A review of the instruments used to assess the quality of life of adult patients with chronic intestinal failure receiving parenteral nutrition at home

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Home parenteral nutrition is an established method of supporting patients with intestinal failure, but this treatment may be life long and imposes severe restrictions on daily life. Impact on quality of life is an important outcome when considering the management of home parenteral nutrition patients. This paper reviews studies in which the quality of life of patients receiving home parenteral nutrition has been assessed. A systematic search of electronic databases and relevant publications was undertaken to identify generic or treatment-specific questionnaires used with home parenteral nutrition patients. Many of the thirty-four reports discovered were small studies. Nineteen used non-specific generic instruments, eight used non-validated questionnaires, four used a combination of both, and three did not use any formal tool. Few systematic patterns emerged. There are few available data on the quality of life of home parenteral nutrition patients, and there is a need for standardised, scientifically validated, treatment-specific instruments to measure quality of life in this population.

Home parenteral nutrition (HPN) is required to prevent the malnutrition and/or dehydration of patients who have long-term intestinal failure (Nightingale, 2001). Scribner *et al.* (1970) first described parenteral nutrition at home. The major aims of HPN are the long-term survival of patients who would otherwise have died, the improvement of quality of life and cost savings in terms of reduced hospitalisation.

Although HPN is an established method in the management of intestinal failure, it is a time-consuming and invasive procedure requiring the careful training of both patient and carer. Several factors may impose severe restrictions on daily life with regard to social activity (Price & Levine, 1979) as well as emotional function (Gulledge *et al.* 1980). Many patients go through several emotional reactions for example disbelief, fear, anger or depression (McRitchie, 1978). They may experience adjustment problems relating to the loss of the basic function of eating (McRitchie, 1980). Few patients on HPN return to work (Broviac & Scribner, 1974; Fleming *et al.* 1977, 1980), impacting on family finances (Gaskamp, 2000).

Patients with end-stage renal failure have been shown to have similar problems to those treated with HPN. Both are long-term, chronic states dependent on a technology for survival that affects daily activities. Both sets of patients experience similar complications, for example septicaemia, electrolyte disturbances and venous thrombosis. There are, however, also differences, which account for the reported higher satisfaction of patients with end-stage renal failure. In particular, the more regular contact that these patients have with health-care professionals and patients with similar problems, including their underlying diseases, seems to contribute to better life satisfaction (Herfindal *et al.* 1989).

The World Health Organization (WHOQOL Group, 1993) has defined quality of life as 'an individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns'. It is broad-ranging concept affected in a complex way by the person's physical health, psychological state, level of independence and social relationships, as well as their relationships to salient features of their environment. Health status is a measure in the adult of the level to which an individual is able to function, physically, emotionally and socially, whereas functional status, which is just one component of health, can be defined as a degree to which an individual is able to perform.

The aims of the present review were to investigate the instruments used to assess the quality of life of patients receiving HPN for intestinal failure, and to determine whether there is a need to develop an HPN-specific instrument.

Methods

This review was carried out by searching electronic databases (in March 2004) using the Ovid Gateway. The following databases were searched: British Nursing Index (1985 to March 2004), Cinahl (1982 to March 2004), Embase (1980 to March 2004)

and Ovid Medline (1966 to March 2004), Ovid Medline In Process and other non-indexed citations, PsychINFO (1974 to March 2004) and the Cochrane Database of Systematic Reviews. Conference proceedings of the British Association for Parenteral and Enteral Nutrition, the European Society for Parenteral and Enteral Nutrition and the American Society for Parenteral and Enteral Nutrition were also searched. The search terms used for the search in each database were 'quality of life' or 'self-rated health' and 'parenteral nutrition' or 'home parenteral nutrition' or 'long term nutrition' or 'total parenteral nutrition (TPN)'. Searches were limited to reports on adult patients (18 years or older) written in the English language. Abstracts or papers were reviewed to find out whether these were studies that merely mentioned 'quality of life' in the text or whether they actually carried out a research study. Criteria for inclusion in this review were the use of generic or treatment-specific instruments to perform quality of life assessment among patients receiving HPN.

The search identified thirty-seven papers. After removing the paediatric studies, twenty-seven papers and five conference abstracts were identified. The papers were reviewed for citations, and two additional papers were found that had not been revealed in the literature search (Cameron *et al.* 2002; Elia, 2002). Of the thirty-four studies reviewed (none of which was a randomised trial), nineteen used generic instruments, eight used non-validated, population-specific questionnaires, and three used a combination. In three studies, no formal tool was used, but clinicians reported their perception of the quality of life of their patients, and in one study the patient and partners were interviewed without a formal tool.

Studies

Fourteen papers compared the health-related quality of life of HPN patients with that published for the healthy population (Herfindal *et al.* 1989; Smith, 1993; Richards & Irving, 1997; Richards *et al.* 1997; Reddy & Malone, 1998; Malik *et al.* 2000; Cuerda *et al.* 2001, 2002; De Francesco *et al.* 2001; Chambers & Powell-Tuck, 2002; Elia, 2002; Malone, 2002; Carlsson *et al.* 2003; Pironi *et al.* 2003); thirteen did not use a comparison group. Two studies compared the subjects with patients with intestinal failure not receiving HPN, two studies compared them with patients who had undergone intestinal transplantation, and in one study a control group was not described. One study compared the quality of life of patients affiliated or not affiliated with a national organisation, and one compared the quality of life of those looked after by a specialised health-care provider or a general health-care provider.

Twenty-six of the studies used patient self-rated assessment (Ladefoged, 1981; Mughal & Irving 1986; Stokes *et al.* 1988; Herfindal *et al.* 1989; Galandiuk *et al.* 1990; Carlson *et al.* 1995; Richards & Irving, 1997; Richards *et al.* 1997; Di Martini *et al.* 1998; Reddy & Malone, 1998; Rovera *et al.* 1998; Jeppesen *et al.* 1999; Malik *et al.* 2000; Cuerda *et al.* 2001, 2002; De Francesco *et al.* 2001; Detsky *et al.* 1986; Bozzetti *et al.* 2002; Cameron *et al.* 2002; Chambers & Powell-Tuck, 2002; Elia, 2002; Malone, 2002; Pironi *et al.* 2003; Siepler *et al.* 2003; Smith *et al.* 2003; Thul & Bauer, 2003), and one used assessment by the patient and family care-givers (Smith, 1993).

Fifteen of the studies examined the short-term consequences of HPN (Stokes *et al.* 1988; Herfindal *et al.* 1989; King *et al.* 1993; Pironi *et al.* 1993; Cozzaglio *et al.* 1997; Richards *et al.* 1997; Rovera *et al.* 1998; Cuerda *et al.* 2001, 2002; Bozzetti *et al.* 2002; Chambers & Powell-Tuck, 2002; Smith *et al.* 2002, 2003; Siepler *et al.* 2003; Thul & Bauer, 2003), whereas nineteen explored the long-term consequences (Ladefoged, 1981; Detsky *et al.* 1986; Mughal & Irving, 1986; Herfindal *et al.* 1989; Messing *et al.* 1989; O'Hanrahan & Irving, 1992; Smith, 1993; Carlson *et al.* 1995; Richards & Irving, 1997; Di Martini *et al.* 1998; Reddy & Malone, 1998; Jeppesen *et al.* 1999; Malik *et al.* 2000; De Francesco *et al.* 2001; Cameron *et al.* 2002; Elia, 2002; Malone, 2002; Carlsson *et al.* 2003; Pironi *et al.* 2003).

Instruments

Quality of life questionnaires can be grouped into those which are generic and applicable to a range of diseases or populations, those which are 'disease-specific' and those which are non-validated and target HPN issues. Table 1 lists the instruments that were used in the studies.

Generic instruments. Eleven publications used the SF-36 (Richards & Irving, 1997; Richards *et al.* 1997; Reddy & Malone, 1998; Malik *et al.* 2000; De Francesco *et al.* 2001; Cameron *et al.* 2002; Chambers & Powell-Tuck, 2002; Carlsson *et al.* 2003; Pironi *et al.* 2003; Siepler *et al.* 2003; Smith *et al.* 2003). This is a widely used generic instrument that has been extensively validated in various populations (Ware, 1994). It examines eight dimensions: physical functioning (ten items), social functioning (two items), role limitations due to physical problems (four items), role limitations due to emotional problems (three items), mental health (five items), energy/vitality (four items), pain (two items) and general health perception (five items). There is also a single item relating to perception of health changes over the previous 12 months. Each domain is scored on a scale form 0 (poor health) to 100 (good health).

The EuroQol was used in three studies (Elia, 2002; Richards & Irving, 1997; Chambers & Powell-Tuck, 2002 (abstract)), one in conjunction with the SF-36 (Richards & Irving, 1997). This is a generic instrument that is widely used for the health-economic assessment of health-related quality of life (Brooks, 1996). It contains five questions relating to physical functioning, mental health and pain. Each domain has two or three categories in each section, including morbidity, self-care, activity, social relationships, pain and mental well-being. There is also a self-rating visual analogue scale ranging from 0 (death) to 100 (best possible quality of life).

Three studies used the Sickness Impact Profile (SIP) in conjunction with a disease-specific instrument (Jeppesen *et al.* 1999; Cuerda *et al.* 2001, 2002). The SIP is a generic measure of patients'

Table 1. Instruments and methods used to measure quality of life in home parenteral nutrition

Generic instruments	Disease-specific instruments	Non-validated instruments
SF-36	Inflammatory Bowel Disease questionnaire (IBDQ)	Time trade-off/category-scaling and direct questioning
EuroQol EQ-5D Sickness Impact Profile (SIP)	Quality of Life Inventory Quality of Life Index Rotterdam Symptom Checklist	Non-validated questionnaires Patient interviews

perception of their ability to function in everyday life. It contains 136 items on two main areas of life: physical (ambulation and mobility, body care, movement) and psychosocial (social interaction, alertness and emotional behaviour, communication); and five independent categories (sleep and rest, eating, work, housekeeping, recreation and pastimes; Bergner *et al.* 1981). At the end of the SIP score, there is a visual analogue scale that patients are asked to complete to mark their overall quality of life from miserable (0 cm) to ideal (9 cm).

The advantages of the SIP are that it can be used in acutely or chronically ill patients. One problem, however, is its length, although there have been attempts to shorten it. The score has been successfully validated against self-assessment of health status, clinicians' assessment of health status and functional instruments. It has been criticised, however, in that it does not correlate well in studies of the clinical outcome of health-care intervention (Messing *et al.* 1989). Although it has been used in studies of quality of life, SIP measures health status, and the authors did not intend it to be used as a quality of life instrument.

Disease-specific instruments. Jeppesen *et al.* (1999) used the Inflammatory Bowel Disease Questionnaire (IBDQ). The IBDQ was designed to measure the subjective health status of patients with inflammatory bowel disease (Guyatt *et al.* 1989). It comprises a 32-item, disease-specific questionnaire examining four aspects of patients' lives: symptoms related to the primary bowel disease, systemic symptoms, emotional state and social function.

Two studies used the Quality of Life Instrument (Di Martini *et al.* 1998; Rovera *et al.* 1998), although the latter study called it the Quality of Life Inventory, to compare the quality of life of total parenteral nutrition patients with those who had undergone intestinal transplantation. This instrument was specifically designed for transplant patients and had previously been validated in liver transplant patients. The self-administered Quality of Life Instrument comprises 130 questions and takes 30–45 minutes to complete. It contains twenty-six domains that cover a wide variety of functions, including emotional state, physical and social functioning, pain and discomfort, relationships and vocation. Each domain contains five questions.

Three studies by the same author used the Quality of Life Index (Smith, 1993; Smith *et al.* 2002, 2003). The Quality of Life Index (Ferrans & Powers, 1992) is composed of seventy items and has been used in the health-status measurement of patients on renal dialysis or liver transplantation, and following cancer treatment. It measures perceptions about satisfaction with regard to health and function, socio-economic status, psychological/spiritual life and family life.

Bozzetti *et al.* (2002) used the Rotterdam Symptom Checklist, which is an instrument intended for use in cancer patients. There are two main scales about physical symptoms and psychological distress (De Haes *et al.* 1996). It comprises thirty-nine questions on 4-point scales ('not at all', 'a little', 'quite a bit', 'very much') exploring well-being (one item), psychological state (eight items) and physical state (twenty-two items). A scale of 'able', 'able with help', 'able only with help' and 'unable' measures level of activity (eight items).

Time trade-off /category-scaling and direct questioning of objectives were used in one study (Detsky *et al.* 1986). Time trade-off involves comparing quality of life with length of survival (McNeil *et al.* 1981). Patients were asked to trade a quantity of survival time for improvements in quality of life. With category-scaling, patients define their own state between 0·0 (dead) and 1·0 (healthy).

Patients were first asked to define a list of objectives in life and then to decide, on a scale of 1 to 10, the importance of each objective; they then scored their ability to achieve each objective on a scale of 0·0 to 1·0.

Five studies (Mughal & Irving, 1986; Stokes *et al.* 1988; Herfindal *et al.* 1989; O'Hanrahan & Irving, 1992; Carlson *et al.* 1995) attempted to measure quality of life using questionnaires that had not previously been validated in a patient population. In the first study, a clinician identified the quality of life items of relevance. Previously reported methods of measuring quality of life were adapted to include questions relating to areas of life particularly important to HPN patients, such as food and eating, the impact of infusions and employment. In the second study, the items included questions relating to the parenteral nutrition service as this was felt to impinge on patients' quality of life.

One of the studies reviewed used patient interview as a method of assessing the quality of life of patients on HPN (Ladefoged, 1981).

The remainder of the reviewed studies (Messing *et al.* 1989; King *et al.* 1993; Cozzaglio *et al.* 1997) did not use a formal instrument of any kind. Instead, the doctor's perception was used to provide a comparison between pre-HPN and HPN dependence.

Results

The studies examined uncovered a variety of issues. Although problems such as emotional functioning, fatigue and systemic symptoms when receiving HPN were identified, the overall impact of HPN was positive. Cozzaglio *et al.* (1997) and Bozzetti *et al.* (2002) demonstrated that, despite a diagnosis of cancer, the initiation of HPN improved quality of life. The studies that identified similar problems but reported poor quality of life compared with patients from a normal population (Reddy & Malone, 1998; De Francesco *et al.* 2001; Malone, 2002) or those with short bowel but not HPN-dependent and those who had transplantation.

Fifteen of the studies reviewed found that the introduction of HPN improved patients' quality of life (Detsky *et al.* 1986; Mughal & Irving, 1986; Stokes *et al.* 1988; Messing *et al.* 1989; Galandiuk *et al.* 1990; O'Hanrahan & Irving, 1992; King *et al.* 1993; Pironi *et al.* 1993; Smith, 1993; Carlson *et al.* 1995; Cozzaglio *et al.* 1997; Bozzetti *et al.* 2002; Cameron *et al.* 2002; Elia, 2002; Pironi *et al.* 2003) despite identifying significant physical and psychological problems. Two studies (Di Martini *et al.* 1998; Rovera *et al.* 1998) reported a significant reduction in quality of life compared with patients who had undergone small-intestinal transplantation.

Four studies reported that scores were similar to (Malone, 2002) or lower than (Herfindal *et al.* 1989; Reddy & Malone, 1998; De Francesco *et al.* 2001) those in the general population. Richards and Irving (1997) reported that forty-one of fifty-one patients (80 %) were unfit to work, and Jeppesen *et al.* (1999) reported an unemployment rate of 86 %. Of the other studies that investigated employment status (Ladefoged, 1981; Detsky *et al.* 1986; Mughal & Irving, 1986; O'Hanrahan & Irving, 1992; Pironi *et al.* 1993; Smith, 1993; Carlson *et al.* 1995; Elia, 2002), the proportion remaining employed ranged from 0 to 52 %. In the survey of home nutritional support patients carried out by Herfindal *et al.* (1989), 217 patients said that, on

average, HPN had a 'somewhat disruptive' effect on keeping a job.

Thirteen of the studies did not compare data to a control or comparison group but compared the quality of life in the pre-HPN and HPN-dependent state.

The frequency of readmission to hospital was considered relevant by seven of the studies. Readmission rates ranged from 0·52 to 4 % per year, much of this being caused by complications of treatment, such as catheter-related bloodstream infections.

Compliance

Seven studies described their method of data collection as a postal questionnaire sent to patients. Compliance with completing and returning forms has been reported as an issue in many areas of disease, and two of the studies reported poor compliance. The British Artificial Nutrition Survey survey (Elia, 2002) reported responses from fewer than half the patients. Possible reasons for this could include the death of some of the patients; in addition, the intermediary reporters responsible for distributing the questionnaire may have felt that it was inappropriate for certain individuals. Herfindal *et al.* (1989) suggested that poor response rate of 30·4 % was one of the major limitations of his study and that this had had a bearing on the interpretation of the results. It was suggested that those who were satisfied with life might not respond. Also, those who were physically unwell might not wish to respond. In contrast, however, Bozzetti *et al.* (2002) found that compliance in their study was good: 268 out of 276 distributed questionnaires were completed and only the question relating to sexual interest was left blank by patients.

Adequacy of existing measures

Seven of the studies using the SF-36 (Richards & Irving, 1997; Richards *et al.* 1997; Reddy & Malone, 1998; Malik *et al.* 2000; De Francesco *et al.* 2001; Malone, 2002; Carlsson *et al.* 2003) demonstrated that, compared with the general population, HPN-dependent patients had lower scores. This was particularly relevant in older patients and those who were dependent on narcotics (Richards & Irving, 1997; Richards *et al.* 1997). The authors used this instrument because they felt that the domains examined by SF-36 were relevant to this group of patients. However, the SF-36 does not provide qualitative data addressing HPN-specific issues. It does not include domains relevant to HPN such as sleep disturbance due to frequent urination, bowel function, sexual dysfunction, dietary restrictions and loss of ability to work due to incapacity or frequent hospital admissions.

By itself, EuroQol is most frequently used for general health-care and cost–utility evaluation. The EuroQol group recognises that, because of its simplicity, the measure should be used alongside other instruments. Richards *et al.* (1997) used it alongside the SF-36 as the domains examined (mobility, self-care, activity, pain and mental well-being) were felt to be relevant in the HPN population. However, as with SF-36, it does not address HPN-specific problems.

Because of the SIP's lack of specific questioning on quality of life relating to HPN, Jeppesen *et al.* (1999) used the IBDQ along with it. The IBDQ was developed to measure subjective health status among patients with inflammatory bowel disease, part of it focusing on bowel-related symptoms. However, although approximately 40 % of HPN patients have inflammatory bowel

disease (Baxter *et al.* 2002) as their underlying disease resulting in the need for HPN, many do not suffer from the symptoms related to inflammatory bowel disease. HPN symptoms such as sleep disturbance and the psychological effects of not eating and drinking normally are not addressed.

Measures of functional status such as the Karnofsky score (Yates *et al.* 1980) have been used in cancer patients. This score was not designed to measure quality of life and has therefore not been validated as such an instrument. It does, however, appear as part of a suggested assessment criterion for cancer patients to receive HPN.

Only two studies reviewed have used instruments developed for the HPN population. Both of these were developed by the investigators and include their perception of items likely to influence the quality of life of HPN patients.

Discussion

Despite the fact that improving quality of life is one of the main aims of HPN, studies addressing this important topic are relatively rare. In a recent bibliographic study of patient-assessed health-outcome measures, no instruments were reported that looked at quality of life among patients receiving HPN, although 100 reports covered 'gastrointestinal disease' (Borgaonkar & Irvine, 2000).

There are several reasons for assessing quality of life in the HPN-dependent patient:

By facilitating communication with patients, it may be possible to identify the range of problems that particularly affect those receiving this treatment. This information may then be used to provide information to future patients and allow them to anticipate and understand the consequences of their treatment. Patients receiving HPN may no longer experience symptoms relating to the underlying disease that resulted in the need for HPN. This may lead to problems of psychological adaptation as they try to come to terms with the prospect of a life-long therapy.

The results of intestinal transplantation are improving, and it may offer a potential life-saving treatment for patients in addition to those who have lost all vascular access or who have developed hepatic disease as a result of prolonged HPN.

A variety of studies have demonstrated the positive effects of HPN on quality of life (Detsky *et al.* 1986; Mughal & Irving, 1986; Stokes *et al.* 1988; Messing *et al.* 1989; Galandiuk *et al.* 1990; O'Hanrahan & Irving, 1992; King *et al.* 1993; Pironi *et al.* 1993; Smith, 1993; Carlson *et al.* 1995; Cozzaglio *et al.* 1997; Bozzetti *et al.* 2002; Cameron *et al.* 2002; Elia, 2002; Pironi *et al.* 2003), and some have demonstrated negative effects (Herfindal *et al.* 1989; Reddy & Malone, 1998; De Francesco *et al.* 2001). The differences in results may relate to method of comparison. Some studies have, for example, compared pre-HPN with HPN-dependent status, and some have compared HPN with the situation after successful intestinal transplantation. Because of the growing number of centres successfully offering intestinal transplantation, data in this field are required to demonstrate patients' subjective perceptions of health and quality of life.

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looked at quality of life among patients receiving HPN, although 100 reports covered 'gastrointestinal disease' (Borgaonkar & Irvine, 2000).

One study found the best quality of life to be among young patients with a long duration of treatment, with high self-esteem, in good personal relationships, and with wealth and employment (Richards & Irving, 1997). The worst quality of life was observed in older patients, those addicted to narcotics, those who were less affluent, single or unemployed, and those who had had a short duration of treatment (Richards & Irving, 1997).

The initiation of HPN does not remove or reduce the systemic symptoms associated with the underlying diseases. Indeed, because of the nature of HPN therapy, a new set of problems, such as physical and social functioning and family and relationship problems, often develops. It is therefore not surprising that quality of life on HPN does not appear good when compared with that of the normal population. When compared with pre-HPN state, however, quality of life appears likely to improve, improving even more when the HPN-dependent patient undergoes successful intestinal transplantation (Di Martini *et al.* 1998; Rovera *et al.* 1998).

Quality of life measures are increasingly used for measuring health outcomes, but there is little standardisation in their use. There has been an exponential growth in the number of reports relating to the development and evaluation of quality of life measures. The SF-36, SIP and utility measure EuroQol have been evaluated in a wide range of patient populations. Using health-status instruments to measure quality of life is associated with several problems related to the nature of health care.

Disease- or treatment-specific measures focus on aspects of health that are relevant to the population. An HPN-specific instrument is therefore more likely to include the aspects of health relevant to that population. Studies carried out to date have used generic instruments and non-validated questionnaires alone or in combination to measure either clinicians' or patients' perspectives. There are no validated, HPN-specific tools available to measure quality of life in this patient population. Carlson *et al.* (1995) attempted to do this, but the author identified the quality of life issues rather than the patients. The use of patients to identify these dimensions is required for content validity of the study tool.

The best way to measure the quality of life of patients receiving HPN is to ask the patients themselves. Many studies have demonstrated that an assessment of quality of life by an observer such as a clinician, a family member or a carer provides inaccurate results (Slevin *et al.* 1988; Addington-Hall & Kalra, 2001). It is therefore necessary to produce a treatment-specific tool that may be used regularly to monitor patients. To allow this to be done effectively and accurately, such an instrument must be self-administered and easily and quickly completed.

The likelihood of being weaned from HPN is significantly reduced after 3 years, and 20–30 % of HPN patients require permanent treatment (De Francesco *et al.* 2001). These may be candidates for intestinal transplantation, so a measurement of quality of life is important to address particular problems relating to HPN. A potential use of a tool would be for individual patient monitoring and management, quality of life being measured within same patient over time to try to determine the likely quality of life after transplantation. Patients who have been transplanted following failed parenteral nutrition or who have intestinal failure not requiring HPN would be suitable comparison groups for studies of quality of life.

There is evidence that when patients are managed under the auspices of a national support and education organisation, outcomes in terms of quality of life, depression scores and incidence of catheter-related bloodstream infections are improved (Smith *et al.* 2002).

Conclusion

We conclude from this review that there is a need to study quality of life as there is at present a shortage of data. There are currently no validated instruments available for the assessment of quality of life in HPN patients. The development of a questionnaire to measure quality of life in the HPN patient population is proposed.

This instrument should be rigorously developed and validated using recognised psychometric methods. It should identify issues of relevance to HPN patients and be sensitive to issues that are of particular importance in this disease area. It should also be developed with international application in mind in order to be applicable across diverse nationalities and cultures. The use of such an instrument would ultimately provide considerable benefit to patients.

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