

# HOME PARENTERAL NUTRITION: AN ETHICAL DECISION MAKING DILEMMA

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## ABSTRACT

**Ethics is a hot topic these days. Home health care providers need not be ethicists, however they do need to be able to identify problems quickly, and know how to address them. This paper explores the ethical issues arising from a narrative analysis involving an advanced cancer patient receiving Total Parenteral Nutrition (TPN) at home. It shows how complicated it is today to make nutrition support decisions that would have been customary less than 30 years ago. For and against arguments of TPN for advanced cancer patients are reviewed. Ethical positions adopted by the medical and nursing professions are explored and contrasted. The importance of patient autonomy, within a holistic notion of care, including decisions incorporating quality of life, are affirmed, providing a challenge to monitoring the status quo in approaches to decision making.**

## INTRODUCTION

The use of TPN for advanced stage cancer patients has significant ethical dimensions, showing the inter-relationship between ethical and clinical decision making. At times, all nurses can ask - are we prolonging life or prolonging death, and for whom are we providing the treatment? Ethical and legal issues concerning TPN for those with terminal illness are becoming increasingly significant to health care providers working in both the acute and home health settings. Certainly, the incidence of cancer patients receiving long-term TPN via complex vascular access devices in the home is increasing. The wisdom of this exercise is questionable when poor quality of life is often the outcome (Goodhall 1997), and this has resulted in a dichotomy of convictions. The ethical dimensions of withholding or withdrawing life-sustaining TPN, however, mirror the controversies reported in the literature. Part of the controversy is of course because of the fact that these people have a survival expectancy that varies markedly, typically from one to several months (Bozzetti 1989).

There are numerous accounts in the literature discouraging the use of TPN for advanced cancer patients because of its expense, associated complications, and the complex ethical realities which confront us (Tchekmedyan 1993; Shaw 1992). This discussion in particular draws upon the experience of a 74-year-old woman (we will call her Margaret) who received TPN to manage intestinal malabsorption secondary to urological malignancy and radiation enteritis. The use of TPN prolonged her life considerably, but also led to complications, both from the TPN and those associated with the natural progression of disease.

Although TPN is increasingly considered as a possible treatment for patients with malignant disease but who are not suitable for surgery, reports on the issues in the literature regarding this practice are conflicting (Philip and Depczynski 1997). In brief, there are polarized extremes for and against such therapeutic intervention. Perhaps for

nurses this reflects the struggles over withholding and withdrawing the very therapy in which we are trained and socialised to spend so much of our energy, time and expertise. There is no question that we will need to be naming and facing these ethical dilemmas for a long time to come.

### Setting the scene

This account relies upon the clinical experience of a nutrition nurse specialist and several other home health care nurses during 1998 in Tasmania. It utilises several narrative interactions between the patient and her home health nurses. Margaret's home TPN dilemma was recorded as verbatim journal entries made by the nursing team. Critical reflection upon such text provided the impetus for this account.

Before she was discharged home, Margaret endured almost four months of complex surgery and treatment for carcinoma of the bladder eventuating in severe radiation enteritis, formation of a high output enterocutaneous fistula, and numerous surgical revisions of her ileostomy and urostomy as a result of her underlying disease process. TPN was administered during this time via an implanted port. However, the level of consultation regarding long term effects of this therapy remained unclear. After this time in hospital, Margaret stated emphatically 'I want to go home', and regain some sense of 'normality' in life. For example, her bed and linen, bathroom, garden and cat figured prominently in defining such normality.

TPN was provided by her home health nurses who also attended to her many ostomy and wound care needs. When she did return home, Margaret was so relieved to be home that her mood improved, as did her clinical status. However it was not long until the clinical side effects of long term TPN set in, and Margaret began to suffer intractable nausea, vomiting and severe discomfort associated with her unmanageable electrolyte imbalances.

The home health care nurses felt helpless as their patient was totally overwhelmed by the many aspects of the home parenteral nutrition therapy - the pump, the supplies and equipment, and the distressing complications. Margaret became irritable and angry at her house and her private space being taken over by the medical supplies. Everywhere she turned there was something related to her surgery, her dressings, her bag changes and her line changes. Nausea became the biggest clinical problem and Margaret was now mentioning repeatedly 'I want it all to stop'. This situation resulted in the home health care nurses feeling extremely uncomfortable and helpless, despite all their efforts in delaying the complications of therapy. Margaret's notion of the risks and benefits of the treatment were at marked variance with that of her treating physicians, who saw the side effects of treatment as those they expected.

Margaret had many other complications related to her overall treatment, and the pressure on her family was becoming evident. Her elderly brother was not coping well with the situation, or the foreign technology in their home. Margaret would often say to the nurses who were tending to her TPN at home, 'Who is this for?', as she became more and more resentful of the side effects of treatment.

Hence, it had come to that time where an elderly woman with advanced cancer and related complications of treatment had simply, in her own words 'had enough'. In her words and actions she began fiercely to resent the treatment that was considered medically necessary. Despite her wishes, Margaret returned to hospital, where she died. She died in a place where she did not want to be, from numerous complications including those related to central venous access and sepsis.

This entire situation epitomised the silencing of the patient's true wishes, so often found in clinical settings. Also, it shows the way in which nursing concerns are often silenced or tacit in clinical decision making, where ethics appears to be defined in medical terms. It also showed how 'treatment' and the more holistic notion of 'care' can be different. Certainly the holistic notion of care is affirmed by the nursing literature (Curtin 1994; Goodhall 1997; Fawcett 1993).

### The burden in reality

Margaret's treating physicians considered that her overall nutritional status and strength would improve with home TPN. Further, it was understood that there may be the potential for improvement in her depression/anxiety associated with long-term hospitalisation, and an improvement in her sense of well being upon returning home. On the other side of the loss/gain equation, the shortcomings of home TPN required analysis. TPN is a high-priced treatment in either the acute care setting of the hospital or one's home environment. Home TPN for Margaret placed further non-economic burdens on her elderly brother, as he needed to take responsibility for learning about and providing the TPN care, as a result of her overall weakness. Margaret also had to withstand the disappointment of her worsening clinical status when it did not improve with home TPN. Home TPN also represented an inherent risk for complications related to central venous access, infection and metabolism. However, it appears that home TPN did prolong Margaret's life with minimal nutritional benefits. Yet, it actually magnified her discomfort, anxiety and suffering - consequently diminishing her quality of life.

### Arguments promoting TPN in cancer therapy

This case raises the need to differentiate between aggressively treating malnutrition in a cancer patient, and providing TPN to an advanced cancer patient who is dying. This discussion is not refuting treatment of malnutrition in the many cancer patients who need more kilojoules than they can consume. It has been documented

that patients with cancer who maintain their body weight have a better prognosis (Daly et al 1990; De Wys et al 1980; Bozetti 1989). Cancer provides significant stress to the body, frequently causing cachexia as the body 'cannibalises' its own protein reserves in a process of catabolism. Quillin (1998) describes tumors as major parasites that drain nutrient reserves from the person while blunting the appetite. Grant (1990) estimated that 40% or more of cancer patients actually die from malnutrition, and not from cancer. He contends that nutrition therapy including parenteral feeding is the only treatment for malnutrition in specific cases.

Mayo (1996) argues that nutrition is 'basic' care that cannot be withheld or withdrawn. This argument takes a number of varying forms, all of which emphasise the basic nature of the treatment discussed. Some authors have perceived nutrition as a necessity of life or as routine comfort care regardless of how it is provided (Mayo 1996; Watts and Cassell 1984). A related contention is that nutrition is usually provided in a minimally invasive manner without pain, discomfort, or significant risk to the patient, that is, that nutrition is rudimentary medical and nursing care. Other medically oriented literature implies that provision of TPN upholds the dignity of the patient whilst enhancing the trust and confidence imperative to the physician-patient relationship (Ashby and Stoffell 1995; Craig 1994; Studebaker 1988). Likewise, it has been argued that nutrition (parenteral, enteral or oral) is equivalent to, or the same as 'food on the table' which has immense emotional and symbolic importance as being part of the most basic bond that exists between two persons from the moment of birth onwards (Mayo 1996; Sanstead 1990). All of these arguments point generally toward a final reasoning that surrogate decision makers cannot ethically waive the provision of TPN, because this treatment is so basic.

Another argument for the provision of parenteral feeding has to do with hope. Turco (1998) explains that hope is vitally important to human existence, and without it, advanced cancer patients may experience hopelessness, helplessness and despair. Hope encourages and energizes people and protects them from being swallowed up by suffering and negativity.

In Margaret's case, the provision of home TPN was in many ways associated with the hope that the treatment would enhance her quality of remaining life. It is this notion of hope, however, that leads us to the arguments against the continued burdensome provision of TPN in the advanced cancer patient. The reliance on hope can also be criticised from an ethical viewpoint. We must question if it is at all ethical to bestow false hope on to a patient with terminal cancer by implementing or continuing TPN treatment, and not acknowledging the reality of the person in receipt of care. Indeed, as Margaret asks us, for whom are we providing such treatment, and we might even ask who is doing the hoping?

## Arguments against TPN in cancer therapy

Dunlop et al (1995) argue that there is no clear evidence that increased nutritional support such as TPN alters comfort, mental status or survival of patients who are dying. Some of the arguments in support of the continuation of TPN can be disputed by the information derived from individual cases, whereas others have been addressed on a broader level. Mayo (1996) argues that TPN is equivalent to other forms of life-supporting care and can be forgone on the same basis as ventilation and dialysis, for example. This reasoning reflects the movement of some ethicists away from the idea that 'ordinary care' and extraordinary care' are at all times meaningful distinctions. For example, life-supporting treatment enhances an essential body function that the patient cannot adequately provide independently. This view suggests, for example, that ventilators provide a delivery system for respiration.

Complex vascular access devices inserted for the delivery of TPN provide nutrition, fluid, and blood products, nothing more and nothing less. More candidly, air to breath and food to eat might read as being 'basic'. However parenteral nutritional support, which requires a surgically invasive procedure, is hardly 'basic' or non-invasive. The numerous risks associated with long term TPN, as well as the discomfort, cannot be disregarded as inconsequential or trivial. Few would equate it with the human dimensions of unassisted eating. Furthermore, patients and their families may well consider the provision of this level of complex invasive care as achieving exactly the opposite of what they are trying to achieve.

Some authors suggest that, despite TPN not being useful for the majority of advanced cancer patients, there is a small subset that may gain benefit (Dunlop et al 1995). Margaret clearly continued to deteriorate, encountering morbidity associated with treatment. Yet she did derive nutritional benefit from home TPN, albeit minimal, in that she maintained her weight although at a level less than an optimal body weight. Fainsinger and Gramlich (1997) similarly maintain that there is clear evidence that the majority of advanced cancer patients derive minimal nutritional benefit via the use of TPN. However, there is agreement that a specific group of highly selected patients do benefit nutritionally. Yet, as with Margaret, such gains involve considerable complications and have clear implications for quality of life.

Within the Western literature, there is a clear consensus on the rights of people to refuse treatment. Mercadante (1995) warns that it is not possible to avoid the influence of the patient's and family's values, personal beliefs, and attitudes when making a decision about withholding or continuing home TPN. The difficulty in estimating life expectancy, and therefore predicting the benefits of treatment, means that patients' desires about therapeutic choices must be given consideration even if the attitude of the health care team members is not in favour of such aggressive treatment.

## Resources

Health service managers exert ever-increasing influence on medical treatment (in home and hospital settings) in an attempt to contain costs. Endorsing the provision of home TPN based on cost raises some interesting issues, displaying the economic dimension to ethical decision making, especially in terms of resource allocation. The North American literature suggests that continuation of such treatment could be a revenue generating exercise that fits comfortably (technically speaking) into the reimbursement/prospective payment model of health care provision payment (Quillan 1998).

In the Australian context of public health care, this concept does not apply, although some variations on a communitarian theme exist in outsourcing of health care by public providers. In the vast majority of Australian situations no revenue is generated by the provision of artificial nutritional support. A few exceptions are associated with private providers of health care, which is an expanding phenomenon given the Federal Governments policy thrust of promoting enrolment in private health insurance.

Macfie (1996) recognises that resource allocation implications will be enormous if all patients in those categories of malnutrition (as defined by the American Society of Enteral and Parenteral Nutrition Guidelines 1993) are to receive nutritional support. This would inevitably lead to some conflicts between clinicians and management personnel. Nonetheless, there is no precedent that deems that resources should be seen as a reason not to treat. This dichotomy represents an ethical minefield - one that can hardly be the focus of this paper.

Those with experience in caring for patients with advanced cancer acknowledge that it is unusual for patients and families to request or insist upon TPN when they have been advised of its negligible medical benefits (Fainsinger and Gramlich 1997). Nonetheless, one would hope that a health care system, regardless of its spatial location, would grant adequate flexibility so that patients and their families/carers could make their own decisions regarding the provision of invasive treatments such as parenteral feeding. It is not unreasonable to ask whether this collaboration between the consumers and providers would be significantly challenged in times of severe budgetary constraint? Australia's current health budget deficit is no exception and indeed, the difference in power between patient and provider provides significant challenges to the provision of an equitable dialogue, as Margaret's narrative shows.

Margaret's narrative helps us to focus on the experience of patients as being vital, not only in making individual treatment decisions but in establishing policy which sees *quality* and *ethics* from a consumer perspective. This is not a case of being pro or anti TPN but recognising that individual case studies are located within powerful institutional and personal settings. Narrative helps us to

understand those contexts and to understand the notions of *appropriate* and *inappropriate* care as being context specific, whilst understanding the socio-political dimensions of care.

## Quality of life

Health care professionals frequently employ the term *quality of life*, yet it is a complex abstraction that lacks shared definition, resulting in inconsistencies in its interpretation (Goodhall 1997). It is often a term that is inappropriately used at the bedside, being represented as an objectified reality. The question of how to define quality of life is complex and as Johnstone (1989) suggests, might never find a satisfactory answer. The acknowledgement that quality of life is overwhelmingly subjective is important. Just as important is the recognition that quality of life is also multi-dimensional, with both subjective and objective components (Meeberg 1993).

In reality, it is difficult for others to understand a person's quality of life without critically appreciating the way our own value systems can operate to mediate or even outweigh the beliefs, feelings, wants, needs and aspirations of patients. More importantly, when making decisions for non-autonomous people their subjective component is clearly missing, necessitating onlookers to draw on their own values, thus challenging us to think critically about our notions of quality of life in others. Margaret on the contrary was completely autonomous, and fully cognisant of that fact that she did not possess the freedom to enjoy a quality life, as defined by her. In Margaret's case, home TPN afforded prolongation of life that lacked quality and indeed created burden disproportionate to the benefit.

## Encountering ethical perspectives

Conflicting ethical viewpoints are often encountered in making clinical decisions regarding withholding and withdrawing parenteral feeding for advanced cancer patients. One of the issues is to be found in the way in which dilemmas are defined in accordance with the norms of the biomedical model. The view that medical and nursing professions have differing ethical foci is well supported in the literature (Goodhall 1997; Tchudin 1992; Tingle and Cribb 1995). Johnstone (1989) suggests that nurses are continually advised by medical practitioners that nursing practice is devoid of any sort of moral complication and that it is nonsense for nurses to assume they have any independent moral responsibilities when caring for patients. Yet, this sweeping statement can hardly be sustained. Nurses must be permitted to identify and fulfill their ethical responsibilities when delivering nursing care, and cannot be expected to ignore or violate these. If nurses were to play a more active role in ethical decision-making, a complementary balance of the two ethical orientations might be accomplished.

Unfortunately, our experience was not based on such a complementary or collaborative approach to decision

making. As a result, this decision-making process was not characterised by the health care professionals having respect for the patient's autonomy, to cause her no harm, to engender benefit, and to consider the interests of her family. Although such an approach is hardly optimal, it is in reality common practice, reflecting the dominant power relationships. Medical practitioners dominate and can even define what constitutes 'the ethical decision making process', resulting in an imbalance which fosters a paternalistic biomedical ethic. This imbalance could be redressed by nurses, and is slowly being addressed by nurses, but it requires us to find the courage and systemic support to take a more active role in ethical decision-making. Nurses may well not be legally empowered to have such a role but in terms of ethics clearly have a responsibility. Here the resolution of such a dilemma requires attention to power dynamics and communication practices by all within the health care team, including ensuring that patient advocacy perspectives are fostered.

## CONCLUSION

Despite an extensive literature search, no randomised controlled trials were located in the area of forgoing parenteral feeding in the patient with advanced cancer. Although this topic is highly contentious, we should not be afraid to care for individuals according to the ideals of palliative care, where control of symptoms, not normalizing of physiological parameters, is the fundamental obligation.

Inspired by an attitude of respect for a good life and death, we have suggested that it is feasible to consider, as a general guideline, that the provision of home TPN should be gradually decreased when it has been determined that a patient has reached the terminal stage, or is in an irreversible deteriorating process, or when the TPN is the cause of additional complications and suffering, or when this action is requested by the individual on the receiving end. Many nurses know the experience of inappropriate or disproportionately burdensome provision of life-prolonging treatment, which only exacerbates a person's suffering. Yet we all know how hard it is to stop providing the treatment. However, the very 'winding down' of aggressive intervention can symbolise an approach to care that goes beyond the medical model, inviting dying patients to begin their final journey and giving us, their health care providers, the chance to take part in their inner dialogues and to offer support. In the discourse of palliation this is all well and good to accept. Yet it does not make the decision making process any easier when confronted with the ethical dilemma of seeking justification of long term parenteral feeding - its use, its cost and whether or not it is wanted by the recipient.

Developments in medical knowledge and technology enable the health care profession to employ greater control

over life and death. However, being able to prolong life in some cases may be in conflict with the ethos of caring, which has as its core empathy for others and relief of suffering. As was our experience with Margaret, inappropriate home TPN can further reduce quality of life through additional pain and discomfort, perceptions of loss of dignity and ensuing complications. That which constitutes appropriate and inappropriate TPN will of course vary from case to case.

This case study undoubtedly challenges us to think beyond automatic assumptions that we must never withhold the basic necessity of food, challenging us to think again about what constitutes food and care in particular circumstances. It is therefore representative of a quandary for those involved in decision-making regarding: to feed or not to feed. These are the continuing ethical dilemmas associated with determining the appropriate path between overtreatment and neglect. As Margaret's case narrative teaches us, not only is the process difficult, but we are challenged to reflect critically upon the following: what do we do in the name of care; whose knowledge counts; and, who are we really treating with TPN in a variety of circumstances?

## REFERENCES

- Ashby, M. and Stoffell, B. 1995. Artificial hydration and alimentation at the end of life: A reply to Craig. *Journal of Medical Ethics*. 21(3):135-40.
- Bozetti, F. 1989. Effects of artificial nutrition on the nutritional status of cancer patients. *Journal of Parenteral and Enteral Nutrition*. 13(4):406-420.
- Craig, G. 1996. On withholding artificial hydration and nutrition from terminally ill sedated patients. The debate continues. *Journal of Medical Ethics*. 22(3): 147-153.
- Curtin, L. 1994. Ethical concerns of nutritional life support. *Nursing Management*. 25(1):14-16.
- Daly, J.M., Hoffman, K. and Lieberman, M. 1990. Nutritional support in the cancer patient. *Journal of Parenteral and Enteral Nutrition*. 14(Suppl 5): 100s-105s.
- De Wys, W.E., Begg, C. and Lavin, P. 1980. Prognostic effects of weight loss prior to chemotherapy in cancer patients. *American Journal of Medicine*. 69(4): 491-497.
- Duff, R.S. 1987. Close-up vs distant ethics: Deciding the care of infants with poor prognosis. *Seminars in Perinatology*. 11(3): 244-253.
- Dunlop, R.J., Ellershaw, J.E., Baines, M.J., Sykes, N. and Saunders, C.M. 1995. On withholding nutrition and hydration in the terminally ill: Has palliative medicine gone too far? A reply. *Journal of Medical Ethics*. 21(3):141-143.
- Fainsinger, R.L. and Gramlich, L.M. 1997. How often can we justify parenteral nutrition in terminally ill cancer patients? *Journal of Palliative Care*. 13(1):48-51.
- Fawcett, H. 1993. Interpreting a moral right: Ethical dilemmas in nutritional support for terminally ill patients. *Professional Nurse*. 8(6):380-383.
- Goodhall, L. 1997. Tube feeding dilemmas: Can artificial nutrition and hydration be legally or ethically withheld or withdrawn? *Journal of Advanced Nursing*. 25(2):217-222.
- Grant, J. 1990. Supplement. *Nutrition*. 6(4):6.
- Guidelines for the use of parenteral and enteral nutrition in adults and pediatric patients. 1993. *Journal of Parenteral and Enteral Nutrition*. 17(Suppl):5SA.
- Latimer, E. 1991. Caring for seriously ill and dying patients: Philosophy and ethics. *Canadian Medical Association Journal*. 144(7):859-864.
- Johnstone, M.J. 1989. *Bioethics - A nursing perspective*. Marrickville. Harcourt Brace Jovanovich.
- Macfie, J. 1996. Ethical implications of recognizing nutritional support as a medical therapy. *British Journal of Surgery*. 83:1567-1568.

- Mayo, T.W. 1996. Forgoing artificial nutrition and hydration: Legal and ethical considerations. *Nutrition in Clinical Practice*. 11(6):254-264.
- Meeberg, G.A. 1993. Quality of life: a concept analysis. *Journal of Advanced Nursing*. 18(1):32-38.
- Mercadante, S. 1995. Parenteral nutrition at home in advanced cancer patients. *Journal of Pain and Symptom Management*. 10(6):476-480.
- Philip, J. and Depczynski, B. 1997. The role of total parenteral nutrition for patients with irreversible bowel obstruction secondary to gynecological malignancy. *Journal of Pain and Symptom Management*. 13(2):104-111.
- Quillan, P. 1998. *Nutrition in Cancer Treatment*: [www.healthy.net/hwlibraryarticles/quillin/technica.html](http://www.healthy.net/hwlibraryarticles/quillin/technica.html).
- Sandstead, H. 1990. A point of view: Nutrition and care of terminally ill patients. *American Journal of Clinical Nutrition*. 52(5):767-9.
- Shaw, C. 1992. Nutritional aspects of advanced cancer. *Palliative Medicine*. 6:105-110.
- Studebaker, M. 1988. The ethics of artificial feeding (Letters to the Editor). *The New England Journal of Medicine*. 319(5):306.
- Tchekmedyan, N.S. 1993. Clinical approaches to nutritional support in cancer. *Current Opinion in Oncology*. 5(4):633-638.
- Tingle, J. and Cribb, A. 1995. *Nursing Law and Ethics*. Oxford: Blackwell Science.
- Tschudin, V. 1992. *Ethics and Nursing (edn)*. Oxford: Butterworth-Heinemann.
- Watts, D. and Cassell, C. 1984. Extraordinary nutritional support: A case study and ethical analysis. *Journal of the American Geriatrics Society*. 32(3):237-242.
- Turco, S. 1998. *What's hope got to do with it?* Edmonton Palliative Care Program. Canada: Capital Health Authority.