Factsheet: dementia

Dementia is a progressive condition for which there is currently no cure. Alzheimer's disease is the most frequently occurring and most commonly known variant. Dementia is characterized by a gradual decline in the patient's cognitive functioning and independence in daily life. The frequency with which it occurs among the elderly and the severity of the condition presents healthcare providers with a real dilemma. The disease is also accompanied by behavior that is often considered to be 'disruptive'. This behavior is not only distressing for close relatives, it is also problematic for healthcare personnel because it is difficult for them to understand and interpret. The family has to gradually say goodbye to ‘the person they once knew' and try to come to terms with ‘the person as they are now'. It is not always easy or possible for them to do this.

What treatment can help the patient and their close relatives?
At present there is no cure for the disease, and treatment with medication only has a limited effect. It is therefore important to develop appropriate care strategies that are not based on medication. The provision of support to care providers via programs of psycho-education and the creation of an adapted, ergonomic and pleasant living environment would seem to be avenues that are worth pursuing.

What is dementia?
According to the generally accepted definition of the World Health Organisation[1], dementia is *“a progressive decline of the memory and the ability to think, which is sufficiently pronounced to adversely affect day-to-day activities, has been apparent for at least six months, and includes a disturbance in at least one of the following areas: language, calculation, judgment, abstract thought, daily tasks, ability to think, or a change in personality”*.

The term 'dementia' is used as an umbrella term for a variety of conditions to which the following characteristics all apply:

- there is a progression over several years – referred to as neuro-degenerative pathologies (progressive degeneration of the brain);
- there is no cure – at least not within the context of the current medical and scientific possibilities (with the exception of some forms of so-called 'curable dementia');
- there is a loss of independence, as a result of an increasingly serious accumulation of cognitive disturbances and disturbances of the central nervous system. This loss of independence can even lead to loss of the ability to walk or to swallow;
- during the course of the illness psychological and/or behavior-related disturbances occur, such as “inexplicable changes in mood, fear, (...), suspicion, repeated screaming, difficultly eating, wandering…”[2].

In summary, SCHUERCH et coll. point out the severity of such a diagnosis: “*If one looks at the patterns of the natural progression of the dementia, one finds that unfortunately they*

[1] “CIM, version 10” ; Wereldgezondheidsorganisatie; 1994.
[2] “Que sont les troubles du comportement pour le neurologue ? Bases neurophysiopathologiques”; Moreaud O.; La Revue de Gériatrie; 2007

all have a bad outcome. At the current stage of development of healthcare and the fundamental sciences, in the case of both a single form and multiple forms of dementia, one is dealing with progressive and incurable pathologies. Due to their cognitive and/or behavior-related symptoms, they disrupt the patient's daily life at a relatively early stage and inevitably lead to the triple-A syndrome (aphasia, apraxia and agnosia). The terminal phase is in most cases characterized by the patient being bedridden and having difficulty swallowing.[3]"

What are the different forms of dementia? (This list is not complete.)
The generic term 'dementia' covers primarily the following conditions:

- Alzheimer's disease;
- Lewy-body dementia;
- Fronto-temporal dementia;
- Vascular dementia.

Other forms of dementia do exist, but the four forms mentioned above account for over 90% of dementia cases (60% of which are cases of Alzheimer's disease).

The impact on patients and their close relatives
As with every progressive pathology in which the fatal conclusion is already known at the time when the diagnosis is made, dementia not only affects the patient, but also their environment and in particular their close relatives. For the patient and their close relatives the disease is a difficult period, not least because of the behavioral and psychological disruption which gradually becomes apparent. There is therefore a need for additional human and material resources to be implemented.

In many cases of dementia 'identification and recognition disturbances' occur in certain stages of the disease. It can happen, therefore, that the patient no longer recognizes himself/herself when they look in the mirror or no longer recognizes close relatives. It also happens that the patient gradually loses any understanding of their disease and therefore no longer understands why they are receiving all this care or why they are being admitted to a hospital or institution. This is referred to as anosognosia, or denial of one's own condition.

These three symptoms together (anosognosia, recognition and identification disturbances, and behavioral disturbances) create a great deal of suffering for the patient's close relatives. They feel as if they are dealing with a family member whose personality is changing and who no longer recognizes them. This can lead to depression in the family members who provide voluntary care, and for the patient it can lead to premature admission to an institution, with gradually fewer and fewer visits from close relatives.

It is for this very reason that one of the basic principles of psycho-geriatrics is: ***"caring for the patient's close relatives also means caring indirectly for the patient themselves"***.

A matter of public health
"Dementia primarily affects the elderly. The Qualidem research, which was carried out by a team of researchers at the University of Liège and the KU Leuven, shows that the number of dementia cases in Belgium is approximately 9.3% of people over 65. Amongst people over the age of 85 this figure rises to 26.4%, and for people over the age of 90 it is as high as 34.8%. Two in every three patients are women."[4]

[3] "Confusion, dépression, démence : superposition, addition, potentialisation" ; SCHUERCH M., FARAG L., DEOM S., Revue Médicale de Liège; janvier 2012.
[4] "Dementie in België"; Stichting voor Alzheimer Onderzoek; 2005

In terms of public health and even in the broader social context, the provision of care to patients with dementia represents an enormous challenge, for the following reasons:

- the number of potential cases is rising linearly each year as life expectancy increases;
- at present there is not a single treatment that is effective against the cause of the disease; researchers do not have sufficient understanding of the mechanisms that lie at the basis of the disease;
- treatment with medication is expensive, both for the patient and for society. The effect of the medication is limited and it also has unwanted side effects.
- the patients become less independent in their day-to-day life, e.g. in washing, dressing and eating. As the disease progresses they require more intensive and more regular care;
- the behavioral disruption associated with the disease sometimes makes it difficult for the patient to live together with other patients. It is essential to develop specialized departments where the personnel have specific training;
- the impact of the disease on the patient's close relatives (fear, depression, exhaustion, …) generates indirect health concerns.

What action should be taken?

In England, France and Belgium the governments have called upon various centers of expertise to investigate how the provision of healthcare can be organized for these kinds of patients.

All reports emphasize the need to not only support medical research but at the same time to also develop care strategies that are not based on medication. The term 'non-medicative' relates to the various resources and techniques which can be roughly divided on the basis of the main target group at which they are aimed:

- care aimed at improving the living environment (help with orientation, adapted architecture, modulated and adapted lighting, …);
- care aimed at improving or retaining cognitive function (memory exercises, brain training, …);
- care aimed at affectivity, emotivity (Validation Therapy, empathic listening skills, …);
- care aimed at the main care providers, the close relatives, and the relationship between the patient and his/her social environment (programs of psycho-education, …).

The four main considerations are certainly of interest, but they are insufficiently backed up by scientific literature for them to be recommended fully. This was the conclusion of the HAS[5] (French health authority) and the KCE[6] (Federal knowledge center for healthcare).

In today's clinical research the cognitive care provision would seem to be losing ground, whilst the support to care providers and the approach via the environment form a source for ambitious research projects, the initial results of which are likely to be published in the coming years.

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