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What is This?
ETHICAL CONSIDERATIONS OF REFUSING NUTRITION AFTER STROKE

Lars Sandman, Ingrid Ågren Bolmsjö and Albert Westergren

Key words: autonomy; ethics; nutrition; refusal; stroke

The aim of this article is to analyse and discuss the ethically problematic conflict raised by patients with stroke who refuse nutritional treatment. In analysing this conflict, the focus is on four different aspects: (1) Is nutritional treatment biologically necessary? (2) If necessary, is the reason for refusal a functional disability, lack of appetite or motivation, misunderstanding of the situation or a genuine conflict of values? (3) If the latter, what values are involved in the conflict? (4) How should we deal with the different kinds of refusal of nutritional treatment? We argue that patients’ autonomy should be respected as far as possible, while also considering that those who have suffered a stroke might re-evaluate their life as a result of a beneficial prognosis. However, if patients persist with their refusal, health care professionals should force nutritional treatment only when it is clear that the patients will re-evaluate their future life.

Introduction

Ethical dilemmas in the clinical care of patients with stroke often relate to decisions about eating and nutritional interventions. Patients who have suffered a stroke often experience problems that lead to an impaired ability to assimilate nourishment. For example, overall stroke severity is an indicator of dysphagia, which has an impact on the development of malnutrition and pneumonia.1,2 In addition to dysphagia, persons with stroke can be affected by problems related to manipulating food on a plate, transport of food to the mouth, unusual eating times, poor appetite etc. Thus, as many as 80% of stroke rehabilitation patients have eating difficulties.3 As a consequence, questions arise about whether to initiate, withhold or withdraw nutritional treatment essential for future life and quality of life (QoL).4 It can be questioned whether a decision to introduce nutritional treatment is essentially different from other treatment decisions that could affect patients’ future life and QoL. These situations are often discussed in the literature.
in relation to patients suffering from a progressive disease, when they are gradually deteriorating. However, in the area of nutritional treatment in relation to stroke, the following factors differ concerning other, progressive, diseases.

First, the acute onset of stroke with its possible effects on functional ability and competence will change the life of the person, rendering him or her unprepared for the decisions called for in relation to nutrition. Such a situation can be characterized by shock and disbelief, which further complicate the decisional situation. Second, it does not give the person time to re-evaluate his or her life before having to make important decisions about nutritional treatment that will affect the future. Third, even if the immediate clinical picture may seem pessimistic after the acute onset, persons with stroke often have a positive prognosis for full or partial recovery. After stroke, about 30–40% of patients experience dysphagia in the acute phase,\(^1,5\) which drops to 16% after one week and 2% after one month.\(^6\)

In addition, studies have shown that patients with dysphagia can improve many years after stroke onset, if properly managed.\(^7,8\)

An ethical conflict faced by carers working in stroke rehabilitation is when a patient refuses to accept the nutritional treatment considered essential for future satisfactory QoL or future life, given the knowledge that the patient has a good chance of attaining an acceptable QoL.

**Aim**

The aim of this article is to analyse and discuss the ethically problematic conflict raised by patients with stroke who refuse nutritional treatment.

**Methods**

A normative analysis was undertaken of the literature, clinical cases and research experience concerning nutritional interventions in persons with stroke. The aim was to identify the various interpretations of the refusal to accept nutritional treatment, as well as different action alternatives relating to central values in health care. The analysis resulted in a discussion about how to balance the different alternatives against each other.

**Analysis of the ethical conflict**

In analysing the conflict, the following aspects must be considered:

- Is the treatment necessary from a biological perspective?
- Why do patients refuse treatment that is biologically necessary?
- What are the relevant values and norms involved in the conflict?
- What are the different alternatives for dealing with the conflict, and how do they relate to the values involved?

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Treatment is biologically necessary

Nutritional treatment should be evidence based with a documented effect of benefiting patients as far as possible. Hence, patients should be able to assimilate the nutrition provided. This demands that the treatment is adapted to their condition both in terms of administration and in the kind of nutrition provided. It also follows that nutritional treatment should not be provided when patients’ biological mechanism cannot assimilate it, for example, at the very end stage of a terminal disease. There is a body of knowledge that indicates that dehydration at the end stage of life produces a natural anaesthetic effect that dulls the perception of pain. Thus, not providing food and fluids may in fact have benefits for some terminally ill patients.9

Moreover, different nutritional treatments may have adverse side effects that will have to be balanced against the benefits. For example, when oral feeding is problematic owing to swallowing difficulties, an alternative could be a feeding tube. However, feeding tubes have long been cited as a risk factor for aspiration pneumonia.10–12

Reasons why patients may refuse treatment

Functional inability

Patients may refuse nutritional treatment because of some functional inability that is difficult to detect. Failure on the part of patients to open their mouth when offered food is not necessarily a sign of unwillingness to eat. It could indicate oral dyspraxia or apraxia caused by damage to the left cerebral hemisphere, which is often accompanied by communication difficulties such as dysphasia or aphasia, which prevents patients from informing carers about the problem. A number of examples are used here and later to illustrate the issues concerned.

A 75-year-old woman, with a previous stroke in the right hemisphere suffered a second stroke in the left hemisphere. She managed most daily activities by herself, could communicate by nodding and was considered competent. She exhibited clear signs of swallowing apraxia, yet expressed a definite will to eat. When performing test swallows with different consistencies of food, she concentrated so hard on swallowing that she grimaced. However, when another person entered the room, the patient turned her head towards the door and swallowed in an automatic way. She received a gastrostomy tube and about two months later regained the ability to swallow at will, when the gastrostomy tube was removed.

If a decision is made not to feed that is based on a misinterpretation of apraxia as unwillingness to eat, patients’ autonomy is restricted and they are harmed; they will eventually die if not given artificial nutrition.

Lack of appetite or motivation

Patients may refuse to eat on grounds of lack of motivation or considering the nutritional treatment unattractive. Hence, it is necessary to adapt the external
circumstances (especially in relation to oral administration) and take into account factors such as wholesomeness, type of food, eating environment and social aspects.13

Misunderstanding the situation

In cases where patients are incompetent or temporarily confused, a refusal could be due to a misconception or a habitual or automatic response. Competence here refers to persons who are capable of formulating and to some extent expressing their wishes as well as being able to evaluate various alternatives in terms of how they correspond to their expectations and desires, and to decide on the preferred alternative. We should be careful not to deem someone as incompetent because of odd or eccentric wishes.14

An 88-year-old patient suffered a stroke that resulted in partial dependency in his activities of daily living. He developed dysphagia and aphasia. According to a CT scan, the damage to the brain was rather small. Thus he was considered to have great potential for recovery. However, the patient was regarded as having limited competence owing to signs of dementia prior to the stroke. The patient was believed to have had a satisfactory QoL before the stroke, thus it was decided, in agreement with his wife, to provide enteral nutrition through a nasogastric tube. This was not accepted by the patient, who repeatedly pulled out the tube almost immediately after it had been inserted.

In pulling out the tube the patient indicated dissatisfaction with the situation. This presents several pitfalls. The patient may be dissatisfied with the present situation and unable to understand the potential for recovery; he may simply find a nasogastric tube difficult and awkward; or he may not understand the purpose of the tube and consider it frightening.

Even competent patients who refuse nutritional treatment may be misinformed about their chances of future survival or QoL and hence may view the treatment as unwarranted.

Lack of acceptance of future life

Patients may, however, be well informed about what kind of life is likely to result from the treatment and not consider such a life valuable. In this there is a genuine ethical conflict between different values. An example is when competent patients choose a more dangerous option such as oral food intake that exposes them to the risk of suffocation. QoL gains from such treatment should be compared with less risky treatments, such as percutaneous endoscopic gastrostomy, which lower the QoL.

A 68-year-old woman suffered a stroke with fairly limited effects apart from severe dysphagia with evidence of silent aspiration, irrespective of the consistency of the food she swallowed. There was no doubt that she was cognitively sound. The patient was informed about the problem and that she would suffer aspiration pneumonia if she continued to eat orally. It was suggested to her that she should agree to artificial nutrition. However, she refused this treatment in spite of the efforts made to persuade her to accept it. She said that she did not experience any difficulties
swallowing and therefore did not need such treatment. The patient was asked to sign a document certifying that she had been informed about the risks associated with continued oral food intake and that it was her own decision. After a while she developed her first bout of aspiration pneumonia, in spite of which she continued to refuse artificial nutrition. Yet again the treatment options were discussed with her without any change in her attitude. She was discharged to her home, still eating orally and without the need for home help. Soon after discharge she was re-admitted to the ward as a result of a second aspiration pneumonia event. On this occasion she agreed to accept artificial nutrition after pressure from her son.

Another situation is when patients abstain from nutritional treatment that is considered to provide an acceptable QoL and hence choose malnutrition and eventually die. The reasons for this are that patients disagree with the assessment of their QoL and also because they place a higher value on other aspects of life, such as independence and being able to manage alone.

An 82-year-old man who lived alone suffered a mild stroke. He managed his activities of daily living by himself. He exhibited clear evidence of malnutrition (low levels of vitamin B and a body mass index far below the recommended limit). His dietary history revealed that he mostly ate sweets and snacks. He lived some distance from any shops. During discharge planning it was suggested that he use meals on wheels. However, he refused this offer despite the fact that he suffered from malnutrition. He said ‘I have managed on my own for my whole life and refuse to accept any help in my own home.’ He found it extremely humiliating that his eating habits were considered inadequate.

**Relevant values involved in the ethical conflict**

In the latter example, genuine ethical conflicts are based on the different values at stake for the patient: the value of continued life, the value of good QoL, and the value of autonomy. The perspective in this article is that the value of continued life is dependent on the quality of that life and that autonomy is both an intrinsic value of QoL as well as being of instrumental value in ensuring that people can achieve their other QoL values.15 To assess whether and to what extent these values can be realized in a conflict situation, a number of aspects need to be considered.

**Prognosis for future life**

It is important to stress that the prognosis concerns patients’ chances of survival and the kind of life they will have. Health care professionals cannot, however, make a prognosis of the quality or value of that future life to a particular patient. In making a prognosis, it is important to be as realistic as possible, based on the available knowledge and the uncertainty involved. There may be a risk of making a too positive and open prognosis in order to influence patients and inspire hope and a will to live; however, the uncertainty involved also makes it difficult to arrive at a prognosis.

A 58-year-old patient suffered a series of strokes. Over a three-month period his state fluctuated between a terminal stage and a more optimistic state. His wife was at his
side almost every day. The patient was unable to communicate. As a result of discussions and doctors’ recommendations, his wife became involved in most decisions. The discussions focused on the prognosis and QoL, and formed the basis for decisions about treatment. His wife's feelings hovered between despair and hope, grief and happiness. After about three months his condition unexpectedly stabilized and more active rehabilitation gradually became possible. At the time of discharge he was able to eat, sit in a wheelchair and communicate by nodding. His facial expressions suggested that he was fairly happy most of the time.

The value of life

The kind of life that results from the provision of nutritional treatment should be assessed in terms of its value. Life can be valued in many different ways and the value placed on it is largely dependent on the individual concerned. Nevertheless, there are also a number of common features in value theory and empirical studies about QoL. The general results from empirical studies may, however, fail to represent the opinion of particular individuals. Although these studies may demonstrate that it is possible to live with stroke and experience such a life as valuable or good, there is a wide range of valuations of life with stroke. Value theories make claims about what can be regarded as valuable in life from a rational point of view and may therefore not represent the views of all individuals, and there is disagreement about what values can be considered rational. A conclusion from both philosophical and empirical perspectives is that the individual patient’s assessment of whether life has value is essential.

However, could individual patients who refuse nutritional treatment be mistaken about the value of their life after a stroke? It is difficult to question any patients’ actual experiences of well-being or lack of well-being. We could question that a patient’s lack of well-being will be permanent and also point to factors in the person’s life that could provide some well-being. We could point to the fact that any patients’ desires about life are or may be fulfilled (provided this is true), even if patients are unable to appreciate this at the time. We could also point out the possibility of finding other ways to fulfil existing desires or discovering new ones (adapting one’s desires) in the changed situation, thus leading to fulfilment and well-being despite the changed circumstances.

Re-evaluation of the value of life

Patients with stroke may misinterpret the information given and assess life after stroke as not worth living. Health care professionals should provide patients with relevant information in such a way that they can understand and take in the knowledge. The information involved in a prognosis of what sort of life patients will have consists, however, of a number of alternative scenarios and we need to be clear about the fact that individual patients assess risks and possibilities in different ways.

Even if patients understand the information about what life after a stroke will be like, they may be unwilling or unable to re-evaluate their life values. Patients may be adamant that life after a stroke is not worth living, which may be correct in view of their desires and values. They may be convinced that it will be impossible to adapt or change. In this case the acute onset of stroke, with the following shock, which allows no time to adapt gradually to a changing situation, is a
complicating factor. It is difficult to assess whether individual patients view their future life wrongly, since it is true that most do adapt and enjoy a reasonably good life. Health care professionals should avoid claiming that patients are wrong about their evaluation of the quality of their present or future life, after having tried to explain whatever misconceptions patients may have.

Autonomy

We can characterize a person as autonomous if ‘... she does what she chooses to do (because she chooses to) and she chooses to do what she does because she wants to’ (p. 115, L Sandman trans.).

The reasons why we should support patient autonomy are that it is a value in its own right, and perhaps even more importantly, because it is the patients who will have to live with the consequences of their decisions and there is an uncertainty about what a life with acceptable QoL implies.

In order to make autonomous decisions, individuals must be competent, as already explained.

When considering patients with stroke, we are faced with the problem of those who are unable to make an assessment of their present or future QoL, or, if capable, being unable to communicate it. This should not be interpreted to mean that patients who are incompetent or unable to communicate cannot indicate that their life is worth living by showing satisfaction or enjoyment with their life, but it does make decision making to solve the conflict more difficult.

Alternative ways of dealing with the conflict

Functional inability and lack of appetite or motivation

If the reason for refusing nutritional treatment is a functional inability or lack of appetite or motivation, health care professionals should adapt the treatment in such a way that these patients will be able and motivated to accept it. A refusal, if it is such in functional ability, is not grounded in any core values of patients. If health care professionals accept the refusal, it may jeopardize patients’ wish to continue their present life, which is sustained by nutritional treatment. In the case of appetite or motivation there is a QoL reason involved: when patients do not enjoy nutrition it affects their motivation and appetite. However, this is not a relevant reason for discontinuing nutritional treatment, since patients do not refuse it because they assess their future QoL as poor. There may be situations when they will not be motivated, regardless of the measures taken by health care professionals. If so, this could be due to a clinical depression that requires treatment or to a more fundamental assessment of their future life as not worth living, thus placing patients in the position of refusing treatment on relevant QoL grounds.

In incompetent patients, or those who are competent but unable to communicate, the ‘refusal’ of nutritional treatment may be caused by other factors and not merely be an expression of their will. Health care professionals need to consider carefully before accepting such a refusal and be creative in trying out other means of administering nutritional treatment.
Misconceptions

In some cases it is obvious that patients have failed to grasp the situation.

A 67-year-old married man who had had a mild stroke two years previously, and who suffered from persistent dysphagia in relation to thin liquids, was admitted to hospital with pneumonia for the fifth time in a year. After the stroke he had been told not to drink thin liquids, only thickened ones but otherwise to eat normal food. Before the stroke he had had periods of high alcohol consumption.

On admission he insisted that he followed the recommendation not to drink thin liquids and that he did not consume alcohol. Blood tests however, indicated a worsening of his liver function. His wife told the doctor in confidence that, although her husband had not consumed alcohol during the first year after the stroke, he had resumed drinking in the previous 12 months. The incidents of aspiration pneumonia during the previous year always occurred when her husband had been drinking alcohol.

He was confronted with the facts that his liver tests indicated that he was drinking alcohol again and that, in order not to suffer further attacks of pneumonia and a worsening of his liver function, he needed to stop drinking. He was also informed that alcohol could worsen his dysphagia symptoms by negatively affecting his brain. He was surprised about the fact that alcohol could cause pneumonia, as ‘alcohol should be clean’, and even worsen his dysphagia. He was told that the alcohol he drank went into his lungs and caused pneumonia. He was offered help to stop drinking, which he accepted.

In this case, the man did not realize that alcohol negatively affected his brain and thereby reduced his ability to swallow, thus causing aspiration. Having been given accurate information, his misconceptions were dispelled. This was a problem with a patient who was lacking competence, but where the need to communicate as well as possible resulted in him understanding the situation.

Although autonomy should play an important role in such situations, respecting autonomy does not imply respecting ignorance. Autonomy implies making an informed decision on the basis of available information. It is an individual decision whether or not one wishes to make an uninformed choice, although it is difficult to see how such a choice could meet the wishes that form the basis of one’s decision, and the possible well-being derived from lack of knowledge would then have to be balanced against autonomy and other values. Hence, when health care professionals inform patients, they are able to make an informed choice about the best possible way to realize their wishes. Health care professionals have a prima facie reason to provide patients with as accurate a picture as possible of the situation and the possible consequences of the various options.

Autonomy

If competent patients refuse nutritional treatment, it is their fundamental right to have a say in decisions about future therapy and to refuse any that they regard as painful, meaningless or humiliating. Studies show that physicians and nurses give priority to patient autonomy when deciding about nutritional treatment for competent patients.

The decision of competent patients to refuse treatment that involves prolonging their life with a poor QoL should be respected. However, it is important that
health care professionals’ own definition of what is an unacceptable QoL does not influence patients unduly. The decision about whether or not to provide nutritional treatment should rest with patients because health care professionals may have too strict a view about what sort of life is worth living. No-one has the right to discontinue life-sustaining treatment if someone expresses the will for it to be continued.24,25

A woman of about 80 years of age had suffered a stroke. She could not eat owing to aphagia (total inability to swallow) and was completely dependent on others in all activities of daily living. She also had aphasia (total inability to speak) but was able to signal her approval by nodding her head. Her lucidity varied over time. It was difficult to assess her level of competence. However, she was informed about the treatment options of parenteral or enteral nutrition, and the risks associated with eating (aspiration pneumonia, suffocation) and with not receiving nutrition (death). She nodded approval at three different times for parenteral nutrition through a central venous catheter and declined enteral nutrition. Having met the patient, the doctor who was to insert a subcutaneous access port contacted the doctor in charge of the case and questioned the decision. After discussion and clarification of the reasons behind the decision, the port was inserted. It was not clear if the health care professionals at the patient’s accommodation could manage parenteral nutrition through a port. The nurses were invited to learn parenteral nutrition management. Thus the patient’s wish was fulfilled and she was able to move to the accommodation and receive nutritional treatment. She died some months later.

Understanding the risks and benefits of treatment

At other times, refusals by competent patients may not be in agreement with assessments made by health care professionals. The examples given of a patient refusing the safer treatment option and suffering successive bouts of aspiration pneumonia, and of refusing the more nourishing nutritional treatment, culminating in malnutrition, can result in death.

If patients understand the risks involved in the different forms of treatment, they should be allowed to choose the nutritional method that best corresponds to their ideas about an acceptable QoL. This is based on the argument that a life without aspects that are considered essential for an acceptable QoL is not worth living. It is also based on the belief that individual patients are willing to take different risks in order to live according to their values, and, since we accept this difference in risk taking in other areas of life, we should also accept it here.

Health care professionals additionally need to make sure that this is what patients want in a given situation, assuming that they are competent, able to evaluate the options based on relevant information, and choose on the basis of their most important values and wishes. If patients have been assessed and found to be competent, health care professionals should be careful not to consider them incompetent because their decisions are not in line with the general view about which choice is beneficial or rational. An important reason for respecting autonomy is to safeguard people’s possibilities to live their life according to their own perhaps idiosyncratic views. It is important to be clear whether individuals have sufficient knowledge about the situation or whether a refusal is based on a misconception. One of the cases described was of a man who wanted to remain independent, as a result of which he ate only sweets and snacks. If this man had lived with such eating habits...
for a long time, although suffering from malnutrition according to standard measurements, he may well have adapted to such a life. If he were to receive proper nutrition, he might find that his life would improve. Health care professionals, however, have to balance the value of an improved nutritional status against the value the patient put on his independence, and it is not certain that he would favour better nutritional status over his independence.

Health care professionals have to establish whether the values on which wishes and decisions are based are unreasonable or uninformed, or perhaps the result of clinical depression. When a great deal is at stake, and if patients are clear about the consequences, we should be wary of forcing nutritional treatment by physical force, manipulation or pressurizing patients into acceptance.

Force and/or motivate

In one example above, a woman finally gave in after her son exerted pressure on her. Was this a problematic intervention in terms of her autonomy? If the son presented arguments that convinced his mother or she chose artificial nutrition in order to please her son, then the answer is ‘no’. We make many autonomous decisions in which we take into account not only what we want for ourselves but also what we want for others. What would have been problematic was if her son exercised such pressure that she felt threatened and did not make the decision based on her own considered opinion. In such circumstances it is important for health care professionals to act as patients’ advocate and defend their decisions based on what they believe to be patients’ wishes.\textsuperscript{26} Even if strongly supporting the autonomy of competent stroke patients, when they express a definite wish or value, health care professionals should not leave them alone with such a decision. They must assist and be supportive in the decision-making process, while at the same time treating patients’ decisions with respect.

Incompetent and incommunicable patients

If patients are incompetent and various alternative nutritional treatments have been tried to adapt to their needs, and motivation has been encouraged, but they still seem to refuse to eat, is it acceptable not to feed them?\textsuperscript{4} If there is an advance directive with legal status, or a legally appointed surrogate decision maker, it is clear what to do from a legal standpoint, even if such a situation remains ethically questionable. However, if there is no such system for decision making, the following options present themselves: (1) allow the health care professionals to make the decision at their own discretion; (2) take the previously expressed wishes or values of the patient into consideration (even if they are not legally binding); and (3) take account of the opinions of significant others.

Health care professionals should consider patients’ previously expressed wishes or life values and also the opinions of significant others concerning what they believe individual patients want and to the extent that these wishes are known.

If this is not possible, the first alternative applies, where health care professionals make a decision based upon what they consider to be patients’ best interests, or alternative 3, which allows significant others to make such a decision.
However, if force is used in order to ensure such patients' survival, there is a definite risk that it will have a negative effect on their QoL, thereby lessening their enjoyment of life. Force should be used reluctantly, sparingly and only when absolutely necessary in relation to patients in whom it is obvious that they will enjoy continuing their life.

If health care professionals are aware that the views previously held by patients support their refusal of nutritional treatment, they are left with the question of whether such patients would have re-evaluated their opinion, given what is known about the prognosis. It is important to consider patients' previous values about what constitutes a valuable life and assess whether the prognosis corresponds to this. It is always open to question whether patients would not have re-evaluated their view on what constitutes a good life if they had experienced and become accustomed to life after a stroke.

The crucial question is whether patients' previous views of what they would want in their present circumstances are more reliable than those of someone who can assess the actual situation. This depends on the extent to which patients have seriously considered all the options and understood what being a stroke patient means. This has to be evaluated individually, although health care professionals should be reluctant to overrule people's previous wishes unless they have very strong grounds for believing that they will benefit. If patients can be given nutritional treatment only by force, this will necessarily interfere with their QoL, especially if they do not understand the reasons for the use of force. Such treatment is also likely to be inefficient and to require a high degree of surveillance.

There is great uncertainty around the prognosis of stroke patients in terms of their future life and well-being. To accept refusal of nutrition will eventually result in patients' death, thus such decisions have more far-reaching consequences than if they wish for a nutritional treatment of doubtful value. Accepting a refusal calls for a conservative strategy, making sure that all ethically acceptable options have been exhausted.

**Conclusions**

Decisions regarding nutritional treatment for stroke patients do not follow the same rules as those for people suffering from progressive diseases in terms of uncertainty about the prognosis and estimations of future optimal QoL. Situations may arise in which stroke patients refuse nutritional treatment despite the fact that there is a strong reason to believe that they will achieve an acceptable QoL. This raises an ethical conflict for health care professionals. Treatment decisions relate to life before the stroke, the present situation and the prognosis. In the acute phase it seems especially important to consider the possibility of a gradual adaptation to a life after the stroke and to the possibility of re-evaluating what constitutes a 'valuable life'. This differentiates the ethical conflicts relating to nutrition for patients after a stroke from those concerning patients with progressive diseases. A stroke will dramatically change the life of a person, leaving him or her unprepared for or unable to make the necessary decisions in relation to nutrition.
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