

Available online at [www.sciencedirect.com](http://www.sciencedirect.com)

ScienceDirect

journal homepage: <http://www.elsevier.com/locate/kontakt>

## Original research article

# Determinants characterizing the life of a caregiver treating an individual with Alzheimer's disease

Katarína Kotradyová \*

Civic society Deti slnka, Spišské Vlachy, Slovak Republic

## ARTICLE INFO

## Article history:

Received 20 June 2017

Received in revised form

11 August 2017

Accepted 23 October 2017

Available online xxx

## Keywords:

Alzheimer's disease

Care

Dementia

Caregiver

Determinants

## ABSTRACT

Alzheimer's disease is currently a serious social problem because by prolonging human life, this type of dementia appears more and more often. In many cases, patients with Alzheimer's disease are treated by family members who provide 24 h continuous care to a relative. The aim of the qualitative research, which we report in the scientific study, was to describe the stressors in caregivers of individuals with Alzheimer's disease, to map the main areas of burden on caregivers, and to identify the emotions that the caregivers/research participants described most frequently. The research was carried out using the focus group method and it was conducted in specialized social counselling in Krompachy. The stress determinants were identified as: the inability of an individual with Alzheimer's to perceive reality understand the spoken word, the possibility of homelessness, and that an individual with Alzheimer's disease often shows signs of impulsivity and irritability. The impact of caring for an individual with Alzheimer's disease creates an emotional, physical and financial burden on the caregiver, but caregivers also describe strong feelings of loneliness. The most strikingly described emotions presented by the participants were anger and sadness. This anger arose from the feeling of real impotence in terms of contributing to the improvement of the health of a relative, and that caregivers lived in constant fear of possible complications in providing daily care. In the context of the research, we also found an interesting finding regarding the emotional survival of caregivers in the paradigm of the loss of positive memories of a family member before the onset of the disease. Loss of positive memories triggered acute sadness in participants and was identified by most participants.

© 2017 Faculty of Health and Social Sciences of University of South Bohemia in České Budějovice. Published by Elsevier Sp. z o.o. All rights reserved.

## Introduction

Global population ageing is one of the determining processes of the 21st century, whereby this global ageing has deep

economic, political and social consequences. It is estimated that by 2030, a quarter of the population in the economically developed world will be older than 65 years, and in almost half of Western Europe 50 years and over [1]. So the world population is ageing, and while the majority of older people

\* Author for correspondence: ul. Železničná 71, 053 61 Spišské Vlachy, Slovak Republic.

E-mail address: [kkatarinay@gmail.com](mailto:kkatarinay@gmail.com)

<https://doi.org/10.1016/j.kontakt.2017.10.004>

1212-4117/© 2017 Faculty of Health and Social Sciences of University of South Bohemia in České Budějovice. Published by Elsevier Sp. z o.o. All rights reserved.

live independently, a large number of them develop some type of dementia [2]. There are 48.8 million individuals with dementia in the world today, and by 2050 it is estimated that this number will rise to 131.5 million [3].

Care for individuals with dementia should be a national priority, not only of public health, but also of social care throughout the world [4].

Dementia is a worldwide problem of increasing prevalence, whereby this fact will have significant impact on health and, ultimately, social services. The most widespread type of dementia is Alzheimer's disease. In this context, it is necessary to remember that in the context of healthcare, individuals with dementia of any type, including Alzheimer's disease, are often admitted to healthcare facilities, so in an environment, which does not have to be suitable for them given the specific nature of their disease. According to Houghton et al. [5], it is therefore necessary to create a suitable environment, improve the level of care, but also focus on educating those who care for people with dementia.

### *Types of dementia and its manifestations*

In addition to Alzheimer's disease, dementias include vascular dementia, dementia with the presence of Lewy's bodies, frontotemporal dementia, a.k.a. Pick's disease, and dementia linked to other diseases. However, the most common type of dementia is Alzheimer's disease, which represents 50% of all dementia. Alzheimer's disease is a neurodegenerative, progressive and irreversible disease [6]. Halová [7] argues that if we focus on the biological aspect of Alzheimer's disease, it is proven that this disease causes a direct change of chemical processes in the brain, whereby there is a gradual breakdown of entire nerve cells and fibres.

According to Hořejší [8], the main symptom of the disease is the disorder of higher cortical functions, which is automatically linked to a progressive and irreversible deterioration of mainly cognitive functions, but also with the onset of various emotional diseases, subsequent behavioural disorders and deterioration in the ability to perform ordinary life activities.

The disease manifests itself differently with each individual, whereby the symptoms partially depend on the previous lifestyle and also on the type of personality [9]. Kučerová [10] includes memory disorders, confusion and disorientation, but also speech disorders and difficulties in the decision-making process among the most common symptoms.

Over time, Alzheimer's disease prevents the individual from doing daily activities, and significantly increases confusion and anxiety, which intensifies the experience of pain and more frequent onset of dementia. There is a distorted perception of the reality of the outside world, paranoia, and often erratic thoughts too. At an advanced stage, individuals with Alzheimer's disease do not recognize their relatives and there is a major disorder of communication with their surroundings [11]. According to Majlesi and Ekström [12], sometimes it is difficult to distinguish Alzheimer's disease from other types of dementia, since the symptoms are the same. Dementia is generally linked to pathological changes of cognitive functions, such as reduced memory function, reduced communication skills, and also a reduced ability to take initiative, as well as to plan and perform tasks.

Recently, improper sexual behaviour has also been included among the general manifestations of dementia, and this is referred to as ISBS. These are challenging and stressful manifestations of dementia, which are very burdensome for the clients, their family and the providers of social and health care. It is true that thus far ISBS has only attracted limited clinical and scientific interest, especially when compared to other neuropsychiatric symptoms that occur within dementia. Therefore, we present the results of a research carried out specifically with the goal of systematically examining the occurrence and attributes of ISBS in the population of individuals with dementia. Of 195 clients (48.7% women), 35 clients (17.9% of the total sample) had ISBS. The logistic regression model showed that the male gender (OR: 5.14, 95% CI: 01:44–18:41) and anxiety manifestations (OR: 4.92; 95% CI: 1.44–16.84) were statistically significantly linked to the presence of ISBS. ISBS is a common expression of dementia [13].

### *Statistical indicators regarding the occurrence of Alzheimer's disease*

In the US, current estimates show that up to 5.2 million Americans suffer from Alzheimer's diseases, of which approx. 200,000 people are younger than 65. Over the coming decades, it is estimated that the increase of people with Alzheimer's disease will be about 10 million. By 2050, in the US, it is expected that a new case will start developing every 33 s, and the total estimated prevalence will be at a level of 13.8 million individuals. Alzheimer's disease is the sixth most common cause of death in the US, and the fifth most common cause of death of Americans aged 65 and over. Total payments in recent years for long-term health and hospital services provided to people with dementia, (and thus Alzheimer's disease) reached \$203 billion a year, not including contributions to the unpaid family caregivers [14]. Additionally, it is estimated that there are 800 thousand individuals with Alzheimer's disease living alone in the US (without an identifiable caregiver). These individuals are subsequently exposed to circumstances that far outweigh the risks faced by people with this disease who live in families. These circumstances include inadequate care for oneself, malnutrition, untreated medical complications, falls, leaving home without supervision, as well as accidental deaths [15]. In recent years, for example, deaths from strokes in the US dropped by 23%, heart disease related deaths decreased by 14%, and deaths from cancer by 11%, but deaths due to Alzheimer's disease grew by 71% [16]. The prevalence of dementia is increasing with the ageing population, whereby most people with dementia die due to acute diseases and therefore many of them have to be hospitalized at the end of their lives. It is necessary to remember that these clients receive the same aggressive, life-prolonging therapies as any other client, and yet there is still a significantly higher mortality rate [17].

There are 7.3 million people suffering from Alzheimer's disease in Europe, and the total costs for social and health care are more than 141 billion EUR a year. In this regard we have to note that there is a direct relation between the severity of dementia and the increasing costs for caregivers taking care of individuals with dementia. The estimated average monthly costs of care for people with dementia in a home environment

Download English Version:

<https://daneshyari.com/en/article/7521413>

Download Persian Version:

<https://daneshyari.com/article/7521413>

[Daneshyari.com](https://daneshyari.com)