

Home parenteral nutrition and the psyche: psychological challenges for patient and family*

Julian Stern

Psychological Medicine Unit, St Mark's Hospital, Watford Road, Harrow HA1 3UJ, UK

The paper discusses the case histories of three patients who have faced the emotional implications of being initiated onto long-term parenteral nutrition (PN). In each case the patient's personal and family history, relationship to their illness and the presence or relative absence of resentments and grievances have influenced their ability to tolerate the training and the transition to home PN (HPN). In addition, the emotional importance of food and feeding from a developmental and social perspective is explored, together with the numerous psychological and social 'losses' experienced by all patients on PN and the adaptations required within the family setting. The 'meaning' of PN to the individual and the need for both internal and external support are identified and, based on clinical experience, a number of features are described that may be indicative of the relative abilities of different patients to cope with HPN. Finally, the role of a dedicated Psychological Medicine Unit closely allied to a nutrition service is discussed.

Home parenteral nutrition: Psychological challenges: Multidisciplinary approach

Experience has shown that for patients with gastrointestinal disorders for whom recovery depends on permanent or long-term parenteral nutrition (PN) the adjustment to the change in lifestyle is frequently accompanied by considerable emotional problems. These patients may require psychological support in addition to the medical and nutritional support they receive. The adoption of a multidisciplinary approach that includes psychological assessment and treatment of such patients, as well as consultation with staff members, can make a large and sometimes crucial contribution to successfully preparing them for home PN (HPN).

The differing emotional impact for individual patients of being initiated onto long-term PN and its effect on the success of HPN will be illustrated by the case histories of three patients.

Case histories of three patients

Patient 1 is 24 years old, and was a healthy and extremely well-built martial arts expert, body-builder and beach fanatic until he became acutely unwell in May 2004. He developed sudden severe abdominal pains, was admitted to

his local hospital and was found to have an infarction of his superior mesenteric artery. He spent 3 months in a local hospital, underwent a number of further surgical interventions and was then transferred to St Mark's Hospital. He was malnourished and dehydrated, had a central line and a stoma and an output of 6 litres, and found his situation to be intolerable. He considered that it would be unacceptable to have a central line at home and a stoma. His life had consisted of maintaining his perfect physique and socialising. His ambition was to train as a lifeguard in Australia.

Before discharge he had numerous anxieties, many of which are shared by patients going home on PN. He was concerned about what he perceived as restrictions to his lifestyle, what his body was going to look like and the risk of infection to his central line. For this patient, there were only two options, 'either you join me up again, or I will get a transplant, even if it means dying'. The thought of living with a stoma and PN for the rest of his life was definitely not an option, and it was necessary to try to understand why. In work with the patient on the ward, some understanding of him and his fears was achieved.

He had always been undersized as a child, was teased at school and had a protective father. As a result of joining

*In accordance with recommendations from within the field of psychiatry and psychotherapy publication, case material pertaining to all three cases has been substantially disguised to safeguard the confidentiality of the patients described.

Abbreviations: HPN, home parenteral nutrition; PN, parenteral nutrition.

Corresponding author: Dr Julian Stern, fax +44 208 2354001, email julianstern@hotmail.com

the school cadets at 13 years of age he became increasingly obsessed with developing the perfect physique, and was determined to meet any challenge. He was attractive to women, and as the only sibling living at home he was indulged. Furthermore, he described a dream that reflected his anxiety about his situation, in which he described being assailed by a gang of 'Mafiosi', intent on intruding on his body with tubes. His resentment of his stoma and PN is therefore understandable, as all his vulnerabilities were now exposed.

He trained well at administering PN, perhaps helped by his interest and pride in his appearance. However, he remained very ambivalent about the PN and was unable to express any gratitude that his life had been saved by the surgery, the nutrition and the hospital staff.

He wanted a total solution, either to return to normality or to die; i.e. 'black-and-white' thinking, representing a primitive state of mind in contradistinction to that of patients who can see the 'grey' (the ambivalence), can mourn losses and get on with life.

Whilst on the ward he was seen by the psychiatrist a number of times, and subsequently a meeting was held with other members of the multidisciplinary team and his parents. The importance of his family background and childhood experiences was ascertained and by the time of discharge he was more resolved to a life on HPN, to trying out a less-radical surgical approach and to returning as an outpatient to the Psychological Medicine Unit if required.

Patient 2 was 24 years old when she was first seen in the Psychological Medicine Unit, at which stage she had developed more than twenty central line infections and was at substantial risk of dying prematurely.

She was born with a congenital malformation that was corrected at an early age by surgery. In her early twenties she eventually agreed to pouch formation. Unfortunately, the procedure had failed, resulting in anastomotic breakdown, fistula formation, a loss of viable intestine and an immensely long period of hospitalisation. Consequently, she was involved in a legal action against the surgeon, alleging that she had not been given full details of possible operative risks and had not been warned about the consequences of its failure, i.e. a permanent stoma and total PN.

She hated her PN and felt imprisoned, spending 16 h/d in her bedroom surrounded by nutrition and stoma equipment, with a daily 'window of opportunity' for 5–6 h between approximately 11.00 hours and 16.00 hours when she might be able to visit the shops or a family member.

She was filled with resentment and sadness, and part of the difficulty in assessing her mental state was related to her compensation claim. It is well known that patients may fail to improve (physically and psychologically) whilst there is a court case or compensation proceedings underway (Lishman, 1987). This lack of improvement is partly conscious, in that the patient might wish to exaggerate their symptoms and disability to improve their chances of a favourable outcome, but is mainly unconscious, being associated with wanting to punish the surgeon or medical team, together with deeper resentments towards individuals who have previously let them down. In this case it was unclear to what extent the patient's mood was likely to alter after the conclusion of the court case. She did report

two dreams that conveyed her sense of entrapment and being operated upon without adequate warning or preparation.

The extremely high rate of line infections was a concern and attempts were made to address this problem with the patient. She blamed her cramped living conditions and recognised that the close proximity between her stoma equipment and her nutrition provisions might not help. She also recognised that sometimes when she felt angry or depressed she compromised the meticulous technique and became very negative. She denied being actively suicidal, but recognised that a part of her would prefer to die, to some extent to punish the surgeon who had let her down. Clearly, her self-destructive impulses were associated with these vengeful impulses. Furthermore, she had also lost her uterus and thus her ability to have children, and had a very restricted social life and no intimate relationships. Her care and abuse of her central line is intimately linked to her psyche, the depression and resentment being prominent factors in the aetiology of her prevalence of line infections.

Patients 1 and 2 contrast with patient 3, a 40-year-old mother who was on the ward for 4 months. She has Crohn's disease that has fistulated, and she has gone home with a stoma, a fistula and total PN. She will need to return for further surgery, but it is likely she will be on PN for life.

She underwent many psychological consultation sessions whilst she was on the ward to help her come to terms with the changes in her life. Although she has a supportive husband and a much-loved young child, she too experienced resentment towards her situation; however, despite her anxiety, she also planned for the future.

So, three patients have been described: patient 1, who is antagonistic, scared, resentful but beginning to shift with some psychological and family help; patient 2, who is resentful, fighting a court battle and perhaps actively sabotaging her line; patient 3, who is beginning to accept the HPN, once again with substantial psychological and family support.

Having discussed specific patients, some broader issues relating to all patients facing PN will now be considered.

The importance of food and eating

From the first days as newborn babies, feeding (initially drinking, then eating) carries profoundly important value, both emotional and nutritional. Feeding may involve periods of prolonged intimate contact between mother and baby, associated with sensuous touching and stroking and substantial bodily pleasure comprising sounds, tastes, smells, sensations and a shifting in and out of sleep. On other occasions there may be less idyllic feelings in both baby and mother of frustration, hunger, pain, irritability, impatience and non-satisfaction.

Parental attitudes

From those earliest moments onwards feeding has great emotional importance. In childhood there are family disagreements and conflict about feeding (too much food, too little food, the wrong type of food, having a 'sweet tooth',

being too fat or too thin) and the end result of feeding (potty and toilet training). Children are praised about their appetites, rewarded, scolded, punished, loved and resented, and recollections of those earliest years or observations of children suggest how much emotional weight surrounds feeding, and elimination. Indeed, in Freud's (1905) famous psychoanalytic theory of child development the earliest developmental stages are termed the 'oral' and the 'anal' stages, referring to the importance of these areas of the body, and their emotional ramifications.

Parental attitudes towards feeding are hugely influential to the developing child. The parental attitude (generous or punitive, liberal or rigid) will affect not only the child's feeding habits, but also their developing body image, attitude towards food and, later on, attitudes towards other aspects of the body, such as sexuality. An example of the importance of family attitudes towards food comes from studies of mothers who have suffered from eating disorders themselves (Stein *et al.* 2001). These studies show that mothers with eating disorders, compared with mothers without an eating disorder, tend to use more strong verbal control and are overall more verbally controlling of their children, especially during play. Furthermore, the conclusion of these studies is that such mothers 'may need help to prevent the extension of the control they exert over themselves, to the interactions with their infants'. Thus, food, control, freedom to play and emotional development can all be seen to be linked. Moreover, a recent study by Senior *et al.* (2005) confirms that both parental cruelty and childhood sexual abuse are strong risk factors for the later development of lifetime eating disorder symptoms (see also Emmanuel *et al.* 2004), and that eating disorder symptoms during pregnancy are predicted by a similar set of early experiences, i.e. parents with alcohol problems or depression, parents being emotionally or physically cruel and having been sexually abused. Thus, early disturbance predicts for eating disorders in adulthood, which in turn predict for excessively controlling behaviour towards the next generation. Food and feeding are invested with substantial emotional importance for each individual.

Social dimensions of eating and drinking

The personal importance of feeding is closely associated with the social dimension. Eating and drinking are often very social acts (arrangements to meet friends and partners are often made around places of eating (restaurants, coffee houses) or drinking (public houses)). The first 'date' in a potential new relationship is often in a public house or restaurant. After-work socialising with colleagues, meeting up with old friends, business meetings, celebrating good news such as job promotions or passing an exam and even mourners congregating after a funeral are all gatherings that may take place in venues of food and/or drink, and eating and drinking are regarded as an integral part of such occasions.

Sex and food

Although sex and food are sometimes kept in separate compartments in the mind, they are linked in multiple

multi-layered ways; examples for consideration include: the ice cream advertisements or the way in which novelists, food critics or film makers portray eating, licking, sucking and smacking the lips; the rituals associated with opening champagne bottles, or the myths associated with oysters as aphrodisiacs; for a baby at the breast, what is feeding and what is sensual and what is a mixture for both mother and baby. And there is always some sense of exclusion from this 'couple', felt by father and the other siblings.

Psychological and social 'losses'

So, when 'normal' eating or drinking becomes impossible, for whatever cause, there are numerous psychological and social 'losses': the pleasure of the food and drink in its own right; the social and the sensual aspects of eating together with others; the nutritional value in the food and drink; a sense of adult independence; the ability to share in these pleasures with others. In addition to these losses there may be other difficulties: when the loss of oral feeding is also associated with the need for PN, there will be the additional risks; when there is also a stoma, then not only is intake through the mouth 'abnormal', there is also an abnormality of 'output' and the possibility of additional social, psychosexual and physical worries relating to the stoma and its appearance and functioning.

Mourning the loss of an organ

An additional loss is less often thought about; that of mourning for a part of one's body that is gone. It is easy to understand the mourning for a leg or arm that has been amputated, and 'phantom' pains in the area of the amputated limb are often described. A leg or an arm is useful, and its absence is not only a hindrance, but also visually obvious. It is also quite easy to think of a woman mourning her womb after a hysterectomy, primarily because of the emotions attached to a womb; it may feel as though the surgeon has removed the very essence of her femininity. In clinical practice women often become depressed after a hysterectomy and complain of abdominal pains that can only partly be explained by the surgery itself.

Is it possible, therefore, that the loss of a part of the bowel needs to be mourned? Just because it is invisible, does that mean the individual has no relationship with it? At St Mark's Hospital many physicians would agree that there seem to be patients who mourn the loss of parts of their bowels, and that this mourning, unless recognised and dealt with, can delay recovery and may mean a higher requirement for pain relief and other medication.

The meaning of intravenous nutrition: why some individuals are phobic or resistant

It is clear that the impact of PN for individual patients can differ: for some patients it will be a bodily intrusion, and every aspect of it will be unacceptable; for some patients it will confirm a grievance or a resentment against a surgeon or a doctor who neglected the patient and it is that other

person's fault, and an aggrieved state of mind will set in; for other patients it is a matter of bad luck that Crohn's or intestinal failure has occurred, and the PN may even be welcomed as a new lease on life.

In the more discontented patients the PN may not be easily accepted, the learning may be delayed and consciously or unconsciously the patient may even allow the PN to fail by getting too many line infections or by neglecting the line care, the ordering of supplies or the care of the feed.

Similarly, the relationships with the members of the HPN team will be fundamentally influenced by the patient's previous experiences. Patients who have had an upbringing that was primarily happy, with no severe abuse or neglect and with parents who attended carefully to their needs are likely to have a basic trust in the good intentions of the nurses and doctors, and errors will not be exaggerated into major breakdowns.

On the other hand, if the patient's basic view of the world is filled with mistrust, fear of abuse and a need to be ultra-vigilant at all times, the relationships on the wards are likely to be fraught, and slight misdemeanours on the part of staff members may be considered to be evidence of gross incompetence, with an increasingly paranoid attitude developing and heightened levels of anxiety among staff, patient and family members alike.

This vicious cycle of mistrust may, in its origins, be unrelated to the competence of the nutrition team, but may be associated with the patient's psyche. However, vicious cycles of mistrust, hyper-vigilance, anxiety and misunderstandings can escalate until eventually the team does make a genuine misjudgement or error that only serves to confirm the patient's worst fears that no one can be trusted (Freud, 1905, 1914; Steiner, 1996).

This situation leads on to the question of external and internal support.

Who copes: external and internal support

How well the patient copes with any surgical procedure, or any illness, depends on a large number of factors. Some factors are related to the procedure or the course of illness itself: was the operation a success; was recovery speedy; was pain relief good; was the hospital setting supportive and competent. However, there are also psychological factors at play, unique to each individual, related to external and internal support. 'External support' is the extent to which there is support available in relation to the practical and emotional issues, and not only in terms of numbers but also the quality of that support (is it offered in a generous, loving manner, or is it filled with conflict, resentment or conditions).

'Internal support' relates to the extent to which past experiences of being looked after can be drawn upon, such that even in the absence of a loving friend or relative at the bedside there is some sense of internal strength, even when things are going badly. The lack of some 'internal support' might lead to panic at being left alone, terrifying thoughts and nightmares, and might even predispose to a negative misinterpretation of the intentions of nurses and doctors. In

other words, the absence of 'internal support' might also mean the patient, unwittingly, drives some of the external support away or becomes more difficult to be looked after by staff, family and friends alike.

Features relating to the ability to cope with parenteral nutrition

Experience suggests that if a patient shows any of the following features the prognosis for their ability to cope with the PN is likely to be poor:

1. a hatred of the illness, an inability to come to terms with the diagnosis or the surgery, especially where there is a sense of injustice;
2. allied to the sense of injustice, a court case pending against a doctor or a Trust;
3. no opportunity for psychological preparation in anticipation of the surgery or the institution of PN;
4. a past history or predisposition to acts of deliberate self harm;
5. a functional bowel disorder with increasing recourse to surgery for essentially psychosomatic complaints;
6. substantial mental impairment, particularly learning difficulty, but also a severe mood or personality disorder that may affect the ability to train in the use of PN;
7. gender effect; there may be a difference between women and men in their response to training in the use of PN and their acceptance of PN in their lives. During their development women have fundamentally different biologically-determined experiences from men, and consequently their relationship with their body is different. However, whether this difference makes female patients more able to cope with the bodily intrusion of a central line, with looking after their own bodies or with caring for the line has not been established;
8. obsessional traits in the personality, which, if present in moderation, for most patients can be harnessed to good effect. Only in excess, does obsessiveness act as a hindrance to personal development, when the rituals, obsessions and compulsions coalesce into severe obsessiveness or obsessive compulsive disorder. Whether the same applies to PN training has not been established.

All these potentially prognostic factors are, however, hypothetical and require testing and refining.

Going home v. remaining in hospital

The members of the multidisciplinary care team who are primarily hospital based will get a skewed picture of the patients' lives. They may seem to do quite well learning the techniques whilst in hospital, with support from the nutrition team, with constant nurturant nursing and meals prepared for them and many fewer obligations, responsibilities and demands than out in the community. Furthermore, patients may complain about being in hospital and may compare it with prison, with their discharge into the

community often feeling like a release from prison. However, released prisoners are sometimes reminiscent and long for the safety and routine of the institution, and in some cases ex-prisoners may even re-offend in order to be imprisoned again. So, it is not unexpected that some PN patients, when confronted with the chaos or the loneliness of life at home, with no nurses or dinner ladies and with all sorts of demands being placed on them, are unable to cope or at least find it much more difficult.

Although the impact of HPN on family members has not been discussed, clearly this aspect is crucially important. It is necessary to understand the meaning of the HPN not only for the individual concerned but also for close relatives (spouse, children or parents), as the response of the relatives will be of major importance in the success of the HPN in every case.

Conclusion

For the three patients discussed, PN had a particular personal meaning that has fundamentally influenced their ability to care for themselves and their compliance with the tasks required to keep themselves well nourished, well hydrated and free of line infections. Their ability to respond to the challenge of PN may have been affected by psychological and social factors that reflect their earlier life experiences, including psychological aspects of food, eating and nutrition during development.

In recognition of the impact of some of these complex psychological factors in patients with nutritional problems, St Mark's Hospital has established a Psychological Medicine Unit so that the staff members (psychotherapist, psychiatrist and social worker or counsellor) can work together with the medical and nutrition team to assess and support patients and offer psychotherapy where appropriate (Stern, 1999, 2003). The 'external support' thus offered is crucial in helping many patients with short-bowel syndrome or other complex nutritional difficulties to cope with the multiple psychological and social losses associated with long-term HPN, and in providing them with a forum outside the usual family support systems to discuss and work through some of their dilemmas and anxieties. In addition, every week the Psychological Medicine Unit offers a period of 2 h in which time is set aside to consider these patients and their psychological status and its impact on their care and self-care, comprising: a 1 h seminar specifically for the nutrition team specialist nurses,

providing them with a deeper understanding of the sorts of issues that their patients may have to confront; for 1 h every week all members of the clinical team (including the dieticians, specialist nurses and ward-based nurses, physicians and surgeons, pharmacists and the psychological medicine team) discuss in great detail the type of issues affecting the patients, exemplified by the three cases described earlier.

This service, and the clinical service of the Psychological Medicine Unit, is available only for patients currently being treated by the St Mark's Hospital for their bowel disorder. This constraint ensures a manageable case-load and maintains the integrated approach, rather than one in which the patients' medical and the psychological needs are serviced independently.

Based on the experience of the effectiveness of this approach, it is recommended that other specialist units should develop similar models for their patients and staff.

References

- Emmanuel AV, Stern J, Forbes A, Treasure J & Kamm MA (2004) Anorexia nervosa in gastrointestinal practice. *European Journal of Gastroenterology and Hepatology* **16**, 1135–1142.
- Freud S (1905) *Three Essays on the Theory of Sexuality*. *The Penguin Freud Library*, vol. 7. London: Penguin UK.
- Freud S (1914) Remembering, repeating and working through. *Further Recommendations in the Technique of Psychoanalysis*, standard ed., vol. 12, pp. 145–156. London: Hogarth Press.
- Lishman A (1987) *Organic Psychiatry: The Psychological Consequences of Cerebral Disorder*, 2nd ed. Oxford: Blackwell.
- Senior R, Barnes J, Emberson J & Golding J (2005) Early experiences and their relationship to maternal eating disorder symptoms, both lifetime and during pregnancy. *British Journal of Psychiatry* **187**, 268–273.
- Stein A, Woolley H, Murray L, Cooper P, Cooper S, Noble F, Affonso N & Fairburn CG (2001) Influence of psychiatric disorder on the controlling behaviour of mothers with one-year old infants. A study of women with maternal eating disorder, postnatal depression and a healthy comparison group. *British Journal of Psychiatry* **179**, 157–163.
- Steiner J (1996) Revenge and resentment in the Oedipal situation. *International Journal of Psychoanalysis* **77**, 433–443.
- Stern JM (1999) Psychoanalytic psychotherapy in a medical setting. *Psychoanalytic Psychotherapy* **13**, 51–68.
- Stern JM (2003) Review article: Psychiatry, psychotherapy and gastroenterology – bringing it all together. *Alimentary Pharmacology and Therapeutics* **17**, 175–184.