

Total parenteral nutrition at home: the implications for a rural practice

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SUMMARY. For various reasons we were faced with the choice of carrying out total parenteral nutrition of a patient at home, or allowing him to die untreated.

The logistic problems of organizing supplies and technical support in a rural practice 32 km (20 miles) from the nearest hospital are described, in the hope of showing that in better circumstances carrying out total parenteral nutrition at home is feasible in general practice.

Introduction

TOTAL parenteral nutrition has become an accepted procedure in hospital (Fischer, 1976) but only rarely has it been attempted on a domiciliary or outpatient basis, and usually only by specialized teams (Jeejeebhoy *et al.*, 1973; Jeejeebhoy *et al.*, 1976).

History

Our patient, a 56-year-old consulting engineer, first became ill in December 1974 when he underwent a laparotomy for acute small bowel obstruction complicated by a mesenteric thrombosis and severe post-operative paralytic ileus. He remained well until July 1976 when he developed a severe obstructive jaundice following a trip to India. At laparotomy his pancreas was noted to be enlarged and nodular and a differential diagnosis of carcinoma of pancreas or chronic pancreatitis was made; however, alcohol was known not to be a causative factor.

Between July 1976 and November 1978 the patient's health steadily declined owing to pancreatic exocrine failure causing malabsorption and a continuing fall in body weight. Two further laparotomies proved necess-

ary for small bowel obstructions due to adhesions, and the second operation revealed a large pancreatic pseudocyst which was drained. Each operation was complicated by paralytic ileus and slow convalescence and was a considerable drain on the patient's resilience. Pancreatic biopsies taken during these procedures still failed to produce any evidence of malignancy and were reported as chronic pancreatitis only. At each operation the surgeon reported a mass of adhesions causing obstruction and the presence of redundant loops of bowel.

The patient's chronic malabsorption produced a fall in body weight from 66.6 kg (10 st. 7 lbs) in 1976 to 39.0 kg (6 st. 2 lbs) in December 1978. His malabsorption was thought to be due to his proven pancreatic exocrine failure and to bacterial overgrowth in redundant bowel (the blind loop syndrome). A glycocholate breath test in July 1978 confirmed the latter. His weight had continued to fall despite administration of exogenous pancreatic enzymes, and a variety of antibacterials including tetracycline, neomycin, and metronidazole (Flagyl).

By the end of 1978 it had become clear that surgery would not offer the patient any relief from his distressing symptoms, and with a body weight of 39.0 kg (6 st. 2 lbs) his life expectancy was only a few weeks. In the face of all these problems the patient had made the reasonable request for a second opinion, and in December 1978 a consultant in gastro-enterology from Edinburgh approached the patient, offering him total parenteral nutrition as a last resort.

A brief description of the patient's character may explain his attitude when the offer was made. Within two years he had declined from perfect health and felt unwell all this time. He had undergone six hospital admissions, extensive and often uncomfortable investigations, suffered a considerable diminution in visual acuity following cataract surgery, and all this in a man who hated the upset of hospital life and valued to the

utmost his health, his privacy, and his dignity. It must be stated that the patient's courage had engendered the profoundest respect in all of us.

His first reaction was to reject total parenteral nutrition out of hand, preferring to die quietly at home than to face further treatment. However, without our prompting, he eventually agreed to a trial period of treatment but reserved the right to ask us to stop, being fully aware of the fatal consequences should he do so.

With the agreement of his wife, who is medically qualified, he refused to remain in hospital longer than seven days, and that only to have his intravenous cannula inserted.

Consequently, he was admitted to hospital in Edinburgh on 18 December 1978, had his cannula inserted the next day, and was discharged home to the care of his general practitioners 92 km (57 miles) from Edinburgh on 23 December 1978, having already begun total parenteral nutrition.

Management

The techniques of total parenteral nutrition are fully described elsewhere (Fischer, 1976). An individual régime was devised by the consultant along conventional lines, but was adapted to suit the patient's own home. Two lines were run, connected by a 'Y' type connector to the indwelling intravenous cannula.

Management of the intravenous lines was greatly helped by the loan of an advanced 'syringe' infusion pump by Sonicaid Ltd, whereby an accurate delivery of fluid by one of the lines was effected.

The régime during a 24-hour period was a mixture of various proprietary preparations containing amino acids, dextrose, multivitamins, and lipids, with the addition of varying amounts of electrolytes and soluble insulin, as indicated by the most recent biochemistry results.

Throughout treatment we were troubled by the patient's symptoms of subacute obstruction which were thought to be due to multiple adhesions following his many laparotomies.

Almost from the start the patient suffered from intractable vomiting and our inexperience led us to disregard the relative fluid depletion which presented a crisis six weeks after the beginning of treatment.

From biochemistry results it was possible to calculate a fluid deficit of about three litres and rigorous treatment with normal saline and five per cent dextrose was required over a period of 48 hours.

This crisis led us to keep much more meticulous fluid balance charts. A nasogastric tube was passed from time to time to aspirate stomach contents. This enabled accurate measurement of fluid loss and led to greater comfort for the patient, who was spared the exhaustion of vomiting.

The patient's haematology was monitored throughout the treatment and after three weeks his haemoglobin had fallen from 10.9 grams/100 ml to 8.7 grams/100

ml. Two units of packed cells were given at this time. His post-transfusion level was 12.1 grams/100 ml. After a further four weeks his haemoglobin had again fallen (to 8.0 grams/100 ml) and another transfusion of two units of packed cells produced a less satisfactory response to 9.5 grams/100 ml. A total dose infusion of iron dextran (Imferon) given at 10 weeks failed to hold his haemoglobin at reasonable levels.

Progress was well maintained between the first and eighth week of treatment. An initial body weight of 39.0 kg (6 st 2 lbs) had risen to 44.8 kg (7 st 0.6 lbs) and the patient had become sufficiently strong to leave his bed, bathe, and even venture downstairs. However, at the end of the eighth week he suddenly became tremulous and collapsed; he was febrile and suffered severe rigors.

It was assumed that this was due to septicaemia due to infection of the cannula, against which stringent aseptic precautions had been taken. Blood was immediately taken for culture and a 'blunderbuss' therapy instituted of intravenous gentamycin, lincomycin, and metronidazole (Flagyl).

It was found eventually that the blood cultures yielded no growth, and it was thought that his symptoms were due to ascending cholangitis derived from the bacterial overgrowth of the gut.

This first febrile episode appeared to be a turning point for the patient and his condition seemed gradually to deteriorate after this. Several more episodes of ascending cholangitis were experienced in the following weeks, which became progressively less amenable to antibiotic treatment.

The patient was first noted to be jaundiced after this eighth week and his liver function tests consistently showed an obstructive picture. Right hypochondrial pain also became a feature and large doses of opiates were required to control this. An acceptable alternative for background analgesia was found in intramuscular pentazocine.

After 12 weeks' treatment the patient's weight was still 44.3 kg (6 st. 13 lbs). However, he took a steadily deteriorating course with increasing jaundice until he died in the fifteenth week of treatment.

Discussion

Intravenous fluids

It was decided that all the intravenous fluids should be supplied from the pharmacy department of the hospital of the Edinburgh consultant physician. There were two reasons for this: first, the difficulty of ordering small quantities from the manufacturers and the need for flexibility in supply which could be provided only by a large hospital department in the event of a change in régime; secondly, the skill of the pharmacist who had taken a special interest in total parenteral nutrition and had a close working relationship with the consultant in charge of the patient.

The obvious difficulties of transporting supplies the 92 km (57 miles) between the hospital and the local retail chemist shop were overcome by enlisting the aid of the wholesaler, who supplied both the hospital and the local shop. The hospital pharmacist was in regular contact by telephone and the appropriate supplies were consigned via the wholesaler's van, which made a journey across central Scotland once a week.

On several occasions during the first weeks this arrangement produced problems. Sometimes it was because different fluids were required urgently before the weekly delivery, because of a sudden clinical change; at other times it was because of physical difficulties in transport, such as the van breaking down. When these occasions arose emergency supplies were made available by kind intervention of the local hospital pharmacy, only 32 km (20 miles) away. The supplies from the local hospital were transported with the co-operation of a bus company, the police, the ambulance service, the patient's relatives, and on one occasion by us.

Intravenous giving sets

When the patient was discharged initially, he was given a supply of intravenous giving sets and 'Y' type connectors. Further supplies were offered by the hospital but we felt that this might overload the transport arrangements for the intravenous fluids, and so we prescribed them in the normal way on our general practitioner NHS prescription forms.

It should be pointed out that the patient could not have been discharged at a worse time. He arrived home on the 23 December, just before most supporting hospital services went on to a skeleton service during the Christmas and New Year holiday period. The first month of treatment was a time of considerable disruption caused by disputes of lorry drivers and hospital ancillaries. Indeed, the supplies of 'Y' type connectors were held up for over three weeks because of industrial action both at Liverpool Docks and the manufacturer's depot. The weather was also the worst recorded in the area for 16 years.

NHS funding

Whilst the main burden of such expensive treatment had been removed from the primary care budget by the hospital's supplying the intravenous fluids, we were worried about the effect on prescribing costs that prescriptions for the intravenous 'hardware' would have. We were also concerned about continuity of supply.

We therefore approached the local Health Board and asked them to make an exception and supply the items required direct from the hospital pharmacy. The response from the District Administrator was not very helpful and he pointed out that as all items were prescribable we should continue to use GP 10. However, a very helpful community medicine specialist agreed to help us out of any immediate difficulty.

Laboratory investigations

One of the main problems of managing total parenteral nutrition at home is that of use of the laboratory, not only in relation to week-to-week checking of normal parameters which can fall into deficit, but also to swift recognition of sudden problems such as fluid depletion.

Our practice is equidistant between the teaching hospitals of Glasgow and the local laboratory at Stirling Royal Infirmary. The laboratory used depended entirely on which direction an ambulance might be going on that day. This arrangement avoided the delay caused by posting samples and the effect this might have on the validity of results, particularly serum potassium results.

We have already described episodes when the patient's clinical condition became critical. In such circumstances it is important to have an immediate response from the laboratory and often to have repeated samples taken in one day. Transport difficulties often restricted the number of samples we could take during any given period, and samples taken late in the day often had to be arranged on an emergency basis with the technicians.

A telephone call to the laboratory to warn them of the despatch of an important sample often helped in securing urgent attention.

Records

Fortunately, the practice had converted to the A4 record system a few months before this exercise was started. We feel that the traditional, smaller record envelope would have been quite useless as an effective tool in the management of this patient. During a period of two years we had accumulated clinical notes that ran to 14 sides of A4 size paper, and 41 hospital letters. A4 filing enabled all this information to be stored in book form in a logical order.

The large number of laboratory results were not filed, but tabulated on a separate flow sheet. In this way not only could individual results be seen easily, but also improving or deteriorating trends.

Nursing

In America and Scandinavia, where total parenteral home nutrition is considerably more common than in the UK, it is usual to spend many weeks in training the patient's family in aseptic technique and letting them become familiar with the equipment. We did not have this time available to us and had our patient's wife not been a doctor we would not have been able to contemplate this procedure at such short notice. However, we do feel that given careful training, an intelligent lay person could look after a patient as long as adequate community nursing support was available.

Our district nurses were not called upon at all, and this may well explain the lack of exogenous infection in our very debilitated patient. However, the patient's wife suffered considerable physical and mental strain while carrying out the superb care she gave her husband.

Medical supervision

There would be little point in a practice contemplating total parenteral nutrition at home if it was not prepared to visit daily for the first few weeks and at least on an alternate day basis after that. We found it an advantage for one partner to take a continuing interest in the patient, but always to have another well briefed and able to take over effectively when necessary.

A fair degree of ability in organization and improvisation is necessary. The general practitioner must be prepared to take decisions if consultant advice is not immediately available. The use of a deputizing service is incompatible with this treatment in general practice.

The arrival of the second author (A.R.M.) to the practice was a great boon, since his previous job had been as a registrar anaesthetist in a large teaching hospital and he therefore had considerable experience of total parenteral nutrition in intensive care units.

Conclusion

Our patient remained on total parenteral nutrition at home from initial insertion of the intravenous cannula until his death 98 days later. During this time he was seen only once by a member of hospital staff.

He required at least a daily visit from the practice, and on many occasions multiple visits during 24 hours.

Many clinical crises had to be handled immediately by his general practitioners with telephone advice from his consultant. However, most other patients would have let us send them to hospital for further treatment.

Most clinical problems were compounded by the lack of immediate supplies and as much time was spent on logistics as was spent on seeing the patient.

We conclude that if this procedure can be carried out with minimal preparation, albeit with a disappointing result, it is feasible for a general practice to consider offering such home treatment in better circumstances.

References

- Fischer, J. E. (1976). *Total Parenteral Nutrition*. New York: Little, Brown & Co.
- Jeejeebhoy, K. N., Zohrab, W. J., Langer, B., Phillips, M. J., Kuksis, A. & Anderson, G. H. (1973). Total parenteral nutrition at home for 23 months, without complication and with good rehabilitation. *Gastroenterology*, 65, 811-820.
- Jeejeebhoy, K. N., Langer, B., Tsallas, G., Chu, R. C., Kuksis, A. & Anderson, G. H. (1976). Total parenteral nutrition at home: studies in patients surviving 4 months to 5 years. *Gastroenterology*, 71, 943-953.

Acknowledgements

We wish to thank all those people, in hospital and in the community, professional and lay, who made the care of this patient possible. In particular we thank the patient's wife and family who gave so much.

Addendum

Dr McGregor is now a principal in general practice in Kilwinning, Ayrshire.



COLLEGE ACCOMMODATION

Charges for college accommodation are reduced for members (i.e. fellows, members and associates). Members of overseas colleges are welcome when rooms are available. All charges for accommodation include breakfast and are subject to VAT. A service charge of 12½ per cent is added. Children aged 12 years and over, when accompanied by their parents, can always be accommodated; for those between the ages of six and 12 years, two rooms are being made available on a trial basis. Children under the age of six cannot be accommodated and dogs are not allowed. Residents are asked to arrive before 18.30 hours to take up their reservations.

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	Members	Others
Single room	£8	£16
Double room	£16	£32
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Royal College of General Practitioners,
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