Health Technology Assessment 1997;Vol. 1: No. 1 (Executive summary)

Review

Executive summary

Home parenteral nutrition: a systematic review

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Health Technology Assessment
NHS R&D HTA Programme

Executive summary

Objectives

The objective was to locate, appraise and summarise evidence from scientific studies on home parenteral nutrition (HPN) in order to answer the following specific research questions:

What patients have received HPN? What has been the experience of patients on HPN programmes? How have HPN programmes been organised, and what techniques and equipment have been used, and to what effect? What comparative information is available on effectiveness? What evidence exists for the cost-effectiveness of HPN? What questions about the provision of HPN could be answered with additional research, and what studies would be most suitable?

Data sources

A comprehensive list of studies was provided by an extensive search of electronic databases, relevant journals and scanning of reference lists, as well as other search strategies outlined in the protocol.

Study selection

Studies relevant to the questions were selected. The inclusion criteria were fairly broad because of the quality of the studies located.

Data extraction

Data extraction forms were used to collect data from studies included in the review. The data were checked by a second researcher to reduce error.

Data synthesis

Quantitative analysis was difficult owing to the type of studies located. The data are discussed in a qualitative manner. Where complication rates have been given, we have attempted to combine the results in a quantitative manner.

Results

The age and sex of patients on HPN varies according to the underlying disease but, on the whole, patients are young. There are trends showing an increased use of the technology at the extremes of the age range. There are marked differences between countries on the underlying diseases for which HPN is indicated. For example, many more patients with an underlying malignancy are treated in Italy and the USA than in the UK (40–67% versus 8%). Morbidity rates for the majority of patients are acceptable, the complications tend to be related to the central venous catheter. It is fairly clear that a minority of patients are susceptible to recurrent problems and that many patients have very few complications. The mortality rate for HPN patients was good for those patients with benign underlying disease (for example, 5% of Crohn's HPN patients die per year), and there are very few reports of patients dying from complications of the technology. The survival of those with malignant disease and AIDS is poor, almost all having died from the underlying disease at one year; despite this, most programme growth worldwide is due to an increase in the numbers of patients with these diagnoses. Quality of life is reasonable for patients with benign disease; no studies were found that examined the quality of life of HPN patients with malignant disease. Economic analysis shows that the cost of HPN treatment is cheaper than the alternative of in-patient care. There is a paucity of comparative studies examining different aspects of the technology, and this accounted for the majority of gaps in the evidence.

What gaps in the evidence exist?

The quality and range of evidence of effectiveness was disappointing. The technology of HPN has been present for almost 30 years and yet there is still very little good quality evidence to support many aspects of it.

- The type of patient who has received HPN has been fairly well documented. There is evidence that, in the UK, there is an increase in the number of those with terminal malignant disease and wasting due to AIDS being treated with HPN. It is hoped that accurate data concerning those patients entered into HPN programmes will continue to be collected as part of a national register, administered by the British Association for Parenteral and Enteral Nutrition Council. Trends in the UK could then be monitored more efficiently.

- The complications, survival, duration of treatment, and reasons for discontinuing treatment are fairly well documented. The quality of life of

patients on HPN has been poorly assessed in the past particularly those with malignant disease and AIDS. A clear survival advantage has been demonstrated for those with a benign underlying disease. However, there is less evidence to indicate whether the complication rates differ for the disease subgroups.

- Organisational models for HPN programmes have been poorly assessed and there are no comparative data that we could locate looking at this aspect of the technology; for example, who should deliver the training and where should patients be trained? Comparative data on many aspects of the technology are completely absent, and those which do exist are marred by non-randomised, poorly-designed, retrospective investigations performed on small samples.

- There is some up-to-date evidence looking at the cost of HPN to the health service. Patient and community costs have not been measured. Only two studies have used a formal methodology for economic appraisal (cost–utility analysis) and these were performed in 1986 (Canada) and 1995 (UK). Comparisons with other technologies have not been made. There are no economic appraisals of HPN used for malignant disease.

Which questions need to be addressed?

- What is the cost per quality-adjusted life year of HPN for subgroups of patients to determine, for example, if it is cost-effective to use HPN in AIDS and cancer patients and other subgroups where the underlying condition is terminal; that is, is HPN of use in palliative care? As part of such a study it is necessary to calculate the typical quality-of-life profile (measured by repeated assessments using a set of validated health status instruments) of patients before, during and after HPN treatments, and to identify moderating factors such as underlying disease. Also, what is the expected survival for patients with terminal malignant disease and AIDS on HPN, and can 'long survivors' be identified?

- What are the most cost-effective organisational models for HPN programmes and does any one model contribute to an improved outcome (for example, small versus large units)?

- What is the best method for training patients for HPN, and should the training be done at home or in hospital?

- Are reservoir catheters associated with less septic episodes than traditional external catheters? Who should then insert central venous catheters, surgeons or interventional radiologists, and what is the ideal position of the catheter tip?

- How cost-effective is HPN compared with other expensive but life-saving technologies?

What methodological issues need to be addressed in future research?

- Larger, multicentre, studies should be performed. They should be prospective with a clearly defined aim. Comparative studies should have a control group and be randomised. Quality-of-life assessments and economic analyses should follow validated methodologies.

- It is important to have complete up-to-date registries measuring patient characteristics and experience. Collaboration and adequate funding is essential.

- Episodes of catheter sepsis, occlusion, central vein thrombosis and metabolic imbalance should be documented as part of centre audit. Standards of care should be compared and maintained.

- Patients should be monitored for the development of liver and bone disease, and these should be recorded as part of the 'total patient experience'.

- All changes in the delivery and management of HPN should be properly evaluated. Comparisons of alternative modes of delivery should preferably be assessed by randomised, controlled trial.

Overall conclusion

The use of HPN for benign intestinal failure is supported by evidence from the scientific studies located. There are, however, large gaps in the evidence, particularly relating to the use of HPN in malignant disease and AIDS.

Publication

Richards DM, Deeks JJ, Sheldon TA, Shaffer JL. Home parenteral nutrition: a systematic review. *Health Technology Assessment* 1997; **1**(1).

NHS R&D HTA Programme

The overall aim of the NHS R&D Health Technology Assessment (HTA) programme is to ensure that high-quality research information on the costs, effectiveness and broader impact of health technologies is produced in the most efficient way for those who use, manage and work in the NHS. Research is undertaken in those areas where the evidence will lead to the greatest benefits to patients, either through improved patient outcomes or the most efficient use of NHS resources.

The Standing Group on Health Technology advises on national priorities for health technology assessment. Six advisory panels assist the Standing Group in identifying and prioritising projects. These priorities are then considered by the HTA Commissioning Board supported by the National Coordinating Centre for HTA (NCCHTA).

This report is one of a series covering acute care, diagnostics and imaging, methodology, pharmaceuticals, population screening, and primary and community care.

The views expressed in this publication are those of the authors and not necessarily those of the Standing Group, the Commissioning Board, the Panel members or the Department of Health.

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http://www.soton.ac.uk/~hta ISSN 1366-5278