For Debate . . .

Ethical conflicts in long-term care of the aged: nutritional problems and the patient-care worker relationship

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Summary and conclusions

The patient-care worker relationship was analysed by observation and unstructured group discussion in four long-stay somatogeriatric wards at Saint Lars Hospital. Investigation centred on patients entering the terminal phase who could no longer be spoon-fed.

The relationship was complicated and reciprocal, and failure by the care worker to interpret her role and the dying patient's behaviour correctly led to emotional conflict and double-binding, with resultant anxiety for both herself and the patient. Infusions and tube-feeding prescribed in such cases were given not for the patient's benefit but to relieve anxiety in care workers and relatives.

Permitting the patient a natural, painless death from water deficiency may be preferable to prolonging pain and discomfort by intervening with infusions and tube-feeding.

Introduction

"I have problems with my health"; "This is the remedy to improve your health"; "Thank you"—such is the standard, unspoken contract[1] between patient and care worker. In the long-stay geriatric patient who cannot accept that she is beyond realistic hope of rehabilitation, however, the contract may be problematical: "I wish to regain my health"; "I am willing to nurse you for the rest of your life"; "Curse you." Clearly such a contract, which may be partly unspoken, may induce great anxiety in both patient and care worker.

We decided to investigate the emotional difficulties facing care workers by long-stay geriatric patients who have no reasonable hope of returning home or to homes for the elderly. Such difficulties were most apparent when patients became unable to feed themselves. Feeding a disabled patient is an intimate activity that exposes the quality of the patient-care worker relationship.

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Subjects and methods

The study was conducted in four somatogeriatric wards at Saint Lars Hospital. The wards housed 96 long-stay geriatric patients—mostly with senile, presenile, or multi-infarction dementia—and were staffed by 92 care workers. The term "care workers" includes doctors, cleaners, sisters, nurses, and auxiliary nurses. The investigation was based on prolonged observation and repeated discussion with caring staff of many years' experience and centred on patients who had become unable to take spoon-feeding. Conclusions were drawn from analysis of tape-recorded unstructured group discussions with staff from each ward. Most patients with feeding problems were women.

Results

Terminal geriatric care may last up to 10 years. During the final phase the patient may become difficult to spoon-feed with adequate amounts of food and drink until eventually her intake is clearly insufficient. If the condition is accepted she dries up, becomes somnolent, is unable to take any food or drink at all, and dies peacefully within a week or so apparently without thirst, hunger, or pain.

To allow a patient to die from water deficiency is contrary to medical training, however, and there is often pressure from care workers to institute feeding by intravenous infusion. Nevertheless, such infusions cause painful inflammation of peripheral veins, so that within three or four weeks all veins suitable for infusion may be occluded by distressing thrombophlebitis and the patient dies anyway. Subcutaneous infusions, on the other hand, do not cause thrombophlebitis and are associated with a smaller risk of pulmonary oedema. Nevertheless, painful swelling may occur at the site of the infusion, the infusion does not provide adequate nourishment, and the patient dies after prolonged deficiency of water and food.

Another method of feeding is by gastric tube. This is simple, safe, and cheap but does not improve the patient's underlying condition: it merely prevents her from finishing the process of dying. A patient may lie for several years with a gastric tube, developing contractures of knees, hips, and elbows and stiffening in a fetal posture. Pressure sores are difficult to prevent since she can lie on only her left or right side. Hence, as in the case of intervention with intravenous and subcutaneous infusions, pain and discomfort are increased during the process of dying, which may be prolonged by months or years.

Because of the consequences of infusions and tube-feeding many doctors would prefer to withhold such treatment and permit the patient a natural and painless death from water deficiency. Nevertheless, such a decision may be hampered not only by ethical considerations but by difficulty in excluding a transient deterioration in the patient's condition; in this respect, however, the course of her aging may be helpful. There are two major reasons for admitting a patient for terminal geriatric care—namely, confusion and urinary incontinence. At first the patient may be able to feed herself, perhaps with some help from nursing staff. Over years rather than months she deteriorates and becomes progressively more dependent on spoon-feeding.

In most cases nurses apparently encountered only minor problems with spoon-feeding. Patients with feeding difficulties, however, may exhibit behaviour requiring individual techniques—for example, because of refusal to take food, spitting, biting, swallowing the wrong way, and incoordination of tongue muscles. Skill and patience clearly

varied among care workers. Eventually spoon-feeding becomes impossible, and in many cases the reason is obscure. Some patients apparently decide not to eat or drink; one woman stopped eating when her husband died. Other patients may simply lack appetite, possibly owing to bad teeth, edentia, mouth ulcers, or nausea. Some patients seem to panic when food is served into their mouths. Whatever the reason for the inability to feed the patients the care worker must decide whether to accept the condition or institute tube-feeding. Delaying death by a few weeks with an intravenous infusion serves only to delude the care worker and relatives, and possibly also the patient.

Discussion

Nutritional problems in long-stay geriatric patients nearing the end of their lives test the quality of the patient-care worker relationship. Though the patient may appear not to be wanting, anxiety in nursing staff may be severe; hence the effects on the relationship are complex.[2 3]

When the patient becomes difficult to spoon-feed her ability for verbal communication apparently disappears. She is therefore unwilling or unable to explain why she does not accept food and leaves the care worker uncertain whether she is thirsty, hungry, or in pain. Such patients may be given infusions, when recognising the signs of a dying patient would show them to be inappropriate. Thus infusions are given to relieve anxiety in the care worker and relatives rather than to benefit the patient.

Patients' behaviour may have many different meanings, which must be interpreted correctly. Hunger and thirst are clearly tolerable to many dying patients, since their refusal to eat and drink is apparently voluntary. Those whose behaviour demands a special technique may therefore be seeking to prolong contact with the care worker. If the care worker becomes impatient, however, the quality of the contact is reduced and the patient must increase the difficulties to satisfy her needs. Thus if inadequate contact is the meaning of the patient's feeding difficulties these may be reduced by improving contact in some other way.

Feeding problems may also represent the patient's need to control her world. The dying patient gradually loses control over her environment and over her own life[4-7] until only negative action is possible.[8] Thus she can still cause discomfort for others and can decide for herself when to die. Encouraging the patient to exercise some positive control over her life, however, may remove the need for negative action and reduce or eliminate the feeding difficulty.

The apparent panic observed in some patients when food is served into their mouths may result from impaired ability to swallow and the consequent fear of asphyxia. Thus the panic is occasioned by acute anxiety about impending death from suffocation. Refusing food brings the primary reward of thwarting death and the secondary reward of increased attention from care workers. Without food and drink, however, death soon comes.

Feeding a disabled patient is an intimate and vulnerable activity, and for the patient to "submit"[4] she must trust the care worker. If she does not—whether justly or otherwise—she may protest. This may lead to a degree of forced feeding, which in turn results in greater distrust and more protest. Spitting and fighting may therefore be an attempt to communicate when the ability to speak is lost.

Regression is virtually inevitable when the biological basis of life begins to crumble, and it is questionable whether steps should be taken to prevent it. Hence expressions of oral and anal sexuality[9 10]—that is, denoting bodily pleasure—must be expected; refusing and playing with food may be a manifestation of anal sexuality.

A skilful spoon-feeding technique and adequate emotional contact are essential. Spoon-feeding may fail if the care worker has personal problems and is tired and irritated. The patient may feel humiliated, and spitting and spilling humiliates the care worker. Hence the care worker may be reproachful because she *feels* unsuccessful, and the patient uses food refusal as a device to punish her.[11]

The relationship between patient and care worker is complicated and reciprocal,[12] and when spoon-feeding becomes impossible at least three states of conflict may be identified—namely, between the care worker's responsibility to feed the patient and the patient's unwillingness to be fed; between the duty to keep the patient alive and the duty not to prolong her suffering; and between the inevitability of death and the reluctance to accept death. Hence if the care worker feels trapped and cannot resolve these difficulties classical double-binding may result[13]: whatever action she takes is wrong.

Care workers may experience difficult emotional conflicts because of faulty interpretation of their role; analysis and discussion of their problems are therefore essential.

Patients admitted to a long-stay geriatric ward are waiting to die. They have a right to expect kind and careful nursing and to die naturally without fear of being killed.[14] Denying the biological reality of approaching death renders the patient-care worker relationship paradoxical, inducing anxiety in both patient and care worker and jeopardising the quality of emotional contact.

Conclusion

Our findings, which are based on observation and discussion with care workers of many years' experience, help to define the nature and hazards of the patient-care worker relationship when the patient is admitted for prolonged terminal care. Emotional difficulties and double-binding must be reduced by analysing and discussing these problems.

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Under what conditions are medical examinations for elderly car drivers demanded by insurance companies?

There would appear to be no common policy among motor insurers as regards medical examinations for elderly car drivers. Each company has its own policy and decides on the facts of the particular case whether or not to insist on a medical examination.