Counselling patients with AIDS-related encephalopathy

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The many uncertainties which surround the whole issue of AIDS-related encephalopathy (ARE) make counselling particularly difficult, because it is not possible to offer definite answers on many vital issues. On the other hand, the uncertainties involved make careful handling of patients and their problems even more crucial. Until a definitive treatment can be offered to patients, counselling, informed by the results of neuropsychological testing and with the emphasis on practical advice, is likely to be a key element in the care of every patient with ARE.

Counselling patients

Many people with AIDS are aware of the possibility of ARE. They are often more anxious about the possibility that they may develop ‘dementia’ than they are about the possibility that they may die.

When patients enquire in a general way about ARE it is important to stress that:
- The incidence of ARE is uncertain, but it does not appear to be an inevitable consequence of developing AIDS.
- Most people who develop ARE develop only mild symptoms which will cause no significant impairment in their everyday enjoyment of life or ability to function at home or at work.
- An effective anti-viral treatment for HIV infection may halt or retard the progress of ARE. It is even possible that it will reverse to some extent the effects of ARE.
- People who are anxious or depressed often feel that their minds are not working as well as they should. They may complain of memory problems and difficulties in concentration. Such changes are partly real but will get better as the levels of anxiety and depression improve, and partly unreal, as people feel they are performing worse than they really are.

Information along these lines often serves to reassure patients. Naturally, where there is anxiety or depression, this should be treated.

As part of good clinical management, cognitive functioning should be assessed every six months. Where this has not been done, patients who complain of cognitive impairment should be referred for psychometric testing and a neurological examination to establish the degree of impairment. If there is none, patients can be reassured and other explanations for their worries sought. If there are signs of impairment they can be discussed with the patient in detail.

Patients are particularly anxious to know whether they will get worse. There is no easy answer to this question, but they should be reassured and encouraged to keep ruminating and self-checking about memory and concentration at a minimum. They can also be assured that by repeating the tests, changes can be detected early and that treatment with centrally acting drugs may be of benefit at this stage.

Patients are also concerned about practical problems. Will the cognitive impairment cause difficulties in their work? Should they continue to drive? Such questions are particularly difficult to answer. The connection between psychometric tests, neurological tests and performance of real life tasks is often difficult to establish. It is more a matter of judgment than of the application of known facts.

Where possible, performance should be monitored on the actual task or set of tests in question. For an accountant worried that he may not be functioning as well as he should, it is usually possible for him to arrange for a colleague to check over a sample of his work; for someone operating machinery the issue is more complex. It would be wrong to suggest that someone should give up a job, say operating machinery, on the basis of very slight changes in cognitive functioning. However, it would be important to arrange regular monitoring of cognitive functioning and, if the impairment became severe, it would be inappropriate to continue in the job. The difficulty comes where impairment falls between the two. In all cases it should be borne in mind that anxiety may lead to absent-minded errors; this does not necessarily mean that the individual is organically impaired.

A patient with severe ARE may have a variety of dysfunctions. It is often possible to suggest how adjustments can be made, even where no treatment can be offered. Practical solutions are often available and patients should be encouraged to maintain a sense of control through looking for ways around minor memory and concentration difficulties. It is surprising how often

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simple measures to get around patients' difficulties are not implemented. A patient who finds difficulty in remembering names may find carrying an address book helpful; a patient who finds it difficult to concentrate for extended periods may obtain help by breaking tasks into short bursts, with frequent changes in task.

Summary

The key counselling roles of the health professional in dealing with a patient with ARE are to provide accurate information and advice, to seek practical solutions to assist the patient to minimise the impact of neuropsychological deficits and to offer support and help. Simply having someone who will answer questions honestly and will listen to what the patient says can improve mental well-being considerably.

Counselling carers

It is easy to overlook the needs of the primary carer who looks after the patient at home. There is evidence that many find the experience of looking after someone with ARE a particularly stressful experience. Indeed, in some cases they are actually more distressed, more anxious and more depressed than the patient [1]. Providing counselling and help to carers must therefore be an essential part of any approach to helping a patient with ARE. If it were not for the intimate carer, the hospital might well have to admit the patient. Moreover, where carers are distressed or have problems, they also have a right to be helped.

Carers are exposed to many sources of stress, particularly where the patient is severely affected. Personality changes can make it very difficult to deal with the patient, who may seem a 'different person' to the carers from the one they knew. They may have severe practical problems. A number of our patients with ARE have been affected in a way which has made it difficult for them to be left on their own. This can make it impossible for the carer not to hold down a job but also to continue a normal social life. Where the patient requires a good deal of physical help, the carer may be put under a great deal of strain by the physical and emotional effort involved. Carers who have been sexual partners of patients with ARE have the additional anxiety that they themselves may develop AIDS-related problems.

Carers are often reluctant to admit that they have problems; they may not wish to 'burden' busy hospital staff with their own difficulties, feeling that the hospital should concentrate on the patient. They may also feel that they have to be 'strong' in order to help the patient. If carers are not asked how they are coping and given time to admit their difficulties, they will often not admit that they have any.

Carers need information in the same way as the patient does. They need to be able to talk over the problem and ask questions. They will also need time with the counsellor and will need practical support and advice. For instance, one of our patients had always been a great reader. As his concentration worsened he found himself increasingly bored and spent a lot of time following the carer around their flat until this became intolerable. Helping patient and carer to develop a range of activities which kept the patient occupied without needing sustained attention was essential, and in this case the patient found considerable pleasure from jigsaw puzzles and listening to familiar records.

If a patient cannot be left alone, arranging a rota of friends and volunteers to stay with the patient can help. Again, carers may need to be encouraged to ask for help from friends. Carers can also be helped practically if a range of services can be provided to ease some of their practical difficulties. Domestic assistance and meals-on-wheels' for the patient can relieve pressure.

Ultimately, some carers find that they just cannot cope with the patient any longer. When this happens they can find themselves trapped, not just by the practical problem of finding an alternative, but by their own feelings of guilt and failure. They may need 'permission' from the health worker to give up their role and will have to be offered considerable support through the difficult period. They will also need help in sorting out some alternative arrangements for the patient, whether in sheltered housing if this is available, or through admission to hospital.

Counselling professional staff

Looking after the severely affected ARE patient is not just stressful for informal carers, it is also stressful for professional staff who may be unfamiliar with the difficulties presented by patients with brain damage. It is easy to misinterpret the problems caused by brain disease as being psychiatric problems or as the result of the patient being 'difficult'.

Where a ward has patients with ARE, staff need to discuss among themselves what is known about their mental state. There is a need to develop a clear plan of action for dealing with the patients, including any particular problems they may present, which everyone understands and feels able to implement. An aid to help staff monitor and recognise signs of ARE, a short checklist of cognitive, personality and behavioural measures can be used along with the care plans. This will facilitate discussion at ward rounds and help break down the problems with a 'difficult' patient. It is particularly important that everyone should treat the patient in a consistent manner.

Developing services

Services for young patients with brain damage, whether caused by infection or by trauma, are poorly developed in the UK. Occasionally it may be possible to place patients in one of the very few specialist units which take such patients but in most health districts there is no specialist service. Patients may find themselves wrongly placed on psychiatric wards; or they may find themselves in neurological or general medical wards. In some cases, young brain damaged patients may even be placed on wards with elderly patients with Alzheimer's disease.

None of these options are at all satisfactory for patients with AIDS. Not only do they have ARE but, in the vast
majority of cases, they will also have other problems associated with AIDS. Most HIV infected individuals will have had several admissions to the local ward dealing with AIDS. They will have formed relationships with the staff and become familiar with its atmosphere and procedures. It is obviously preferable for someone who has clinically apparent dementia, and is unlikely to live much longer, to be in a familiar environment. Specialist wards should therefore have their facilities extended to be able to accommodate these patients.

In addition, the following facilities may be needed:
- Sheltered accommodation or supervised hostels for those who cannot stay at home, but do not need full-time ward care.
- Provision for nursing ARE patients at home where necessary.
- Provision of services which can help maintain a patient at home, such as ‘meals on wheels’, domestic assistance, someone to help patients look after their finances, help with any necessary adaptations of the home.
- Assistance in ensuring that patients receive the welfare benefits to which they are entitled.
- Arrangements for respite admissions to relieve carers, either into hospital or into supervised accommodation.
- Arrangements for ‘patient-sitting’ to relieve carers during the day or to have the occasional evening off.
- Day care arrangements for patients whose carers go out to work.

At present, few health districts or local authorities outside large cities will have a high enough number of patients with severe ARE to justify the expense of sheltered housing or hostel provision, but with the number of cases of AIDS in the UK doubling every ten months, there is a need to start now to plan these services for the near future.

This article is based on a paper delivered at a Conference on Neuropsychiatric Disease and AIDS held at the Royal College of Physicians of London in October 1987.

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