Common psychiatric concerns in home parenteral nutrition[1]

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In home parenteral nutrition (HPN), the patient is dependent on a machine. This can contribute to family problems, organic brain syndromes, depression, grief, or drug dependency. It is important to establish the base-line mental status of the patient before instructing him or her in HPN procedures.

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Home parenteral nutrition (HPN) often represents the final treatment for a variety of gastrointestinal problems which impair adequate nutrition. However, few studies have focused on the common psychological and social problems HPN has created, in particular, family difficulties. As with other machine-dependent situations, HPN families frequently experience signs of strain—even rupturing of previously stable relationships—which in turn may only add to the burdens of the patient as he or she struggles to cope with the persistent issues and changes associated with HPN. Problems commonly seen with HPN include depression, delirium, drug dependency, grief, anxiety, and occasionally impaired cognition because of preexisting central nervous system involvement.[1-6]

Delirium

Encephalopathy (delirium) may be secondary to many conditions, among them electrolyte imbalance, hypovolemia or hypervolemia, central anticholinergic syndromes, and "central clouding" resulting from anxiolytic, hypnotic,

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or analgesic medications. Hyperosmolar states, vitamin or trace element deficiencies, infections resulting from impaired immunologic competence, and several types of anemia may be confused with symptoms or signs of reactive anxiety and yet frequently present as anxiety states, mood disturbances, or agitation.[2,6] Successful treatment requires determination of the cause of the encephalopathy while at the same time providing a structured and consistent environment with the support of the staff and the HPN team. Psychotic states (impaired reality testing), if present, are generally of short duration; often they are confused with psychological reactions to the patient's numerous medical or surgical problems. However, if both psychosis and delirium are present, low-dose parenteral neuroleptic medication such as phenothiazines or butyrophenones are usually effective, while concentrating on reversing the causes of the delirium.

The most common problem with psychiatric states is failure to recognize encephalopathy presenting as anxiety or mood disturbances, because of the lack of a carefully detailed examination of mental status. For this reason, thoughts, feelings, and behavior should be evaluated even before the institution of HPN in order to establish a base line so that, if anxiety or depression occurs later, reactive issues can be separated from organic problems.

Reactive issues

Inability to eat like others produces problems when going out to a restaurant, taking a snack break, or eating at parties. This usually results in a significant change in life style for both patient and family and requires talking things over with them for several weeks so that they can think through what HPN really means to them. Depression is often confused with grief because in both conditions the patient may cry, be irritable, suffer from insomnia, or have difficulty concentrating. However, in grief, self-esteem is usually preserved so that treatment must focus on carefully determining what losses the patient believes he or she has experienced and allowing him or her to discuss thoughts and feelings in detail. Such losses commonly center on the inability to enjoy food like other people, lead a reasonably independent life, and adjust to the numerous bodily changes or functions imposed by an ostomy or HPN catheter.

If the patient describes himself or herself as worthless, helpless, or hopeless, the problem may be depression rather than grief. Unfortunately, anti-depressant medication is often ineffective because of impaired absorption due to either a rapid transit time or inadequate length of bowel. Such individuals frequently experience significant side effects of the medication, such as orthostaticism, tachycardia, or xerostomia, and as a result, the usual doses and schedules are not applicable. When anti-depressant medication is given orally, it has to be titrated accordingly; one useful approach is to start with a low dose, titrate the medicine very slowly, and be prepared to use a higher dose than usual to achieve a good therapeutic effect.

Anxiety can be a major reaction because of the fear of losing control over physical or psychological functions, as well as the effects of prolonged hospitalization; the patient may feel overwhelmed by intensive treatment efforts, the need to deal with a large number of strangers, fatigue associated with chronic pain, or attempts to adjust to an altered body image.[1,3,5,6] Loss of sleep associated with nocturnal infusions may impair the patient's usual circadian rhythm, resulting in the development of day-night reversal of sleep patterns which, if prolonged, could lead to the patient feeling "out of phase" with the environment or family. Careful attention to these issues while providing education and support and restructuring approaches to therapeutic objectives is usually sufficient to diminish apparent anxiety or reactive depression.

The family and HPN

Before they can identify strain or dysfunction in a family dealing with HPN, the home care team needs to know what normal was for this family unit before, and how illness and treatment affected them prior to the institution of HPN. HPN means different things to each member of the family, since the needs of each individual are significantly influenced and altered depending on whether the member is a child, adolescent, spouse, parent, or grandparent. Depending on family beliefs, attitudes and social support,[7] and the perceptiveness of the home care team, the type and extent of psychological problems need to be recognized and dealt with in order to prevent maladaptive behavior in response to HPN.[8]

If the members of the family are young, they may be inattentive, have problems processing educational information, and even demonstrate

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depression or anxiety on the part of a parent or child. If the patient is a child, it is not uncommon for the parent to experience helplessness and anger at the possibility of death and such feelings should not be regarded as abnormal or pathologic. Family members usually benefit from the opportunity to talk about such worries and feelings with members of the home care team without having to fear that they will be perceived as unstable, too emotional, or bothersome. For many families, the team often provides the first and only opportunity to talk about their worries, fears, and frustrations after a long series of operations or efforts at treatment. At times, guilt is a problem; family members may feel they have not properly cared for the patient in the past. However, discussion, education, and support usually allow such guilt to be "worked through." If the patient is married and there are young children in the family, the team needs to know which parent originally assumed what responsibilities; if parenting was primarily the patient's role, then the spouse will often need help to shift roles so that the children's needs will be properly met while the new duties are incorporated into the other demands of daily life.

The "middle years" frequently find parents in their forties and fifties, with children either in their teens or young adulthood. Despite their attempts to master their own identity, adolescents may find "distancing" from the family more difficult because of having a sick parent; and this in turn may intensify the usual turmoil of growing up because of the frustration of having to deal with chronic and perhaps terminal illness. If the patient is an adolescent, parents may become excessively overprotective, producing a strained relationship between child and parent which may spill over into the usual adaptive processes of growing up and ultimately result in resistance to HPN or problems with compliance. The adolescent with a sick parent may seem detached or unconcerned to others, when in fact he or she may be attempting to cope with intense inner goals and feelings.

In the "older family" whose children have grown, or who have no children, illness of a spouse can intensify fears of loss and loneliness at a time when both parties need more affection and caring. Repeated surgery, hospitalization, and dealing with death can magnify such issues, with the nuclear family often being fragmented by geographical separation. It is at this specific point in a family's life that community resources, friends, religion, and ethnic and social surroundings frequently became important in easing the patient and family into HPN. If members of the family have struggled in the past, HPN simply compounds problems when attempting to adapt to illness within the stages of the family's development.

For these reasons, inquiries into the family's status should be made when beginning HPN. Pertinent questions might include:

1. Has the family been able to openly deal with issues? If not, communication regarding HPN will usually be more difficult, trust will be harder to establish, and the staff will need to demonstrate how openness improves difficult situations. More time and energy will be required to help this kind of family adjust to and cope with HPN.

2. Does the family pattern reflect closeness and stability? Are family members showing strain because the patient has heretofore been the one who primarily established cohesion and stability? Particular attention should be directed toward how HPN affects young children and adolescents, while making sure their basic emotional needs are being met and the well parent is getting help to adapt to new roles.

3. What non-family resources are available, or is there evidence that other reliable persons in the community can be of aid? Does the family show a willingness to allow outside support? If not, dependence on the HPN team will probably increase; this may lead to the behavioral problems associated with chronic illness, which require more intensive psychological treatment if independence and a more active life style are to be realized with HPN.

Drug problems

Difficulties with drugs are most frequently seen in patients with prior chronic gastrointestinal problems such as Crohn's disease, irradiation enteritis with multiple abdominal fistulas or abscesses, or numerous abdominal operations. People with these conditions have often been subjected to frequent hospitalizations, chronic pain, and prolonged stays away from home while being removed from the usual responsibilities and activities of daily life. Being in pain and dependent on others for such extended periods often creates a situation in which the patient uses narcotics, hypnotics, or anxiolytic drugs not only to relieve

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physical discomfort but also to escape from emotional reactions. Consequently, anxiety may be the first symptom of withdrawal because drug tolerance and dependent states have gone unrecognized and inadequate medication has been prescribed. Almost a third of such patients at this hospital have an addiction problem. It is strongly recommended that a careful review of the duration, type, and dose of medication be part of the initial assessment. Frequently, these individuals require a slow detoxification program to prevent undue anxiety or agitation which interferes with the learning of self-care. When a drug-dependent state is identified, attention also has to be directed toward the possibility of the patient slipping into an illness-oriented lifestyle; if this happens, efforts should be directed toward promoting health and independence rather than illness. Changing over to greater autonomy often requires formal psychological intervention over a sustained period of time, which may be the most difficult problem for the patient and family trying to adjust to HPN.

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