



Original article

The impact of Home Parenteral Nutrition on the lives of adults with Type 3 Intestinal Failure



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ARTICLE INFO

Article history:

Received 9 February 2018

Accepted 11 February 2018

Keywords:

Home Parenteral Nutrition
Intestinal Failure
Need fulfilment
Parenteral Nutrition Impact Questionnaire (PNIQ)
Qualitative research

SUMMARY

Background & Aims: Several studies have been published reporting on the impact of Home Parenteral Nutrition (HPN) on the lives of people with Type 3 Intestinal Failure. These studies focused on symptoms and functional limitations resulting from the treatment. The aim of this study was to determine how dependence on HPN affects individuals' ability to fulfil their human needs.

Methods: Unstructured qualitative interviews were conducted with people dependent on HPN, who were asked to explain how their lives were affected by the treatment. Theoretical thematic analysis was conducted on the interview transcripts to identify statements describing aspects of human needs that were left unfulfilled. Care was taken to separate the impact of HPN from that of the underlying disease.

Results: Interviews were conducted with 30 patients (53% female; mean age, 55.9 (range 35–76) years). Most of the sample (87%) had short bowel syndrome. Major aspects of need affected by HPN were related to: autonomy, cognition, relationships, role fulfilment, socialisation, appearance and self-esteem, appetite and perceived vulnerability.

Conclusions: The study illustrates how patients' lives are affected by HPN. Statements generated from this qualitative study were used to produce the Parenteral Nutrition Impact Questionnaire (PNIQ), a patient-centric measure of quality of life specific to people using HPN.

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Introduction

Patients with Type 3 Intestinal Failure (IF) require long term Home Parenteral Nutrition (HPN) [1]. This treatment, while life-saving, requires extensive training in its use and, by its nature, is restrictive [2,3].

Reviews of published qualitative work on the impact of HPN have investigated various outcomes including symptomatology, functional limitations and quality of care received [4–6]. Mueller and colleagues [4] reported the impact of HPN on

functioning and perceived health in patients with cancer. However, the study did not report on how interviewees responded to these limitations. Tsang and Carey [7] conducted eight interviews with patients on HPN focusing on their ability to function. They found that interviewees had activities such as swimming and travelling restricted and that eating habits had changed. Social activities did not appear to have been affected in this small group of patients. Huisman et al. [8] reviewed 26 studies of the impact of HPN; of these, 22 used standardised generic measures of health-related quality of life (HRQL). They concluded from the review that, on average, HRQL seemed to be acceptable in this patient group. In contrast, Winkler [9] reported that HRQL in this group is worse than that in healthy groups or for patients with other intestinal diseases not requiring HPN. Such conclusions must be treated with caution, as generic HRQL measures may not allow accurate comparisons between different groups [10–13]. This is because diverse

Abbreviations: IF, Intestinal Failure; HPN, Home Parenteral Nutrition; HRQL, Health-Related Quality of Life; QoL, Quality of Life; PNIQ, Parenteral Nutrition Impact Questionnaire.

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<https://doi.org/10.1016/j.clnesp.2018.02.003>

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groups of patients may interpret the same question in different ways, based on their experience.

Winkler and colleagues [14,15] conducted interesting studies investigating the impact of HPN on the lives of patients. They identified the importance of autonomy and socialisation to the lives of this patient group. These studies are important as they are the first to identify issues of importance to people on HPN that go beyond HRQL.

While HRQL assessments describe the potential impact of an illness or intervention on a patient, they do not evaluate whether that individual's life is actually affected by the symptoms and functional limitations measured. For example, not being able to go swimming will be of little concern to someone who does not enjoy the activity. Rather than focus on HRQL, it is possible to measure directly how the individual's life is impacted [16]. The needs-based quality of life (QoL) approach is widely applied in health research [17]. This theoretical model forms the focus of the current study. It argues that life gains its quality from an individuals' ability to fulfil his or her basic human needs. QoL is poor when few human needs are satisfied.

This article reports on qualitative interviews conducted to explore the impact of HPN on the needs-based QoL of patients. Data generated from this study were used to develop the Parenteral Nutrition Impact Questionnaire (PNIQ; [18]).

Methods

Ethics committee approval for the study was granted by the National Research Ethics Service Committee North West (11/NW/0171).

Participants

Interviewees were recruited from the Intestinal Failure Unit at Salford Royal NHS Foundation Trust, a national referral centre for individuals requiring HPN. Patients were invited to take part if they were 18 years of age or older, had a confirmed Type 3 IF diagnosis due to a benign underlying disease and could provide written informed consent.

Previous qualitative studies have demonstrated that sampling saturation can be achieved with thirty participants [19]. Consequently, this was considered the optimal sample size for the study.

Interviews

One-to-one unstructured, in-depth interviews were conducted with people on HPN by experienced researchers. Open questions were adopted to allow participants to talk freely about the impact of HPN on their lives. The interviews, which were audio-recorded, were conducted in the patients' homes or in a private room at Salford Royal NHS Foundation Trust, depending on the patient's preference. Participants were assured of the confidentiality of the interviews and informed that any identifying information would be removed from the transcripts.

Interviewees were asked to report on how their lives were affected by HPN. They were not asked to compare themselves with how they had been prior to commencement of the treatment or to consider what life would be like without HPN. This approach was important as the intention of the study was to determine current quality of life. Where interviewees reported symptoms or functional limitations experienced, they were encouraged to provide additional information about how these impairments influenced their lives. Care was taken during the interviews to determine whether responses were related to HPN or to the underlying

disease. Only issues directly related to HPN were relevant to the current study.

Data analysis

Theoretical thematic analysis [20], guided by the needs-based model of QoL, was the qualitative approach adopted in the study. The interviews were transcribed verbatim. Each transcript was coded independently by two researchers (who had not interviewed the patient). Statements relating to need fulfilment impaired by HPN were identified. The research team then met together to categorise these statements into themes.

Results

Participants

Sixty-seven patients were invited to participate in the study and 30 gave consent. Demographic details of the participants are presented in Table 1. Most of the sample were retired or on long-term sick leave. The mean (standard deviation) age of the sample interviewed was 55.9 (11.2) years (range = 35–76 years). Most patients administered the HPN themselves, with six relying on a healthcare professional or family member to connect/disconnect the parenteral nutrition. Interviewees had been on HPN between 1 and 31 years. Mean (SD) duration was 7.2 (8.4) years. Participants used HPN between 2 and 7 nights a week, with a median of 6 nights.

Interview findings

Some respondents made unprompted comments about the value of HPN prior to the start of the formal interview. Symptoms related to Type 3 Intestinal Failure have a major impact on the lives of patients and these improve markedly with HPN:

"I'm very grateful for it, you know. You do get used to it. At first you think 'ooh golly this is going to be a pain'. But no, you don't let it be a pain. It is your friend, it is keeping you well and well-nourished and so on, and without it you would be lost" (Female, 67)

"It made me feel better, I wasn't tired, I wasn't lethargic, I wanted to go out ... And so for me, it's the best thing for me being on it, it really is." (Female, 44)

Table 1
Details of the interview sample (n = 30).

	n	%
Gender		
Male	14	46.7
Female	16	53.3
Employment status		
Employed	3	10.0
In unpaid employment	2	6.7
Retired	13	43.3
Long-term sick leave	11	36.7
Missing	1	3.3
Marital status		
Married/living as married	19	63.3
Divorced/widowed/single	11	36.7
Pathophysiological classification/primary mechanism		
Short-bowel with jejunostomy	11	36.7
Short-bowel with jejunocolic anastomosis	12	40.0
Short-bowel with jejunoleal anastomosis	3	10.0
Dysmotility	2	6.7
Mechanical obstruction	1	3.3
Mucosal disease	1	3.3

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