

Publication

Quality of Life in the Management of Home Parenteral Nutrition.

JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

ID 4699553

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Year 2023

Title Quality of Life in the Management of Home Parenteral Nutrition.

Journal Annals of nutrition & metabolism

Volume 79

Number 3

Pages / Article-Number 326-333

Keywords Home parenteral nutrition; Parenteral nutrition; Patient-reported outcomes; Quality of life; SF-36v2

Mesh terms Humans; Female; Male; Quality of Life; Prospective Studies; Parenteral Nutrition, Home; Surveys and Questionnaires; Health Surveys

Home parenteral nutrition (HPN) is a rare but challenging therapy for patients with mostly severe underlying diseases. We aimed to investigate patient-reported health-related quality of life (QOL) of patients receiving HPN and its development over time in particular.; We assessed QOL of HPN patients in a prospective multicenter observational study (SWISSHPN II study). We designed a questionnaire to record symptoms and negative impacts of HPN and completed the validated Optum[®] SF-36v2[®] Health Survey with the patients.; Seventy patients (50% women) on HPN were included. HPN commonly affected feelings of dependency (n = 49, 70%), traveling/leaving home (n = 37, 53%), attending cultural and social events (n = 25, 36%), and sleep (n = 22, 31%). Most frequently reported symptoms were diarrhea (n = 30, 43%), polyuria (n = 28, 40%), nausea/emesis (n = 27, 39%), dysgeusia (n = 23, 33%), and cramps (n = 20, 29%). At baseline, mean (standard deviation) SF-36v2[®] physical and mental health component summary scores (PCS and MCS) were 45 (20) and 57 (19), respectively, and there was a trend toward improvement in PCS over the study period, while MCS remained stable. Satisfaction with health care professionals involved in HPN care was high.; QOL is a crucial and decisive aspect of HPN patient care. Symptoms related to the underlying disease and PN are frequent. Impaired social life and an ambivalent attitude toward the life-saving therapy are major concerns for these patients and should be addressed in their care.

ISSN/ISBN 0250-6807

Full Text on edoc ;

Digital Object Identifier DOI 10.1159/000530082

PubMed ID <http://www.ncbi.nlm.nih.gov/pubmed/36934718>