

Preparation the family to care of the patient with Alzheimer's disease

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Abstract

Purpose: Evaluation of the level of the family readiness to look after a person suffering from the Alzheimer's disease.

Material and methods: In the research an authorized questionnaire was used, which comprised knowledge concerning the disease, coping with the situation, looking after a patient and an open test.

Results: It was shown that the level of knowledge about Alzheimer's disease corresponds to the level of education ($p < 0.05$). Most families 67% look after the patient in their own houses, although they don't belong to any support group. Adapting to a new situation is difficult for people, although, most of them devote most of their energy to the patient with the support of the other members of the family. Family support and the level of knowledge aren't related with the patient acceptance ($p < 0.05$).

Conclusions: Family support and the level of knowledge aren't related with the patient acceptance. There is a relation, however, between the education and the level of knowledge about the Alzheimer's disease.

Key words: Alzheimer's disease, care, family.

Introduction

The progress of civilisation and medical sciences causes an increase in the number of people advanced in their years.

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It's been estimated that between 1992 and 2050 the number of people over 65 will from 6.2% to about 20% of the population. Therefore, senile dementia becomes more prevalent, and this kind of disorder is diagnosed in about 8 to 10% of people over 65 years old [1-3]. The most frequent cause of dementia is Alzheimer's disease, a chronic, progressive and irreversible brain dysfunction leading to the state of dementia. Short-term memory is early affected. Then, visually spatial disorders and cognitive dysfunctions concerning attention, communication, thinking, perception and planning, which causes worsening of well-being and an increase of emotional liability, appear [4,5]. Patients become more irritable and their attitude towards the closest people changes. Progressing personality changes are usually characterised by initiative and responsibility decrease and apathy growth. High level of aggression and hostility can be observed in patients with diseases personality. As the disease gets more advanced difficulties, concerning any life activities and contacts with the outside world, develop until those activities become impossible [6,7].

The disease frequently develops slowly in the environment of stabilised family life, where everyone has his/her particular role. It changes family's life situation seriously, but family members are neither able to control course of the disease nor take nursing care of the patient [8].

Family adaptation to the new situation, conditioned on the disease, is difficult and requires many changes, but most of all, an understanding of the disease essence and development of proper care attitude are necessary [9].

The purpose of this study was to recognise a level of family preparation to take care of a person suffering from Alzheimer's disease.

Material and methods

In order to gather data the following tools were used: (1) questionnaire form including items assessing level of knowledge presented by the family members, organisation of care and

ways of handling of an Alzheimer's patient, (2) evaluation scale of family approval of a sick person, (3) test built of unfinished sentences, which recognise family adaptation to new situation.

The study was conducted in 2003 and families of patients with Alzheimer's disease treated in The University Hospital of Cracow, outpatient clinic of The Memory Dysfunction, Psychiatry Clinic were examined.

Results

The study group comprised of 30 people taking care of patients with Alzheimer's disease, 19 (63%) were females and 11 (37%) were males. The majority of the respondents (37%) were between 41 and 60 years old, 33% – 20 to 40 years old and 30% were from 61 to 80 years old. The mean aged mounted to 41 years old, women 50.

Eleven respondents (37%) received secondary education, 10 (33%) – university education, and 7 (23%) – vocational education. 26 participants (87%) had close family and 4 of them were lonely. Office work and pension were the most common livelihoods (10 participants – 33%). 18 respondents (60%) lived in the country and 12 (40%) in the city. Almost half of the group (14 = 47%) had good financial situation, 40% – medium, 10% – bad and only one person had a very bad financial situation.

It was estimated that 80% of the respondents presented good level of knowledge about Alzheimer's disease. More than 90% of the participants knew that both men and women suffered from Alzheimer's disease and the aim of the Mini Mental State Examination scale. According to 60% of the respondents the main cause of patient's fall was: waxing the floor (60%), lack of rugs or doorsteps (17%), and lack of handrails (10%). The respondents named the following causes of burn risk factors: working hair dryer (50%), switched off electrical equipment (30%), closed gas (10%), and controlled smoking (10%). For 30% of the respondents the disease lasted 8 years, for 20% – less than 3 years, for 10% – to 15 years and 40% of the sample didn't know how long this disease could last. There is a relation between education level of the family members and the level of their knowledge concerning Alzheimer's disease. The test Student's significance level p was lower than 0.05.

Care of the patient and organise their lives in the families

Most of the families take care of the patient and organise their lives. Ninety percent of the respondents lived with their families, and 10% lived separately. Forty percent the participants took care of their sick relative 24 hours a day, 23% spent with the patient 2 hours a day, 7% – 5 hours a day, while every fourth participant met the patient two times a week. The vast majority of the sample (67%) didn't take advantage of any kind of help and didn't even consider it. One third of the respondents took an institutional care into consideration. Twenty three percent of the participants took advantage of social welfare centre, 7% had a surrogate carer, and only 1 person stayed in a day-care centre. Forty three percent of carers could count on the support, 40% – sometimes and only 17% of family members said they could always count on help. Only 23% of the sample participated in

a support group and 77% didn't use that kind of help at all. Sixty seven percent of the respondents believed that their care of the patient caused limitation of family social relations, 20% of the participants found new friends and 13% was convinced they had lost not only their acquaintances but also their friends.

Cooping methods with disease Alzheimer's. As far as the ways of spending free time were concerned, 33% of the sample was thinking up simple activities of everyday life, 10% read books to the patient, 27% went for a walk, and 30% didn't take any actions.

More than half of the respondents (53%) helped the patient with remembering through frequent repeating, 20% didn't move things around the house, and 27% didn't do anything. The most common form of communication was verbal contact and touch (47%), 43% kept only verbal contact and 10% of the sample were silently present.

In the case of communicational difficulties, 63% of the group dealt with this problem by speaking slowly, 17% – waited patiently, 13% – left the patient alone, and 2 respondents admitted they had raised their voice. When excitation of the patient was discussed, 40% tried to talk to the patient and draw his/her attention away, 10% limited the choice, 2 respondents raised their voice, and one left the patient on his/her own.

If the patient left home and lost the orientation, more than half of the group (53%) said they looked for him/her unaided, 27% informed the police, relatives and friends. Only 3 participants claimed they waited calmly until the patient returned home, and the same number didn't do anything about it but felt guilty. As far as gathering things was discussed, 20% of the participants searched the lost thing, only 2% gave something in return or they do nothing.

Seventeen percentage of the respondents took a walk in the situation when the patient suffered from insomnia, 13% – suggested the patient some music, 10% left the patient alone, 7% raised their voice, and one person prepared a warm bath.

Patients who suffered from urinary and faecal incontinence, 50% of the carers used nappies, 40% – washed the patient, 13% didn't do anything and one person reduced fluids.

Adjustment to the new situation. The analysis of the unfinished sentences test showed that 26% of the respondents felt that adjustment to the new life situation was hard and difficult. However, 34% believed that life, despite all the difficulties caused by care for the Alzheimer's patient, was a valuable gift, and the disease accounted for the worst hopelessness for 69% of the respondents. So, health seemed to be the biggest value and the most expected one (for 43% of the participants). Almost 20% of respondents wanted peace, and 30% – freedom and well being. The smallest group wanted love (7%). The disease brought a lot of suffering instead, and other's help was very valuable to 37% of the respondents, it was a gift for 2% and for 10% it was a duty. Only three participants claimed they didn't need any help. Almost 50% of the sample devoted their energy to the patient, 23% – towards their job, 20% – their family, and 10% directed their energy to their own development and education. 33% of the group needed constant support from their families, 20% waited for help from other people, 10% demanded motivation, and the same number needed approval in order to continue care for the Alzheimer's patient.

Despite the difficulties concerning patient's care 32% of the sample were usually bright. However, 33% (almost the same number) were susceptible to cry. Fifteen percent showed patients, a little less demonstrated fatigue and depression and 9% – self-control and calmness. 20% of the respondents manifested susceptibility to remorse, 17% to anger, 13% to meditations, and 7% regretted their decision.

The analysis of the acceptance scale showed that 60% accepted the patient fully and appreciated patient's work and efforts 33% of the sample very seldom criticised the patient and weren't ashamed to talk about the disease with others. 37% didn't fully accept the patient, but they considered patient's needs and expectations. Conflicts were solved openly and directly. Only one person didn't accept the patient and couldn't get closer. Only 10% didn't allow the patient to decide for him/herself even in the simplest matters of every day life. The test Student's correlation on the significance level $p < 0.05$ between the acceptance of the Alzheimer's patient and level of knowledge showed by the family members and support received from the family turned out to be of no meaning.

Discussion

On the basis of the research, which has been carried out, the analysis of its results as well as observations and considerations of the people involved the conclusion appears that, apart from providing the family with appropriate knowledge about Alzheimer's disease, it is also extremely important to make them realise the patients' needs towards those, who are nursing them. The acceptance of the patient by his or her family means positive attitude, respect towards his or her individuality and care shown in every situation. Family, which fully accepts its ill member, is

characterised by the ability of active and understanding listening and assuring patient's psychological needs. These needs were described by The American Alzheimer Association as extremely important as far as the quality of Alzheimer patients' nursing is concerned [10].

In summary there is a between the level of education and the level of knowledge concerning Alzheimer's disease. The level of knowledge presented by the family members and support received from the family have no relation with acceptance of the patient.

Actions aiming at increasing approval of the patient shall be improved through developing support groups and self-help.

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