Some ethical issues in dementia research

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Author’s abstract

The ethical problems associated with dementia have been thrown into focus by the ageing population. The elderly form a disadvantaged group in society and the author wonders if it is morally justified to pursue research into ways of arresting pathology without concomitant attention being paid to the quality of life of the surviving elderly. Precise diagnosis of dementia requires invasive, and potentially injurious, brain biopsy. Recent thinking has pointed to some of the advantages of biopsy. The question of consent in a patient with impaired mental function has to be borne in mind. As for the special ethical problems associated with Huntington's chorea, it is argued there is no justification for withholding information from, or for authoritarian direction of, patients and 'at risk' relatives but the importance of full discussion before undertaking predictive procedures is stressed.

The future extent of the problems to be posed by old age and senile dementia is not in dispute. Dementia refers to an acquired condition in which memory, intellect and personality are adversely affected, often but not necessarily in a progressive and irreversible way. Ninety per cent of cases of dementia occur in the senile population and about 10 per cent of the patients are pre-senile. The dividing line between senile and pre-senile groups is the age of 65, a purely arbitrary distinction traceable, it is alleged, to Bismarck who decided that State old age pensions should be payable at that age. The causes of dementia are several, dementia merely being the common end-point of several pathological processes. Though senile dementia accounts for by far the most cases with over 700,000 patients in England and Wales, there are small but significant numbers of other kinds of demented patients – for instance about 5,000 sufferers with dementia due to Huntington's chorea – and many of these often raise special problems of their own.

About 80 per cent of cases of dementia are beyond the scope of any reasonable prospect of cure and most dementing illnesses, in particular those due to Alzheimer's disease and multi-infarct vascular disease, tend to reduce life expectancy to a fraction of that to be expected in the healthy of the same age.

In the 20 per cent or so of cases who present with a picture of dementia and expect to be treated, there is at least a possibility that pathology if not chronology may be reversed and the sick old patient returned to society as a healthy old person. Straightaway, we are faced with the question of whether or not it is permissible to do research into dementia in the elderly.

Obvious though it may be, one has to emphasise that research into dementia is quite distinct from research into ageing. The problems of the normal aged in the population have become well known, especially since their numbers have begun to change the demographic balance. The wider question it is legitimate to ask is whether it is justifiable to seek to transfer scarce resources in order to reverse sickness and prolong life by researching a group of patients who when they are freed of pathology may well, in contemporary society, expect in general to experience hardship and a certain measure of rejection by younger people.

If the elderly were invariably able to lead their lives with satisfaction and dignity in the absence of sickness, there would be no difficulty in urging that our energies be directed towards the pursuit of such knowledge and its application. But in a situation such as the one that obtains it might be felt that the traditional scientific belief in dispassionately pursuing any subject of interest may have to be tempered by the realisation that simply freeing people of pathology can raise other ethical problems. As in numerous other clinical situations the wider question of the quality of life to be enjoyed by the patient, or his counterpart when rendered free of illness, must be taken into consideration. Also, though the milieu of the elderly might already be considered unpromising it is a sobering thought that when the fruits of current research come to be consumed, the expectation must be, at present, that the socio-economic circumstances of the elderly will have worsened and the quality of their existence become so much the grimmer.

It might be argued, therefore, that the researcher into dementia, before he becomes too carried away in his enthusiasm for errant molecules in synapses, has a moral duty to engage the younger members of society

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and confront them with the fact that it is not enough to
assuage their consciences by sanctioning research into
one of the more serious illnesses in old age while
continuing to choose to turn away from the larger issue
of social provision for the elderly population.

Sound clinical research begins with precise diagnosis
utilising all available investigatory tools. For the most
part investigations on demented patients, including
clinical assessment, psychometric evaluation, electro-
encephalograph (EEG) recordings, most blood-flow
techniques and computerised tomography are non-
invasive and are accepted without controversy. Unfortu-
ately, in our present state of knowledge, the
diagnosis of the most important cause of dementia,
Alzheimer’s disease, is possible only by cerebral biopsy
and by subsequent histological and, to a lesser extent,
histochemical study. Any invasion of the brain arouses
profound suspicion. Though the procedure for brain
biopsy has a small but definite risk of complication, the
objection and opposition to the operation is not so
much this risk but perhaps the emotional difficulty on
the part of patients, relatives and doctors in accepting
an assault on this last great bastion of human anatomy.
In this respect the issues are similar to the problems
associated with electroconvulsive therapy (ECT),
though the latter is part of therapy, the former part of
diagnosis. With ECT the possibility of aggravating
underlying brain lesions and of producing memory
impairment is also a small but definite risk to be
weighed against the generally accepted efficacy of the
procedure on severe, chronic and intractable cases of
depressive illness. But the generally cautious and
selective use of ECT these days has not damped very
much the lively controversy that has surrounded this
procedure, which has now been in use some fifty years
and, again, the criticisms are not always based on real
and calculable risks but on the grounds of ‘assault’ on
the patient’s mind and dignity by this largely empirical
procedure.

When it comes to cerebral biopsy, can the real risks
of the operation on a given patient justifiably be set
against the real risks of failure to gain precise
knowledge of groups of patients by not performing it?
Undoubtedly at present a diagnosis of Alzheimer’s
disease is likely to be only of academic interest as far as
the individual patient is concerned. However, there is
much work going on into the illness. When and if
potentially therapeutic agents become available there
can be little doubt that a reversal of the symptoms of
the illness will only be successful if treatment is carried
out immediately after early diagnosis. Current interest
is focused on memory difficulties with histochemical
correlates which need to be detected and countered by
replacement chemicals. When this form of chemical
treatment might become fully established and available
is uncertain; but if the experimental drugs are not used
on trial patients with early symptoms – subject, of
course, to the usual ethical considerations applicable to
clinical trials – there probably will not be any prospect
for development of this treatment. Similar
considerations apply to other potential treatments.
However, the later stages of dementia, involving
intellectual deficits and personality disorganisation as
well, are not at present thought to be reversible.

Further, some 20 per cent of demented patients are
 treatable by conventional management of the causes of
their dementing state. It is possible to argue with some
conviction in this context that a negative biopsy result
(meaning that the cause of the dementia is not
Alzheimer’s disease) may add extra impetus to the
further search for a treatable cause. We know that
Alzheimer’s disease is not only one of the commoner
causes of dementia but also that it is one of those that is
at present untreatable; on the other hand if a biopsy
does not reveal Alzheimer’s disease the chances that
the cause is a less common but perhaps therapeutically
more promising condition greatly improve. In these
circumstances it might be thought that ethical
pressures would be in the direction of performing an
early biopsy. Moreover, as Torack (1) has discussed,
a normal biopsy result may afford a more favourable
prognosis than any pathological result, even when the
dementia is of comparable severity. (This may seem
confusing but dementia is a clinical evaluation; the
biopsy refers to a technical procedure. It is possible to
be demented with a known cause, unknown cause or
even with normal ‘pathology’ on biopsy). If it is agreed
that there is a moral duty to inform patients fully of the
implications of their illness, it may be argued there is a
strong case for low risk brain biopsy in the search for
relevant information about that illness.

Before any procedure is undertaken there is an
assumption of consent, implied or explicitly given, on
the part of the patient. Consent implies a rational mind
able of understanding the issues and possessed of
the judgement necessary to consent. Unfortunately,
among the cardinal features of the dementia syndrome
are loss of insight, intellect and judgement. The very
features which are of clinical interest are those the
patient is deprived of when called upon to give consent.
Except in the earliest stages of the illness the patient
probably has little capacity to give fully considered
consent to any procedure which the investigator wishes
to undertake and as the illness proceeds this capacity is
reduced even further to the point that a rational
decision cannot reasonably be expected from a patient.
In the later, and terminal, stages of dementia consent
regarding, say, autopsy and removal of the brain can
only be obtained from relatives who will also be called
up on to approve serial investigatory procedures, the
first of which might have been done when the patient
was in reasonably full possession of his or her faculties.
In an effort to overcome this difficulty the idea has
been mooted of the ‘penultimate will’ through which the
patient, at the time of diagnosis (assuming it is
relatively early in the course of the illness), makes his
relatives the guardians of his body for the rest of his
life. In theory this would seem an admirably simple
solution. In practice it is most likely that intolerable
pressure would be put on most relatives who might
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It seems extremely unlikely, in the light of the evidence from several countries, that subjects who submit themselves to tests will agree to go away empty-handed when the results become available to the investigators. Whether there is ethical justification under any circumstances for deliberately depriving subjects of knowledge that has been obtained by doing tests on their bodies is questionable. And whether an authoritarian – that is what it will be in practice – ban on the activities of individuals on grounds of probability is likely to be ethically justified (or effective) is moot.

One approach is to discuss the issues with persons ‘at risk’ before the tests are undertaken. The nature of Huntington’s chorea makes most relatives perfectly aware at first hand of the consequences of having the disease and if the subject opts out of a situation which might bring him face to face with a fateful future it is likely to be a well-considered decision.

The full extent of the ethical problems surrounding dementia may only be realised when senile dementia becomes, as it threatens to in the remaining years of this century, one of the main public health problems. On the other hand and ironically, the sheer extent of the problem may well ease some of the ethical difficulties with which we are preoccupied today. The morality and ethics of birth control and abortion once preoccupied people to an inordinate degree and led to repressive attitudes on the part of those in authority. The realisation that strictures on birth control and abortion were incompatible both with increasing personal freedom and with the need for population limitation helped change attitudes. It is possible that realistic appraisal of a situation likely to arise in the fairly near future could exert a similar influence on our consideration of the ethical issues in dementia.

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