

When consent is unbearable—a case report

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Informed consent has become one of the central problems in medical ethics. At first sight, it would seem that no argument can be made against a person's right to be fully aware of the extent, course, and implications of his medical condition. It seems equally obvious that it is the patient's right to participate in, influence, or fully and solely assume the decisions of medical actions that should be undertaken or withheld with regard to his disease.¹ Nevertheless, there are circumstances in which these commonly held assumptions about a patient's rights may not apply. It is the purpose of this report to describe a case where informed consent was deliberately not sought, and to discuss the ethical issues involved.

Case report

A 56-year-old man was referred to an orbital tumour clinic because of progressive protrusion of one eyeball. This man worked as a farm labourer in a rural area of an under-developed country. He was the father of five children, and his monthly income was approximately equivalent to £20.00 (40 US dollars).

The patient's medical history was unremarkable, except that he never had any useful vision in his left eye, due to an uncorrected squint which he had had for quite some time. His present complaint consisted of progressive out and forward displacement of his right eye, with accompanying dull, but not intense, pain of the orbital region, and some loss of vision.

On ophthalmologic examination, a tumour was found, which displaced the right globe and decreased visual acuity to 0.4. The left eye was deviated and amblyopic, with vision of counting fingers.

After a complete medical examination, which was normal, the patient was operated on, and two large, well-encapsulated tumours were removed from his right orbit. On histopathology, the growth was labelled an adenocarcinoma of the lacrimal gland. Although the pathologist was confident of her diagnosis, she expressed some doubts as to its certainty. Nevertheless, she advised the currently recommended treatment of exenteration of the orbit, that is, complete removal of the eye and orbital contents.²

The attending physician did not follow the

pathologist's advice. The patient was told that a malignant tumour had been removed, and that the patient should come for follow-up visits at regular intervals. After the operation, the patient recovered full vision in his right eye and was discharged without pain or discomfort. He was regularly followed up for two years without any evidence of local recurrence or metastatic spread. The patient presumably has continued to be seen at the same institution, although his physician transferred to another hospital, but further information about the case is not available.

Ethical considerations

The reasoning behind the attending physician's decisions centres around the evaluation of the circumstances that make moral issues much less clear-cut than standard ethics might wish.

Three ethical problems are apparent in this medical case:

1. Information was withheld from the patient.
2. Medical decisions were taken without his consent.
3. A conservative management was chosen against the recommendations of the pathologist and current medical thought.

Withholding information

The patient was not told that the malignant tumour removed from his orbit were, in all probability, of a nature whereby cancerous cells have remained in the orbit or were spread through the bloodstream. A large series of patients with adenocarcinoma of the lacrimal gland report no patient to be alive and free of recurrences and/or metastases, regardless of whether the tumour was cut out or the contents of the orbit remained. In other words, the patient was not informed that he had a fatal, incurable disease.

The decision to withhold information was based on a set of premises derived from the specific patient involved, the nature of the disease, and, certainly, a biased attitude of the physician.

The pathologist, although confident, was not absolutely certain of her diagnosis, nor of the prognosis, in view of the unusually well-developed fibrous encapsulation of the tumour. Therefore the patient would receive information, and be required to make decisions, on the basis of a high probability, not a certainty.

Medical experience available on the biologic behaviour of orbital adenocarcinoma was considered to be insufficient to allow clear appraisal of the probabilities involved in making a correct diagnosis and prognosis of the lesion.

The patient, an intelligent and cooperative person, was an unskilled farmhand with little formal education. Although he would have been fully able to grasp the dimensions of his medical problem, he was in no position to change any of the factors which governed his social and economic life. The confrontation with a life-threatening condition in addition to the option of choosing blindness would certainly cause psychologic and emotional stress, but could not be considered as information he could usefully elaborate to change his or his family's material circumstances. The patient's family was unknown to the physician, and the country where this problem occurred did not offer social, economic, or rehabilitational facilities that might have been effectively used by the patient to adjust to his possibly being handicapped and/or terminally ill.

Finally, it was considered that information could still be offered at the time when the appearance of recurrences or metastases clearly supported the expected fatal outcome.

Informed consent

Because the patient was not advised of the implications of his illness, informed consent was not possible. The decision made by the physician and not shared with the patient had been reduced from two options: concurring with the current recommendation of exenterating the orbit, which would mean iatrogenically blinding the patient in an attempt to postpone or eliminate death through tumour excision, or leaving the patient with his eye intact and the almost certainty of tumour-induced death. The patient therefore was not given the choice between blindness with probable death and conserved vision with almost certain death. In this alternative pair, the difference between 'probable' and 'certain' death is statistically insignificant.

The decision to bypass informed consent of the patient in the management of his case was based on two considerations: The options to be offered were equally discouraging (elective blindness and possible death vs. retained vision and possible death) and medical experience was clearly confused as to the current management of these cases (*vide infra*); the physician had little in the way of informed arguments to help the patient decide between two similarly cruel alternatives.

Current therapeutic recommendations

In spite of the pathologist's insistence, the physician

did not offer the patient the possibility of an exenteration. Here, the decision encompassed considerations offered by the medical literature.

'If the neoplasm is not too large and exenteration has not been deferred too long, rarely a patient may escape the inevitable fate that most must face'.² 'Not only is the mortality [of orbital adenocarcinoma] high but also the patient may suffer long periods of continuous pain before exhaustion brings about an end to the uneven tussle. Furthermore, in the interval between discovery of the tumour and death, the patient usually is subjected to several radical surgical procedures in an attempt to circumvent the tumour. Also, high doses of radiation may add a burden of malaise to an already miserable patient'.² 'If future surveys ... confirm the apparent futility of present treatment methods we will have to revise our recommendations for a radical surgical approach'.²

In other words, the decision to be made balanced radical, painful, and in all probability futile treatment, in this particular case aggravated by sudden and optionally chosen blindness, against passive observation and the knowledge that the final outcome would be equally fatal as with treatment.

The decision to withhold radical treatment was based on doubts about the certainty of the diagnosis, scepticism about the advantages of radical treatment, the particular problem of avoiding blindness in this patient, and the general consideration that restrained treatment was a reversible attitude, whereas exenteration of the orbit implied blindness, pain, and a probability of later recognition that aggressive treatment had been unnecessary (if the histopathologic diagnosis were ever revised) or futile.

In conclusion, this case confronts the physician with the unusual circumstance of choosing to present his patient with two equally hopeless alternatives. Their hopelessness was considered to be sufficient ground to withhold information and to bypass consent for no further treatment. The physician elected to adopt a paternalistic, rather than contractual relationship with his patient.³ The two-year favourable follow-up of the patient is certainly satisfying, but can in no way be considered as an argument in favour of the original decision.⁴

It should be considered that, had the physician abided by the basic rule that a person is due full information about his disease, there could have been no ethical issue at stake, since the next step, informed consent to institute or withhold treatment, would have been in the hands of the patient. I think this is an important and neglected aspect of medical ethics. If the decision is put in the hands of the patient, the physician is relieved from any ethical dilemma. Medical ethics are only applicable to situations and issues where the physician is fully involved in the act of decision-making, and

affected by its unavoidable ingredients of risk, loss, and responsibility – risk because alternatives can be no more than fragmentary solutions; loss because choosing also implies discarding; and responsibility because deciding must be a process subject to account. Had the physician in this case elected to inform fully the patient of his condition, and asked him to take the decision of exenteration vs. follow-up, there would have been no further moral issue: The doctor would no longer have any decision to make, and the patient would be confronting a horrifying game of survival probabilities.

References

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