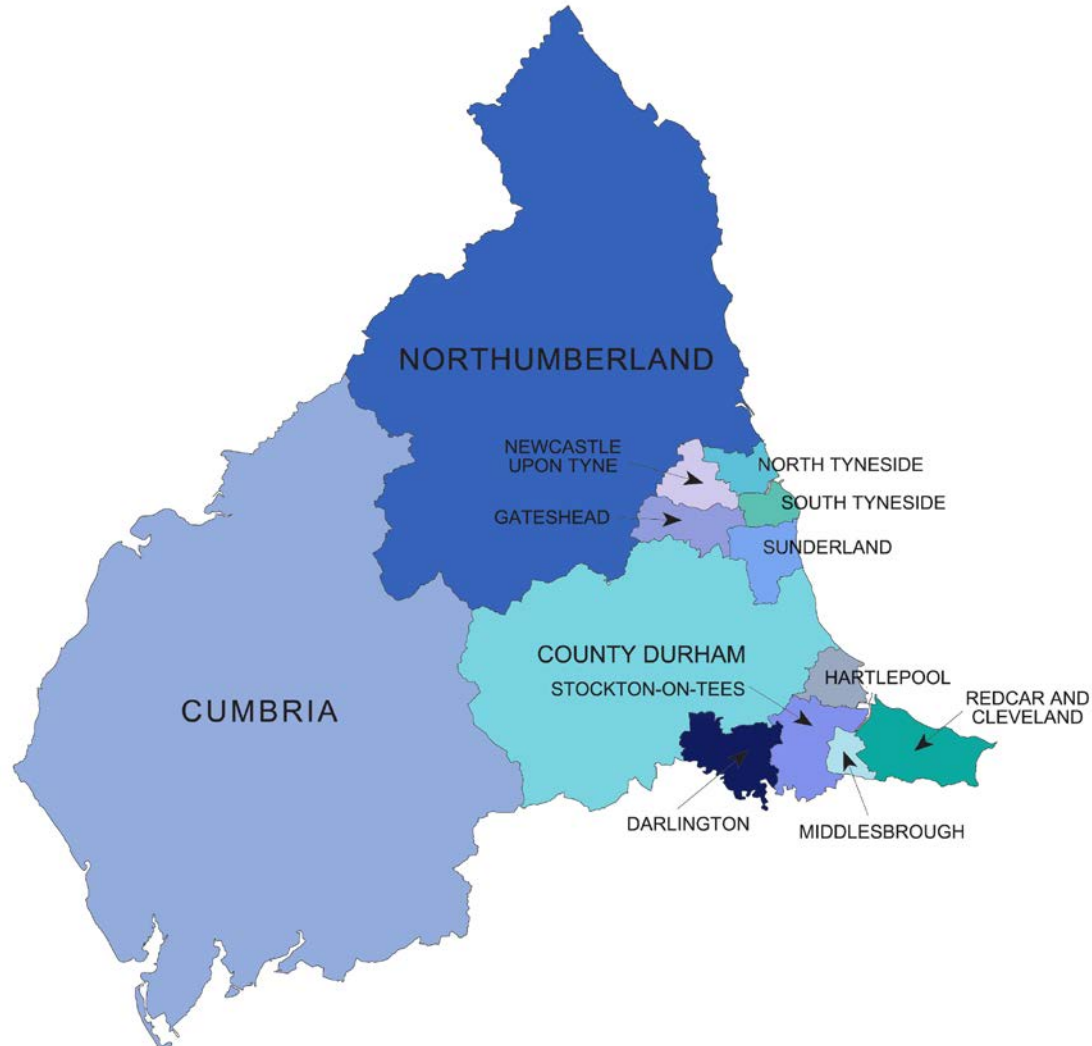
Newcastle-upon-Tyne

8th November 2016

Background

- Many factors that have potential to impact Quality of life (QoL) in HPN patients*
 - Underlying condition and associated symptom burden
 - Impact of treatment:
 - Infusions lasting up to 14 days up to 7 days per week
 - Central venous catheter problems
 - Infections
 - Dehydration & electrolyte imbalance
 - Impact on family, professional & personal life
- Paucity of data particularly in UK patients

*Dreesen M, et al. *Outcome Indicators for Home Parenteral Nutrition Care: Point of View From Adult Patients With Benign Disease.* JPEN Sep 2015



Data Collection

Original Communication

The Clinical and Psychometric Validation of a Questionnaire to Assess the Quality of Life of Adult Patients Treated With Long-Term Parenteral Nutrition

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Data collection

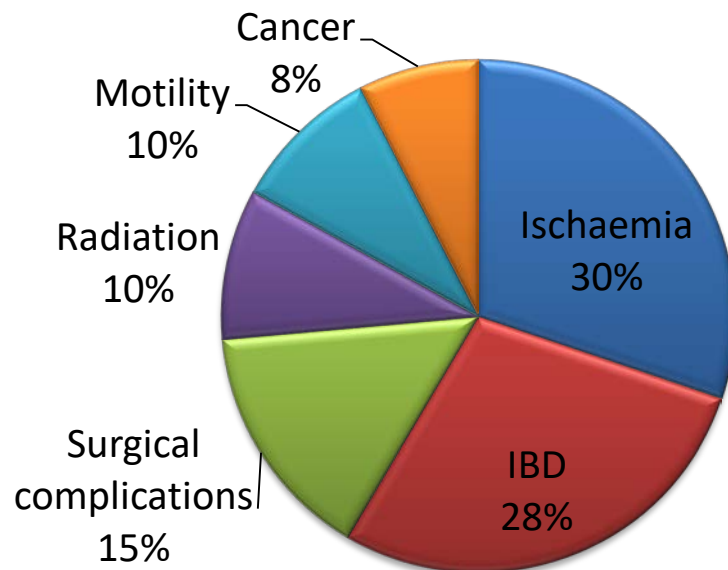
- 47 questions plus 1 free text
- 22 questions assessing 9 domains of function
- 22 questions assessing 9 domains of symptoms
- 3 global numerical rating scale questions on QoL
- Based on recall of function and symptoms in the past week, 4 weeks, and since starting HPN, depending on question
- Responses for each domain scaled to a score out of 100

Methods

- Cross sectional study from February – July 2015
- Questionnaire explained to patients in clinic then sent out in post with prepaid return envelope
- Voluntary participation
- Exclusions: Patients with life expectancy of less than 3 months
- Responses anonymised and scaled scores analysed and compared between patient subgroups
- Scaled scores for each domain of function or symptoms compared using Kruskal-Wallis test

Results

- 55/67 (82%) response rate. 2 excluded from analysis
- 22 male (42%), 31 female. Median age 55 (range 19 - 85)
- 37 with stoma (70%), 16 without stoma



Symptom and functional burden

Symptoms

Functioning

Highest burden

Fatigue	(60.7)
Sleep pattern	(54.1)
Other (non-GI) pain	(52.6)
Stoma/bowel problems	(45.2)
Immobility	(44.3)
Attractiveness	(43.6)
Body image	(34.0)
GI symptoms	(33.9)

Lowest burden

Sexual function	(16.0)
Employment	(21.3)
Ability to holiday/travel	(22.1)
Physical function	(31.7)
Ability to eat & drink	(50.0)
Emotional function	(50.9)
Coping	(56.1)
General health	(71.1)
Nutrition team support	(90.2)

Lowest function

Highest function

Analysis by stoma status & aetiology

- Patients **without** a stoma (n=16) reported more GI symptoms (pain, bloating, nausea) (50.7 vs 26.0, p=0.010)
- Patients with motility disorders (n=5) experienced more problems with oral intake compared to those with other aetiologies excluding malignancy (n=4). (p=0.034)
- Whilst not reaching statistical significance (p=0.058), they also tend to report more GI symptoms.
- No significant difference in other domains of function and symptoms by aetiology.

Number of HPN infusions per week

- No significant association between number of PN infusions per week and function scores
- Patients having 2-4 infusions of HPN per week reported higher GI symptom scores than those on 5, or 6-7 infusions per week
 - (61.6 vs 29.5 & 25.5 respectively $p=0.012$)
- Patients having 2-4 infusions per week reported more non-GI pains than those on 5 or 6-7 infusions per week
 - (70.8 vs 37.2 & 51.2 respectively $p=0.035$)

Analysis by Duration on HPN

- Patients on HPN for 2 years or less (n=21) reported better travel ability scores (28.8 vs 18.3, p=0.04) than those who have been on HPN for >2 years (n=31).
- No significant difference in age and number of infusions per week to account for this difference.
- No significant difference in other domains of function and symptoms by duration on HPN.

Summary

- The majority of patients on HPN experience problems that have potential to impair quality of life.
- Areas of specific concern to patients are highlighted in responses and can help to serve as a prompt to maintain a patient focus during consultations, acknowledging and tailoring solutions to the individual
- Limitations:
 - It is not possible to ascertain how much problems related to the patient's underlying condition or to HPN itself
 - Limited patient numbers

Thank you

Authors:

Max Hu, Hannah Cook, Hayley Leyland, John Leeds, Dina Mansour, Nick Thompson, Chris Mountford

