The functioning of patients with Alzheimer's disease in the opinion of their families

(Funkcjonowanie osób z chorobą Alzheimera w opinii ich rodzin)

H Król 1,A,D, B Zboina 2,E, G Nowak – Starz 1,F, M Biskup 1,C, M Surma 2,B

Abstract – Introduction. In Poland, Alzheimer's disease affects around 200-250 thousand patients. The disease manifests itself by dementia – the patient ceases to be interested in the environment, loses his or her memory, sense of time and place. There occur behavioural disorders, neurological symptoms and speech disorders – a general decrepitude. The affected person requires comprehensive full time care.

Aim of the study. The aim of the study is to determine the opinion of families and carers of people diagnosed with Alzheimer's disease regarding the functioning of the latter.

Materials and methods. The study was conducted in 2012 at the Caring and Therapeutic Institution in Radom, the ‘Neuromed’ clinic in Radom, the Surgery for the Treatment of Memory Disorders in Radom, the Radom Association of Families of Patients with Alzheimer's “Helping Hands” and the Nursing Home in Wrzosowo. The study group comprised 91 family members and carers of people with Alzheimer's disease. The age of the patients was diverse, the dominant range being that of 76-85 years old (nearly 55%). Caregivers were over 50 years old (56-70 – more than 47%, 41-55 – almost 32%). Both patients and their carers live in an urban environment. The diagnostic survey method has been used in the study. A non-parametric Chi-square test has been implemented to verify the statistical correlation of selected features.

Results. The individuals diagnosed with Alzheimer's disease are mainly women (68.13%). The patients’ carers are their adult children (over 47%) or spouses (more than 35%). They are affected by problems with memory (nearly 88%), an impaired sense of time (over 71%), speech disorders (over 68%), and emotional problems – they often cry (23.07%). More than 56% experience delusions and hallucinations (nearly 44%) as well as sleep and nutrition disorders.

Conclusions. Gender has a significant impact on the morbidity of Alzheimer's disease. Longer duration of the disease and the advanced age of patients worsens their motor functions. The functioning of patients is not related to their place of stay. The patient’s age does not affect the degree of his or her withdrawal from daily activities.

Key words - Alzheimer's disease, health, carers.


Cel. Celem pracy było poznanie opinii rodzin i opiekunów osób z rozpoznana chorobą Alzheimera odnośnie funkcjonowania ich podopiecznych.


 Wyniki. Osobami z rozpoznana chorobą Alzheimera były głównie kobiety (68,13%). Opiekę nad chorymi sprawują ich dorosłe dzieci (ponad 47%) i wspólmałżonkowie (powyżej 35%). Chorzy mają problemy z pamięcią (blisko 88%), zaburzeniami orientacji czasu (ponad 71%), zaburzeniami mowy (powyżej 68%), stanem emocjonalnym - często płaczą (23,07%). U ponad 56% występują urojenia i omamy (prawie 44%) oraz zaburzenia snu i odżywiania.

Wnioski. Pleć ma zasadniczy wpływ na częstość występowania choroby Alzheimera. Czas trwania choroby oraz wiek pa-
I. INTRODUCTION

Alzheimer’s disease is one of the most frequent diseases in old age – it accounts for as many as 60% of all dementia cases [1]. Approximately 200-250 thousand of people suffer from this disease in Poland [2]. It is predicted that in the coming years there will be an increased morbidity of Alzheimer’s disease due to the ageing population. As a general rule, the number of patients doubles every 5 years on average for the population aged between 65 and 85 [3]. Patients diagnosed with Alzheimer’s disease constitute an ever-increasing medical, social and economic challenge [4].

In spite of extensive research, the origin of the disease is yet to be established [3]. The results of the existing studies point to the influence of genetic, neurochemical and immuno-inflammatory factors as well as some types of exogenous poisoning on the morbidity rates of the disease [5]. Among the major risk factors are age [6], gender – women are affected more frequently [7], education, familial incidence – early symptoms even between the age of 35 and 60 [8] and genetic factors [9]. Crucial as well are vascular risk factors such as: diabetes, smoking, uncontrolled high blood pressure, obesity, low physical activity or high plasma homocysteine levels [10]. Not insignificant may be: a past head injury [11], depression [12], an advanced age of the childbearing woman (over 40 years of age) – a risk factor for the child [13], hormone replacement therapy [1] and an early hysterectomy [14].

Usually, to diagnose Alzheimer’s disease, three scales are used which are included in the International Statistical Classification of Diseases and Related Health Problems (ICD-10), the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR), and in the Criteria by the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer’s Disease and Related Disorders Association (NINCDS-ADRDA). These scales specify the presence of dementia symptoms and the lack of disorders of consciousness as the causes of cognitive disorders and the lack of other diseases of the central nervous system which cause dementia. [15].

According to the scale used in Poland (ICD-10), dementia is a decline in memory and thinking abilities to a degree which impairs the everyday functioning. Memory disorders comprise receiving, processing and recalling information. This definition encompasses associated symptoms such as: disturbed thinking and judgment as well as emotional changes [16]. However, the criteria of DSM-IV-TR and NINCDS-ADRDA specify dementia as a syndrome in which, apart from memory disorders, numerous cognitive deficits occur, including: aphasia, apraxia, agnosia or executive dysfunction [2].

The diagnosis of Alzheimer’s comprises psychological testing in order to establish the severity of the disease, a general medical interview, detailed blood and urine tests, a full neurological interview and examination as well as CT and MRI neuroimaging.

Alzheimer’s disease is characterised by several consecutive stages. Stage 1 (early) – mild dementia with changes in the scope of intellectual capacity, everyday functioning and behaviour. Patients require care from time to time. This stage lasts about 2-4 years and the patient seeks treatment due to memory disorders (93%), mood disorders,
depression (34%), difficulties in performing everyday activities (31%) and behavioural disorders (30%). Weight loss is often a crucial symptom [17].

Stage 2 (middle) – moderate dementia, evident memory and cognitive disorders (speech disorders, forgetting words), behavioural disorders, biological rhythm disturbance (sleep, hunger), psychotic symptoms (delusions, hallucinations). The patient requires permanent care. This stage lasts 2-5 years [6].

Stage 3 (late) – severe dementia, restricted or non-existent verbal communication, sleep disorders, aggressive behaviour, eating disorders, decline in mobility or even complete loss thereof. This stage lasts a short period of time – roughly a year – and the patient requires nursing care [18].

In spite of extensive research on Alzheimer’s disease, no cure has been found yet which could reverse the symptoms of Alzheimer’s or at least halt its progression [19]. Pharmacological treatment focuses on symptomatic treatment of memory and cognitive disorders, and particularly, on delaying further development of the disease [18].

As far as the residential environment of the patient is concerned, major changes to the daily routine must be avoided since they may increase the patient’s anxiety. Free movement should be possible while surrounded by familiar objects [20]. A fixed daily schedule ought to be adhered to, physical activity should be planned, contact with family and friends should be provided as well as undisturbed rest because it all gives the patient a sense of security [21]. Practising everyday activities makes continued independence possible. Movement therapy adds considerably to the patient’s fitness, and it is a basic element of preventing bedsores and muscular dystrophy at an advanced stage of the disease [20].

The aim of the study is to learn about the opinion of families on the functioning of their dependants diagnosed with Alzheimer’s disease.

II. MATERIALS AND METHODS

The study was conducted in 2012 at the Caring and Therapeutic Institution in Radom, the Nursing Home in Wrezosowo near Radom, the ‘Neuromed’ clinic in Radom, the Surgery for the Treatment of Memory Disorders in Radom and the Radom Association of Families of Patients with Alzheimer’s “Helping Hands”. The study comprised 91 family members or carers of patients with Alzheimer’s, from whom approx. 35% were spouses, nearly 48% adult children, and carers (nearly 10%) or siblings (approx. 7%). The diseased were of various age, the dominant range being that of 76-85 years old (close to 55%). The carers were above 50 years old. (56-70 – over 47%, 41-55 – almost 32%). About 65% had graduated from higher and secondary education institutions. Both the patients and their carers lived in an urban area. The diagnostic survey method was used in the study. A non-parametric Chi-square test was implemented to verify the statistical correlation of selected features.

III. RESULTS

The conducted research demonstrated that patients diagnosed with Alzheimer’s disease were mainly women (62 people; over 68%). Men constituted 31.87%. The ill were mainly cared for by their adult children (47.25%) and spouses (over 35%). A small group were unrelated carers (nearly 10%) and siblings (7.69%).

The carers were aged 56-70 (over 47%) or 41-55 (almost 32%). Only 5.49% were young people (25-40 years old). An alarming fact is that over 15% of the study group were elderly people aged over 70 who might themselves soon require help.

More than 46% of carers graduated from secondary schools and over 24% hold a higher education diploma. The remaining ones have obtained basic vocational (about 21%) or elementary education (slightly less than 9%).

A dominant group of patients were elderly people aged 76-85 (almost 55%), patients over 85 years of age (16.50%) and those aged 66-75 (15.38%). Many fewer were patients aged from 55 to 65 (13.18%).

It was found that the main place of stay of the patients was the Caring and Therapeutic Institution (about 43%) or their own home (over 40%). Few lived with their families (15 people, which is 16.48%).
The results of the study indicated that more than 48% of the patients had been ill no longer than 5 years. A large group were patients who had been ill for 6 to 10 years (over 35%).

It was discovered that as many as 92.30% of patients had problems with memory and nearly 88% with logical thinking. 73.62% of the study group believed that their dependants “rarely” recalled recent events or they “sometimes” did (over 18 %). Only under 8% of the examined replied in the affirmative.

The respondents stated that as many as 68.13% of the patients could not remember important information from the distant past (e.g. dates of birth and marriage and places of work). Only slightly more than 7% could memorise a short to-do list, e.g. a shopping list.

Functioning in the place of residence posed difficulty for the patients. Over 74 % “rarely” found their way to closed rooms such as the kitchen or bathroom. As few as 21% “rarely” repeated the same questions or activities. Almost 65% of the ill “often” experienced self-identity disorientation and 71.42% tended to have difficulty identifying place and time (close to 77%).

Table 1. Duration of the disease

<table>
<thead>
<tr>
<th>Duration of the disease</th>
<th>Number of patients</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>n</td>
</tr>
<tr>
<td>0-5 years</td>
<td>44</td>
</tr>
<tr>
<td>6-10 years</td>
<td>32</td>
</tr>
<tr>
<td>11-15 years</td>
<td>9</td>
</tr>
<tr>
<td>Above 15 years</td>
<td>6</td>
</tr>
<tr>
<td>In total</td>
<td>91</td>
</tr>
</tbody>
</table>

The respondents found that 68% of the patients had difficulty expressing themselves and building sentences (about 77%) or they were “lost for words” (almost 77%), which made communication difficult.

Table 2. Speech disorders – difficulty pronouncing words

<table>
<thead>
<tr>
<th>Difficulty pronouncing words</th>
<th>Number of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
</tr>
<tr>
<td>Yes</td>
<td>62</td>
</tr>
<tr>
<td>Sometimes</td>
<td>20</td>
</tr>
<tr>
<td>Rarely</td>
<td>9</td>
</tr>
<tr>
<td>In total</td>
<td>91</td>
</tr>
</tbody>
</table>

The study has revealed that over 80% of Alzheimer’s disease patients “often” refrain from doing everyday activities. All the chores are taken over by the carers.

It was also found that the patients experienced low mood. They often felt sad (over 56%) and cried (47.24%).

The patients are highly susceptible to psychotic symptoms: hallucinations (nearly 44%) and delusions 56%. They see absent people, hear voices, believe that someone has been stealing their belongings, trying to poison them or mistreating them.

According to the respondents, their patients are disturbed emotionally. They are frequently upset, irritated (more than 59% for both emotions), aggressive (nearly 21%) or they feel unsafe (above 48%).

The surveyed group confirm that their patients have a disturbed day-night rhythm. They take naps during the day (over 86%), find it difficult to fall asleep at night (over 71%), they wake up and walk at night (approx. 65%).

The results of the study demonstrated the existence of nutrition disorders affecting the patients, which are often manifested by a decreased appetite (over 35%) or the converse, by asking for food more frequently (about 21%). Nutrition disorders often lead to constipation (over 27%), less often to diarrhoea (below 8%).

Table 3. Patient’s activity – withdrawal from everyday activities

<table>
<thead>
<tr>
<th>Patient’s activity – withdrawal from everyday activities</th>
<th>Number of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
</tr>
<tr>
<td>Often</td>
<td>73</td>
</tr>
<tr>
<td>Sometimes</td>
<td>14</td>
</tr>
<tr>
<td>Rarely</td>
<td>4</td>
</tr>
<tr>
<td>In total</td>
<td>91</td>
</tr>
</tbody>
</table>
It has been found that 84% of patients require the help of others while dressing themselves. Barely 26.37% manage to eat meals unaided.

Over 92% are not able to maintain their own personal hygiene. Fewer than 22% control their physiological functions and the remaining patients suffer from disorders related to passing urine and stool.

According to the respondents, their patients have visibly impaired motor functions. Scarcely 22% move from place to place unaided. Over 37% require help, especially the bedridden patients (about 18%). Immobility often brings about various complications – contracts or bedsores. More than 52% of the respondents confirmed that their patients suffered from such complications.

The statistical analysis of the correlation of selected features demonstrated a relation between: the place where the ill person was staying and the degree of his or her withdrawal from everyday activities (p=0.05), the motor functions of the patient and the duration of illness (p=0.05), the motor functions of the patient and his or her age (p=0.05), and finally between the occurrence of hallucinations and the duration of illness (p=0.05).

### Table 4. Independence in dressing

<table>
<thead>
<tr>
<th>Independence in dressing</th>
<th>Number of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Without help</td>
<td>n=14, %15,38</td>
</tr>
<tr>
<td>With help</td>
<td>n=42, %46,15</td>
</tr>
<tr>
<td>Not capable of dressing</td>
<td>n=36, %38,47</td>
</tr>
<tr>
<td>In total</td>
<td>n=91, %100,00</td>
</tr>
</tbody>
</table>

### IV. DISCUSSION

The study has demonstrated that the respondents’ patients are decidedly elderly people, older than 65 years of age (nearly 87%), mainly women (over 68%), which confirms the validity of the main risk factors adopted by numerous authors, which are: age, gender and education [1,3,6,7].

All the patients are provided with specialised medical care regardless of their whereabouts (family environment, institutional facility). It must be emphasised, however, that the patients come from urban areas, which considerably facilitates access to a specialised doctor and relevant institutions providing care for the chronically ill. It is a crucial fact that their carers also dwell in the city, and they hold higher education (over 24%) or secondary education (over 46%) diplomas, which is assumed to have a positive effect on the quality of care.

Nevertheless, it must be emphasised that the conducted analysis has confirmed a statistically significant correlation (p=0.05) between the whereabouts of the ill person and the degree of his or her withdrawal from everyday activities. It may be presumed that patients staying in the family environment are more often actively involved in everyday household activities than the ones staying at care facilities.

Depending on the duration of illness, patients with diagnosed Alzheimer’s disease behave and function differently, which generates new, often unexpected tasks for their carers [6,17,18]. According to the respondents, their patients had been suffering from the disease for various periods of time, up to 5 years – over 48%, ranging from 6 to 10 years – more than 35%. It must be underlined that the respondents providing care for their family members (adult children – over 47%, spouses – over 35%, siblings – below 8%), were either people above 40 years old, i.e. they were in the period of professional activity, or individuals older than 70, i.e. elderly people who may themselves be burdened with illness and who may soon require help.

Alzheimer’s disease causes major mental disorders, physical and social restraints [2, 6,15-23], which has been further confirmed by the study. The ill cease to take interest in the environment, they have problems with memory (more than 92%), lose their bearings and sense of time (over 77%) and become confused as to their own identity (nearly 65%). Furthermore, the examinations have shown that patients suffer from emotional disorders, a markedly changeable mood ranging from aggression (almost 21%) to sadness (over 56%) and crying (more than 47%). Also, they are not capable of performing the following everyday activities: dressing themselves (over 84%), cleaning their body (more than 92%) and eating meals (56%).

A long duration of the disease and advanced age considerably limit the motor skills of patients (p=0.05). A statistically significant relationship has also been confirmed between the duration of the disease and the occurrence of hallucinations (p=0.05). Such a state lowers
the activity of patients, it renders them passive and indifferent to the environment.

Bearing in mind the unfavourable prognosis concerning the increase in Alzheimer’s disease cases, coupled with the numerous disorders and limitations resulting from the disease as well as the challenges which it poses to carers, it is highly recommended that research be continued so that results applied in practice can markedly improve the quality of life of patients.

V. CONCLUSIONS

1. Alzheimer’s disease patients require comprehensive care.
2. Age and gender constitute major risk factors.
3. Longer duration of the disease and more advanced age have an adverse effect on the psychomotor and social functions of the ill.
4. Functioning of the ill is not related to their place of stay.

VI. REFERENCES