Case Commentary

I had admitted a thirty-six year old woman with a six week history of increasing headaches and then an epileptic seizure. Her CT scan showed a large mass in the right frontal lobe of her brain. Fortunately this is an area which, if removed, has no detectable effect on the patient. This operation is formally known as a right frontal lobectomy. In "One Flew over the Cuckoo's Nest" Jack Nicholson's character was severely affected after receiving a bilateral frontal lobectomy. Even though the procedures have the same name they are different in an important way (the operation in the movie is bilateral) and they have very different results (bilateral frontal lobectomies affect personality and motivation).

I carefully explained to this woman what was proposed including a wide resection of this frontal tumour or mass and I explained the minimal effects of such an operation on her intellect or personality. Having reassured her on a number of specific points, she readily signed the consent form. As I turned to leave she said, in a joking way, "I'm so relieved that something can be done, I think I would have signed for anything except for one of those frontal lobectomy things". What should I have done then?

COMMENTARY ONE

Lynley Chirnside
Charge Nurse,
Neurosurgical / Neurological Ward

The doctor-patient relationship, from the patient's point of view anyway, is based on trust. Most patients still trust in the ability and judgement of their doctor to provide the best possible medical care for them. Coupled with that today is a very real recognition that the relationship has developed to become a two way street. Many patients now expect to be equal partners in their health care. They want to be more informed and take an active and assertive role in making decisions relevant to their health care and ultimately, their lives. In order to participate fully in this process, the patient must be fully informed about the nature, options and consequences of the proposed course of treatment.

The provision of "full" information poses the age-old problem of how much information is enough. Patients who do not have a medical background are immediately at a disadvantage when confronted by the health system. They may not know what questions to ask. They become vulnerable sometimes to groundless fears, power relationships, and misunderstandings especially when doctors, as they often do, have difficulty explaining complex ideas and principles in terms that can be understood by the lay person. When the information given is not understood, truly informed consent cannot be given. The problems with the gaining of informed consent lie not only within the content of the discussion, but with the manner in which it is conducted. In hospitals we separate patients from the familiar and comfortable surroundings of their home, deprive them of supportive contact, submit them to painful and sometimes humiliating investigations, take off their clothes, tell them they have a tumour in their brain and then expect them to make a rational decision about an operation they heard about in a movie.

The woman in the case history demonstrates just this problem. Although the doctor appears to have gone to some lengths to explain what he saw as important about the proposed course of treatment, the explanation failed to include what the patient might have seen as one of the most important points.

The doctor now knows that the woman has signed the consent to a procedure that she would probably refuse if she knew its name. He is now presented with two choices. The doctor could continue as though she had said nothing; after all, she has signed the form. There may or may not be adverse consequences to such an action - she may never find out. If she did, however, what trust there was in their therapeutic relationship could potentially be destroyed.

The alternative is to start over, and include the name of her operation. This course of action will take much more time but will be less likely to lead to a decision based on misconceptions.

It is my belief that if we want to pay more than lip service to the doctrine of informed consent the latter course must be chosen.

COMMENTARY TWO

Fay McDonald
Patient Advocate

The woman's joke shows that in spite of the discussion she has just had with the consultant, and the consent she has given for the surgery, there are still unresolved issues for her. By using a joke she has raised what she may recognise as a type of community myth, which has not seemed to her during the discussion to apply here. But it's clearly in her mind. By raising it she puts the initiative back to the consultant to respond to her concern, but in such a way that it can be responded to lightly, if it is irrelevant.

The consultant must face this new issue immediately. It is clear that she has not been using the formal name of the procedure, and so has denied the woman full information and the right to make a fully informed decision. The word "lobectomy" raises only one image for many people - perhaps the very reason why the consultant avoided using it in the first place. It is regrettable that the two procedures have such similar names, and that one of them has a bad image in the community. But that is the reality and it must be faced now.

By talking to the woman as a person, rather than as a patient, the consultant

may be able to keep the original decision in place. But unless the issue raised by the woman's joke is addressed immediately, openly and without defensiveness, there is a good chance that she will lose confidence in the consultant and may decide against the suggested procedure at a later point. However, by giving her the extra information and a further opportunity for discussion, the consultant takes the risk that she will decide against the recommended surgery, either temporarily or permanently. That risk is present in every situation where someone has to decide for or against a major procedure, and this is a risk that the consultant must take now, as always. But because she failed to give all the information at the beginning, the consultant now has a greater risk of hearing a decision she doesn't want. She may be wise to suggest a second opinion from a colleague of the woman's choice, or she may just have to wait while the patient assimilates the new information, and reconsiders whether or not to go ahead.

The one thing the consultant must not do is to allow the joke to pass, just as a joke. She must put out of her mind the other people waiting for their appointments, or resist the temptation to have a further round of the conversation next week. For without a doubt the question will be raised with the patient in the future, either by a friend, a family member, or in some unrelated casual conversation and at that stage, the issue would have to be dealt with, but as a more complex issue. So clearly, now is the best time for it, whatever the immediate outcome. Most people make good decisions for themselves when they are given full information and support. This may well be one of them.

COMMENTARY THREE

Janusz Bonkowski
Neurosurgeon

Although I appreciate that this case is hypothetical the initial paragraph with its confusion between a right frontal lobectomy and a prefrontal leucotomy leads me to assert that a solecism underlies the apparent dilemma. A right frontal lobectomy is an operation whereby the right frontal lobe of the brain is removed. This operation is carried out in order to remove a brain tumour or to gain access to structures deeper within the brain. As the preamble dictates, conventional medical wisdom dictates that a lobectomy, as long as it is unilateral should have virtually no effect on higher brain functions such as intellect, emotion or memory (but see below). In the 1940's procedures for controlling psychotic and obsessive patients were developed which collectively came under the name of bifrontal leucotomy: they were sometimes referred to as bifrontal lobotomies, orbital undercuttings, cingulotomy etc. These operations divided large interconnecting brain tracts from both frontal lobes into deeper brain structures and had quite profound effects on mentation. The classic representation of the leucotomised patient was as portrayed in "One Flew Over The Cuckoo's Nest". The operation performed would have been a bifrontal leucotomy: not a bifrontal lobectomy. The operations have different names and different end-results. The names do bear a certain similarity and in the public mind there is an occasional propensity to confuse them.

Be that as it may let us presume that the patient has a tumour of the right frontal lobe necessitating wide excision, probably with a substantial margin of surrounding brain tissue but flatly refuses to undergo "one of those frontal lobectomy things". My approach would be tempered by my knowledge of the pathological basis of the conditions which require frontal lobectomy. Modern neurosurgery has become sufficiently sophisticated that in cases where tumours lie on the surface of the brain or underneath the brain these lesions can be nearly always removed without any sacrifice of brain tissue. Even in those cases where lesions can be completely removed but lie embedded deep with the brain, access is usually available by passing through the brain, of necessity possibly disconnecting some nerve pathways but again not sacrificing substantial amounts of brain tissue. The only situation under which we would remove not only a tumour but a substantial area of surrounding brain tissue, at times even extending to a complete right frontal lobectomy, would be in the case of a malignant tumour which was infiltrating through the brain without any defined cleavage plane. The harsh reality of such situations is that these tumours are brain cancers, any such surgery is almost invariably palliative and I think it would be dishonest to ever promise or even suggest that we could somehow "cure" such a patient. Hence in my mind I would know that if the patient did not have the operation she might die within a few months; if she did have the operation then her existence might be prolonged but realistically the lesion would still almost certainly recur and kill her within a year or two.

The first scenario is that I carefully explain to the patient that we intend carrying out a right frontal lobectomy because she has an aggressive tumour and our only hope of achieving prolonged palliation is to carry out a radical clearance and that this might involve a right frontal lobectomy. Leucotomies and cuckoos would not enter into the conversation. If the patient signed for a right frontal lobectomy and then promptly proceeded to tell me that she would have signed for anything except one of those right frontal lobectomies, this would raise serious doubts in my mind whether the patient was orientated. Patients with tumours affecting both frontal lobes suffer a dementing process known as "wittelsucht" which is German for "happy madness". Such patients are seemingly rational but respond to any request requiring real information with jocular riposte rather than a coherent answer. I note the patient said" ... in a joking way ..." is she actually dementing? I would carry out some clinical tests to assess whether the patient was indeed demented and if that was indeed the case it would strongly suggest to me that the tumour had grown so extensively that it had started to infiltrate the opposite frontal lobe and was therefore involving both sides of the brain. In those situations carrying out an extensive tumour removal does not usually have any beneficial effect on the patient's poor mental state and carrying out a large operation simply to maintain a demented patient in a prolonged state of mental and intellectual torpor is not justified. I would therefore recommend a biopsy or a limited procedure to establish the diagnosis and seriously discuss with the family whether aggressive treatment to maintain the patient in a protracted demented state was appropriate.

The second scenario is that the patient is a particularly insightful and intelligent individual who, when

confronted with the necessity of actually cutting into her brain tissue to remove a lesion, potentially disconnecting or even removing brain cells, asks for the scientific basis on which I state that such an operation has only minimal effect on intellect or personality. After all the brain cells are there and are connected to all the other cells and are presumably doing something and surely any removal or disconnection must diminish not only the brain reserves but even more particularly the crispness or focus of the neuronal hologram that underlies all our mental activities. For example patients who lose their visual cortex and are cortically blind often refuse to recognise that they can not see even though they patently cannot. The brain is a self-referring organism and how can one be wholly conscious of oneself if one is no longer whole?

Medical knowledge is a rather curious epistemological process and only has the barest relationship to scientific knowledge. It is in many ways more akin to the mythology or folklore of prescientific societies. By that I mean that many of the "facts" or "truths" which doctors bandy about as established scientific dictum have been handed down by teachers and we rarely explore the database on which such truths, many almost elevated to dogma, are based. One of these scientific facts or myths (depending on one's view of the subject) is the concept of "silent areas" of the brain. By this we mean that any portion of the brain that does not control some specific motor or sensory function and is presumably largely concerned with higher thought processes has an exact representation of itself on the opposite side of the brain. One of the main underpinnings of this theory is the seeming ability of previous generations of neurosurgeons to lop off frontal and temporal lobes and then state that the operation appeared to have little effect on the behaviour, intellect or mood of the patient. However one sees that most of these original reports were often relating to only small numbers of patients, the "mental examination" often consisted of little more than a few sociable bedside chats to the patient and when one searches for the vast scientific literature looking at thousands of patients studied in their psychological and social milieu one realises that the hard evidence is actually very sketchy. In fact neurosurgeons believe this because we were told by our teachers that this is true and they were told by their teachers who removed the occasional frontal or temporal lobe and noted that the patients appeared to show no gross ill mental effects from the procedure. Therefore faced with a barrage of insight I would have to say that removing a frontal lobe has little in the way of "detectable" effect on the patient to external observers; whether she would be the same person or as complete a person after such a procedure is impossible to know and that if the fear of such a prospect was greater than her dread of the short term effects of the tumour itself then she should not allow herself to be operated on.

Ultimately then the answer to "what should I have done then" is to keep talking until the patient and doctor can agree and ultimately if there is no agreement then there can not be a bond or a contract between them and for the doctor to treat the patient or for that matter the patient to allow themselves to be treated by that doctor would be inappropriate. There are now very few cases where a directive approach or the old "take your medicine because I am the Doctor and know what's good for you" is appropriate and this is not one of them.

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