

This response was submitted to the consultation held by the Nuffield Council on Bioethics on *Dementia: ethical issues* between May 2008 and July 2008. The views expressed are solely those of the respondent(s) and not those of the Council.

Question 1

ANSWER:

According to my experience, as a senior psychiatrist dealing with dementia for about 18 years (and as a relative 15 years ago) social help is still the most important nowadays. And herewith I mean, information, services, material help for those in need of, legislation to protect patients (even against relatives sometimes) and legislation also for relatives (in what concerns for example work schedule for example...)

Question 2

ANSWER:

I am just following a lady (around 70) which was brought to me for medical assessment by her younger sister. Both families are very wealthy. This sibling tells she has a great debt to her eldest sister, because their mother died early and it was she who brought up them all. The lady patient widowed several years ago and lives alone in the best part of town in a nice and large home with garden, etc, refusing any kind of help/company, although one can see that she is no more able to be independent in her ADLs. I even suspected that she could like one or more drinks (I am a senior psychogeriatrician), and one could invariably see some discrete stains on her fine clothes. After a short time she agreed to join a special day center for people with dementia (upperlevel). She is driven by a taxi and likes it there now very much. It is obviously expensive. Eventually she agreed to try an aid at home and a maid comes now daily. She is now quite happy with it. One day her sister asked me if I could receive her niece (the patient's eldest daughter, 40 something and teacher) because she was not understanding very well her mother's disease. Once I started listening to her (what I did for one hour, a follow-up session coming next week...) it was clear to me, that she found it senseless wasting money (her mother's money) with such an expensive day center and a home aid, the best solution being probably a regular old age home. But worst than that, it was clear to me that this lady had a paranoid disorder. She told me the worst things about her mother and how she had always hated her, telling me also that her sister, (physician) was schizophrenic and a terrible person, not able to care after the mother neither after herself (a bad relationship between both most probable). For some unknown reasons I suspected that this lady was somehow desperated in reason of financial problems. The patient's sister told me meanwhile that she fears her niece wanting to interdict her mother, and subsequently her (psychotic?) sister too. The patient would then run the risk of being "removed" into a rubbish home. This is now an ethical problem for me, because if the daughter asks the court for interdiction of her mother (and of her sister...), the judge will ask an expert (which is not going to be me) to assess the patient and normally doesn't ask the patient's physician (in this case me). I really would like to know what you think

about this.

Question 3

ANSWER:

Yes, of course.

Question 4

ANSWER:

It depends on many things. In a country like Portugal where health services are very heterogeneous and the Health Ministry exists apart from the Social Security Ministry, this last one ignores a lot of important needs. But in what concerns ethical questions different cultures may not necessarily be a major problem in our country. The major one is the financial power of the patient, which may also be an ethical one.

Question 5

ANSWER:

As a physician, actually a psychiatrist, and secondary a clinical researcher I personally don't trust on "rat scientists". - Concerning the next drug line, there were two branches at the beginning, let's say 10-15 years ago. Some were for beta-amyloid and some for tao (there was even a joke, about baptists and taoists). For some for me unknown reason, scientists got more interested on beta-amiloid, when we all knew, since the work from Braak and Braak, that Alzheimer's started at the hippocampus, where tao plays a huge role. Anti- Tao drugs should therefore if not first, at least at the same time be worked on as anti beta-amyloid... Memory is very much a paradigm of Neurologists. But it is not the most problematic in a patient with dementia, or more specefically with Alzheimer's disease. The most problematic is the lack of initiative and the loss of orientation in all internal and external dimensions. Paralell to drug treatment there is a lot of very important treatments like stimulation of many competences in the field of occupational therapy, entertainment for neuronal reahbilitation, light therapy against sundowning, reflexology for agitation, snoezelen...

Question 6

ANSWER:

I also work on the Genetics department. I herewith mean that at the Psychogeriatric department I have weekly 2-3 new patients with deficits or dementia, while at the Genetics department I receive patients with different kinds of genetic diseases (Huntington, Neurofibromatosis, Paraamyloidosis, X-fragile syndrome, etc), most of them quite young or parents of school children. There I follow strict rules for knowing if and when we are going to tell people the result of the tests. For Alzheimer's disease there is no predictive test, what can I say to a person who comes to me with some deficits, with 1 aunt or grand

mother who had atherosclerosis, with a CT scan which has some troubles, but not more than other people of same age have, and with an MMSE of 24, let us say? My colleagues Neurologists want me to send them those patients in order to get a lumbal puncture. At the end, assuming that I have got less precise neuropsychological tests, which I consider most valuable, what I am going to tell? Obviously not that this person has or will have Alzheimer's disease. But I see many jurists (in Portugal and in Spain at least) discretely trying to force physicians to tell the diagnosis to the patient. I wonder why...

Question 7

ANSWER:

As a terrible disease. Particularly when a relative gets it. One has to explain all the details, give booklets, recommend support groups, show movies and keep along with the patient as well as with the carers.

Question 8

ANSWER:

It depends. But once one loses the identity, he loses a lot of other things.

Question 9

ANSWER:

This is a matter of the type of dementia, of the stage of the disease and most of all it is a matter for the social assistance.

Question 10

ANSWER:

This idea is for all patients, not only for those with dementia. Remembering Tom Kitwood we learned a lot, but one has to center care on the patient as well as on the carer.

Question 11

ANSWER:

The person loses the ability to understand part or all of what is going around and inside of ones self. Once confused the person is no more able to choose or to take decisions in full. It has to rely on another person.

Question 12

ANSWER:

This question gives the answer. If the changes are in a positive direction, it is not all that bad.... it also depends on the wishes. In some instances an

advanced directive of will is a good solution.

Question 13

ANSWER:

According to her past wishes, etc if they are good for the present situation and if they are executable by the carers, doctors, etc

Question 14

ANSWER:

According to the country laws and if there is an advanced will.

Question 15

ANSWER:

It shouldn't. A patient with dementia is like another patient which lacks temporary capacity for deciding (for example, a patient with delirium, a patient with an acute episode of psychosis...the doctors, nurses, etc have to struggle for the patient's life at first place.

Question 16

ANSWER:

It should have been written by the patient in advance, what he/she wants to be allowed or forbidden, or whatever the case is, by the welfare attorney. There may arrive for sure many problems, they always arrive. In case the problem is complicated and doctors disagree with the attorney, then a court, of course, should always be involved.

Question 17

ANSWER:

People should be encouraged to complete such directives and to review them yearly. The example here given is the most confusing one. Measures to prolong the life have not necessarily to do with antibiotics (some infections may even cure without antibiotics), this is a symptomatic treatment. In case of life saving, this for example a pneumonia, an intensive care situation problem, physicians and nurses know well what it is, let them answer and handle, and in such extreme cases, then of course, we must respect the patient's wishes. I also would like me to be respected, once I would be the patient, this has to do with dignity of the human beings. Again to the case, many patients in such situations may not need/benefit from the actual "anti-dementia" drugs (actually we do not have any specific drug for most dementias...).

Question 18

ANSWER:

We, in Portugal have a Mental Health law quite recent. It does not cover specific rights for elderly people. And it is quite vague about people with dementia. Our law is roman based, not anglosaxonic.

Question 19**ANSWER:**

I think one must be careful how and to whom you tell the truth. If the patient has a dementia, not an MCI, this means that he might not be able to understand all I am going to tell him, dementia being the diagnosis. I may explain what he is or not able to do, how things are going to run, but some diagnosis as Alzheimer disease, are not easy to make 100% sure. Shall I say, well it may be, it may be not?. Maybe jurists tell the final truth themselves to the patient and assume the consequences. We physicians can not be forced to tell something we many times are not sure about, what something that is going to hurt the patient, without medical benefits in the horizon.

Question 20**ANSWER:**

According to my experience they err too much. Evaluation is a need and regularly, each case is a case. Physician, nurse, carer, etc must get together and define the risks and manage them according to safety and good sense.

Question 21**ANSWER:**

Restraint is sometime a need, in order to preserve the safety of the patient, but only temporary. If at home, it is not possible, most of the times to control it, even in residences...but in the hospital one has to ask for permission, unless it is only for a couple of minutes or one night, just to let medication work, otherwise the patient would be in danger.

Question 22**ANSWER:**

By health or social affair departments or by associations/societies. It is a need.

Question 23**ANSWER:**

I think I would like them, should I be the patient. But they are expensive (I have mixed feelings, since I saw the flyer of it in the business cabinet of a former health minister), and they should by all means, not substitute human help.

Question 24

ANSWER:

Very few and the legislation is very poor. In Portugal Social affairs and health ministeries are separated. even diapers are paid by the health ministry many times. The social assistance cares about antisocial people, gipsies, etc giving them our money for hanging around and starting trouble, but for the real people with cronic diseases (adults, elderly, even children...) there is misery.

Question 25**ANSWER:**

Being enroled in a support group is one of the best solutions.

Question 26**ANSWER:**

This an old question which would take too much time to be answered here. Anyhow, 10 years ago, at least, we did a remarkable work joining together all the countries of europe and doing a course for informal and formal caregivers (University of Cologne) as well as many other documents. I wonder what results they did bring, but the work has already be done.

Question 27**ANSWER:**

Again, each case is a case. One has to access them.

Question 28**ANSWER:**

The professional has to take a lot of time to listen and to know the family as well probably also houseworkers, neighbours, friends and colleagues. I know a ladie (formerly treated by me), whose husban was a physician and died 1st year, Having 7 children, 2 of them physicians, one of them lawyer, the lady with a very good financial position, and she ended shortly after the death of the husband in a luxus residence their 7 children in court 50% against the other 50%. A professional has to share at the simultaneously the whole truth with all the children. But in this case not even the judge ordered a mental health examen until now.

Question 29**ANSWER:**

The same as in other diseases: Health, social and family wellbeing (research is not all medical). On the basis of the best for the patient and for the family should be funding based, without hurting them.

Question 30

ANSWER:

It is preferable to not involve such advanced cases in research. There are plenty of patients who can still decide by their own in such a matter. What I always see is that people are not conveniently informed, and they consent, in case of relatives of an advanced stage patient, trusting on the professionals and thinking that they are contributing for the discovery of the cure. This is not acceptable, in my opinion. They are most of the times very badly informed about the risks, and a lot of research involving dangerous procedures should not be that easily done.

Question 31

ANSWER:

No, to my knowledge I don't think that this is the case.

Question 32

ANSWER:

Yes, the question of a discreet wish for prescribing the so called "anti-dementia" drugs indiscriminately by all physicians to all patients (and not patients!!), on one side, and the high prices of the same drugs for the patients who really need them. In Portugal there should always be a generic of at least one antedementia drug, but it got a stop somewhere without a plausible reason. A good home care, I mean leaving those in their own homes, who want it, should also be a must.