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Hospital Topics

Ethical problems in feeding patients with advanced dementia

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Summary and conclusions

Aged patients with dementia if not stricken by an acute disease sooner or later approach a terminal phase that is distinguished by a failure of spoon feeding. This condition induces great anxiety in the workers who care for these patients. The interaction between patient and care-worker during spoon-feeding failure is described by the psychological model of double-binding. Two serious consequences of double-binding are the distancing of the care-workers from the patient and scapegoating among the care-workers. It is essential that the pressure of double-bindings in the wards should be reduced.

Introduction

In the terminal phase of the care of elderly long-stay patients with dementia the patient becomes difficult to spoon-feed. The patient bites, spits, swallows the wrong way, and refuses to eat. Some years ago it was common in Sweden to feed such a patient with a nasogastric tube or by intravenous or subcutaneous infusion. Today there is a tendency to avoid both tube-feeding and infusion.[1] A patient who is tube-fed may be bed-ridden for years with contractures, bent like a fetus, with no mental contact with the care-workers. It is hard work to save the patient from decubital ulcers. Some geriatricians in Sweden will not accept patients being fed with gastric tubes from other departments. They believe that the care-workers who gave the patient a gastric tube should take responsibility for the patient to the end. A patient on infusion can be kept alive for only about four weeks. The veins are brittle in these patients. After a few weeks it is no longer possible to feed the patient intravenously. Then she—most of these patients are women—has to be fed subcutaneously. Many care-workers believe that the infusions cause the patient only pain, and hence they also try to reduce the use of infusions.

The restrictive use of tube-feeding and infusions has, however, made spoon-feeding more distressing for the care-workers. In the past when care-workers had difficulties in feeding a patient with a spoon they were able to resort to tube-feeding or infusion. Now they have to decide whether to continue the spoon-feeding or let the patient die from lack of water and food. This is a difficult decision to take because of lack of knowledge. If the patient dies from water deficiency, has she suffered from thirst? When nurses turn a dehydrated patient they feel that the muscles of the patient are hurting. Consequently care-workers try to continue the spoon-feeding as long as possible.

We describe a psychological model of the interaction between demented patients with imminent spoon-feeding failure and their care-workers, the double-binding model developed by Bateson *et al* in the study of schizophrenia.[2] We also describe two consequences of double-binding: the use of defence mechanisms, leading to distancing,[3] and scapegoating[3] games.[1 4]

Patients and methods

The study was done on four geriatric wards at Saint Lars Hospital housing 96 long-stay patients—mostly with senile, presenile, or multi-infarction dementia—and staffed by 92 care-workers. The term "care-worker" 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

When the patient is difficult to spoon-feed the care-workers may feel conflicting demands:

You must keep the patient alive—It is not easy to decide, "Now the patient takes too little food and drink; we will not, however, give the patient more food by tube or infusion; we accept the coming

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death of the patient." When signs of dehydration appear, the care-workers may feel guilty.

You must not cause the patient pointless suffering—The care-workers feel that they frighten and hurt the patient by spoon-feeding when:

(*a*) The patient reacts as though the food hurts her stomach when received.

(*b*) The patient regularly swallows the wrong way and is almost suffocated.

(*c*) The patient shows panic.

Some patients look panic-stricken when food is spooned into their mouths.

You must not force the patient to eat—You have to respect the will of the patient. Suppose that the patient lets you know that she does not want to be fed. She may say, "I wish to die, so I don't want food." Or she may shut her mouth, spit, and fight. Then the care-worker may feel that he is trying to break the patient's will. The elderly patient with dementia, contractures, and little ability to communicate has little capacity to defend herself. She is more or less helpless against forced feeding.

You must not talk about death, suffering, and force (or maybe you must not even think about it)—Thus you must not "metacommunicate." Sometimes this conflict is so distressing to care-workers that they forbid themselves to talk or even think about it. They behave as if they were not aware of what is happening. This has serious consequences.

It is not possible to escape—The natural reaction to conflicting demands is to flee. Sometimes the care-workers cannot flee. They have to make the patient's bed, clean her, and *feed* her, all the while having to look at her and touch her.

Discussion

Care-workers who must spoon-feed elderly patients with dementia are placed in a very distressing quandary. The contradictory demands made on them, the prohibited "metacommunication"—that is, thinking and talking about the suffering one may be causing the patients and about their eventual death—and the impossibility of escaping may be understood as a double-binding.[1 2] Whatever the care-worker does, he does the wrong thing. If he feeds the patient he causes her pointless suffering and forces her. If he does not feed her he causes her to die and perhaps to suffer from thirst and tender muscles. When everything you do is wrong, you feel guilty. You defend yourself against guilt by using the defence mechanisms of the ego. It is reasonable to assume that there are many different defence mechanisms and combinations of defence mechanisms[5] at work in the care-workers around a patient in spoon-feeding failure. Two consequences of the use of defence mechanisms with serious results for both patients and care-workers are the distancing of care-workers from the patients and scapegoating among care-workers.

DISTANCING

Distancing is probably the first consequence. The care-worker says to himself, "This is not Mrs Smith whom I have nursed for years, and whom I like very much. This is only a demented patient. She does not understand and feel." At worst the care-worker treats the patient like a thing. A thing is handled routinely and mechanically, not nursed with tenderness and understanding.

Distancing may lead to a course of events. In the first stage the care-worker becomes less sensitive to the needs and the feelings of the patient. He does not identify himself with the patient. The final stage of this development may be sadism.[3 6] The care-worker hurts the patient physically or psychically in order to reduce his own feelings of guilt and anxiety. We think we must admit that at least psychological variants of sadism cause a problem in the care of patients with dementia. We also must identify and reduce the double-binding that occurs in the care of patients that may produce sadism.

It is not only feeding that produces double-binding, there are many situations in the ward[7] that produce it. Other factors in the care of these patients may also produce sadism—for example, double-bindings in the family life of the care-workers. The primary aim of nursing research is, however, to reveal the double-bindings in long-stay wards. It is reasonable to assume that group discussions reduce the pressure of double-bindings on the care workers, since discussion provides a kind of "metacommunication."

SCAPEGOATING

Scapegoating is a pathological social game.[4] If you feel guilty, one thing you can do in order to reduce this feeling is to project your guilt on another person. In patient care you can demand orders from your supervisor, the sister or the doctor. If you are spoon-feeding a patient who gives you feelings of guilt, you may try to get the sister to give you an order: you must serve the patients so many millilitres of milk. By obeying orders you achieve two goals:

(*a*) You may concentrate on obeying the order. You look at the glass and think: 100 ml. You can neglect the patient. Your attention is focused on the order, not on the patient.

(*b*) If what you do is wrong (and if you are in a double-binding, whatever you do is wrong), the guilt is not yours but the person's who gave you the order. You can then blame the decision-maker. If the order is "no tube, no infusion," you can ask (of course indirectly and non-verbally) "Why do you kill the patient?" If the order is "tube, infusion," you can ask "Why do you hurt the patient?" "Why do you force the patient?"

Scapegoating has serious consequences for staff co-operation. The person who is blamed flees—the doctor comes to the ward less and less. Then he knows less about the patients; his basis for decision-making diminishes; more and more often he makes a wrong decision; other care-workers find more legitimate reasons to blame him; and he flees again. A vicious circle starts.

The hypothesis, based on group discussions in four wards over two years and on analysis of the published work, is that the problems of feeding may be felt as double-binding by some care-workers with regard to some patients. This implies that double-binding in care-workers may lead to distancing from the patients, sadism, and scapegoating. It is essential to reduce the pressure of double-bindings in wards.

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