

Summary

SUMMARY

This is the third report within the framework of the 'Healthy Ageing' project which Pfizer and the Stichting STG/Health Management Forum initiated in 2003. In this report the results are presented of an exploratory survey of the effects of ageing on care for dementia patients .

With this report the initiators of the project intend to contribute to wide-spread acknowledgement and awareness of the problems and challenges of health care caused by an ageing society and, subsequently, to increase willingness to look for and implement solutions in care for persons suffering from dementia for the immediate and later future.

The 'Healthy Ageing' project is in line with the policy framework of the WHO concerning active ageing, a policy document which has next been developed in a UN plan of action concerning ageing. Improvement of the health of elderly persons ('healthy ageing') is described by the WHO as follows:

- > "A reduction of (environmental as well as behavioral) risk factors for chronic illnesses and reductions in functioning, and an increase in protecting factors, can promote people's enjoyment of a (qualitatively as well as quantitatively) better life. As a result of this, fewer of the elderly will require expensive medical treatments and healthcare services."

Dementia

Dementia is not a disease as such, but a syndrome: a combination or series of related symptoms. It is characterized by a gradual increase of mental dysfunctions. Usually impairment of memory is dominant, often combined with one or more cognitive disorders. As such it is not uncommon that cognitive skills diminish at a higher age. However, in case of dementia there is an accelerated deterioration of these skills. The rate and pattern of deterioration in case of dementia differ from one person to another, but in most cases it is an irreversible and progressive process ending in death.

Starting from their way of development several forms of dementia can be distinguished. The two most common forms are Alzheimer disease (AD) and vascular dementia. In patients suffering from AD the brains show diffuse defects and wither as a result of atrophy. The dementia process in AD starts in general insidiously and next develops according to a somewhat recognizable pattern of gradual deterioration. In vascular dementia defects in blood vessels of the brains occur without the neurodegenerative defects which are found in AD. In this form of dementia the disease starts in an abrupt manner and the condition of the patient deteriorates intermittently. Combinations of Alzheimer and vascular dementia also occur so frequently that the boundary between them seems to disappear as scientific insight in the occurrence of dementia increases.

The occurrence of dementia is based on a complicated interplay of genetic sensitivity and circumstantial elements. Age is the most distinct determinant for dementia. A far advanced age is the major risk element of dementia. Dementia occurs in 1-2% of the persons between 65 and 70 years and in about 40% of persons over 90 years old.

Although various risk elements have been described, knowledge of their link with dementia is still limited. For this reason the possibilities of (primary) prevention are also very limited.

There are more and more indications that risk elements for the occurrence of heart and vascular disorders are also risk elements for the occurrence of dementia (both in AD and in vascular dementia). Although strictly speaking no proof has yet been given, the time is considered ripe to award this topic a more prominent position in public information on healthy living and to progressively incorporate it in directives concerning detection and treatment of high blood pressure, diabetes mellitus, atherosclerosis and increased cholesterol in otherwise healthy adults. To furnish proof a large-scale prospective study has to be carried out. Thus it seems to be a simple matter of more time and effort before a workable preventive approach of dementia can be put into practice.

Present therapeutic options for inhibiting cognitive and functional deterioration in dementia (in particular anti-dementia drugs) are extremely modest and it does not seem likely that within the near future a drug will be found which may be used to counter all symptoms. So far treatment of dementia aims therefore in particular at additional symptoms (delusions, depressive state of mind and behavioral disorders) and maintenance or improvement of wellbeing (quality of life) of patients and their families.

It is estimated that of all patients suffering from dementia 65% live independently at present and almost 35% have been institutionalized. Two thirds of dementia patients therefore live at home and depend to a considerable degree on volunteer aid and home care. Volunteer aid (in most cases the partner or another close relative) is a crucial component of care for home-based dementia patients.

As from 1 January 2005 the Landelijk Dementie Programma (LDP; national dementia program) has started. The LDP develops the advice of the Dutch Health Council (Gezondheidsraad) issued in 2002 and aims at getting all regional providers of care and services for dementia patients to cooperate and better gear their support offer at the questions and problems of patients and aid volunteers. At the same time it contributes to a larger and more efficient offer in future to meet the increasing demand for care of dementia patients.

Trends and Developments

The ageing phenomenon entails a considerable increase of the number of dementia patients and the inherent appeal to care in the years to come. Half of the care dependency of older persons can already be assigned to dementia. Since there will be more and more elderly people, of an increasingly higher age, the number of dementia patients will grow from about 200.000 at present to an estimated over 300.000 in 2030. More and more persons will have to deal with someone suffering from dementia in their direct environment.

By reason of demographic developments the ratio of retired persons and potential working population (the 'grey pressure') will increase considerably, on the long term (2000-2020) even by about 50%. Health care will have to rely relatively more and more on the supply of labor available on the general labor market. On the Dutch labor market where growth will distinctly decrease after 2010, one must therefore not only further expand the number of care providers, but also commit oneself to improve productivity of health professionals and efficiency of work processes.

In the government policy concerning elderly persons the ability to live independently is the key-element. In this the aim is restriction of institutional care, and this implies a shift from formal to informal care. Such a shift means that care-needing elderly persons must (be able to) lean more on volunteer aid in the future. The Commission on Dementia of the Dutch Health Council is of the opinion that a shift from formal to informal care for elderly persons suffering from dementia is only possible to a very limited degree. In particular, expansion of the number of aid volunteers should not be considered to be a solution to the capacity problem in formal health care of elderly people with dementia. And so the Commission finds it infeasible that in the near future care for dementia patients can be provided without a substantial expansion of formal health care provisions.

In order to allow analysis of the effects of different scenarios on future health care provisions a dementia care simulation model has been developed. The model does not only map the effects on the patients, but also shows the effects of inappropriate care on persons who provide informal care to the patients (volunteer aid).

Conclusions

Based on scientific articles, books, interviews with experts and an invitational conference the following conclusions have been drawn in respect of the effects of ageing on dementia care.

- 1 Dementia is not a disorder as such, but a syndrome. Since there are over sixty disorders in which dementia may occur, dementia is nothing but a clinical diagnosis which does not say anything about the underlying cause.
- 2 Based on demographic developments the number of persons suffering from dementia will increase by 44% in the period from 2000 to 2020.
- 3 Labor capacity is the major restrictive element in meeting the increasing care demand of demented persons and the persons looking after them.
- 4 A (further) shift from formal to informal care of elderly persons suffering from dementia will only be possible to a limited degree.
- 5 General practitioners have become more alert when diagnosing dementia. Nevertheless, in most cases the diagnosis of dementia is not made but in a late stage. The reason for this is that general practitioners do not have sufficient knowledge of and experience with dementia on the one hand, and they often decide not to make the diagnosis for lack of medical treatment perspectives on the other hand.
- 6 The knowledge of determinative and risk elements of dementia is still limited. For this reason the options of (primary) prevention of dementia are also still limited. Age is the most distinct determinative element of dementia.
- 7 New options to prevent the occurrence of neurodegenerative disorders will most likely not come about in the next decade.

- 8 There are indications that risk elements of the occurrence of heart and vascular disorders are also risk elements of the occurrence of dementia. Preventing the occurrence of vascular damage in the brains could therefore provide a real option to reduce dementia prevalence.
- 9 Current therapeutic options for inhibiting the dementia process are extremely modest. Although a lot of research is being made, this will not result into new options in the near future.
- 10 The (medical) treatment of persons suffering from dementia mainly aims at additional symptoms (delusions, depression, behavioral disorders) and the maintenance and improvement of their well-being (quality of life).
- 11 Two thirds of the patients suffering from dementia live at home and depend in this on volunteer aid and home care to a considerable degree.

Agenda for the Future

The agenda for the future can be founded for an important part on the advices of the Dutch Health Council issued in 2002 and 2005 respectively. The major recommendations in them are:

Primary Prevention

- 1 The fact that risk elements of heart and vascular diseases most likely also increase the risk of dementia, should be focused on in public information concerning healthy living and in directives for detection and treatment of high blood-pressure, diabetes, atherosclerosis and increased cholesterol in otherwise healthy adults.
- 2 Study of the effectiveness of such measures to prevent dementia should be awarded top priority.
- 3 By means of regulation, supervision and financing the government can guarantee the independence of scientific research into anti-dementia drugs.

Secondary Prevention – Dementia Care

- 4 Each general practitioner should be able to recognize the symptoms of dementia. When suspecting dementia he should work towards diagnosis while taking due care.
- 5 A national health care program has to be set up including quality conditions concerning the content of care and monitoring of persons suffering from dementia and aid volunteers.
- 6 Regional offices of the Center Indicatiestelling Zorg (CIZ; formerly Regional Indication Organs (RIOs)) must operate in conformity with transparent directives including indication criteria for patient and aid volunteer.
- 7 Considerable expansion of home care facilities and of the number of places in institutions is required to allow adequate care for dementia patients.

- 8 When determining the need of formal aid the restrictions of the demented patient should be decisive and not the availability of a partner or other relatives.
- 9 The government should inform citizens of the importance and options of drawing up statements of will.
- 10 Quality and organization of dementia care should be improved in particular as far as integration and cohesion of care provisions concerns.
- 11 The more the part of non-native nationals increases among the elderly population, the more their number will increase among dementia patients, and therefore the need of specific care for these patients and their caretakers.

At the STG invitational conference on dementia (on 24 June 2004) it was studied in particular which elements of the current (policy) agenda require supplementation or adjustment within the framework of phrasing a future agenda:

- 12 The participants in this conference concluded that in particular the development of care in small-scale facilities should be awarded more priority.
- 13 Such care should be offered from a chain approach also involving social welfare facilities.
- 14 By making the diagnosis in an earlier stage the duration of the disease is prolonged for dementia patients. The care provided to patients in an initial dementia stage should be expanded.
- 15 In order to avoid unnecessary early institutionalization the so-called “respite care” (such as visiting and sitting services, homes for temporary stay) should be further developed.
- 16 Case management should be focused on.
- 17 Policy-making bodies will have to make a joint effort to increase the offer of provisions in conformity with an increasing number of dementia patients.