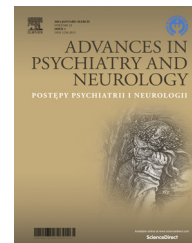


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Review/ Praca pogładowa

# The stigma of dementia

## Stygmatyzacja w otępieniu



Katarzyna Urbańska\*, Dorota Szcześniak, Joanna Rymaszewska

Wrocław Medical University, Department of Psychiatry, Division of Consultation Psychiatry and Neuroscience, Wrocław, Poland

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### ABSTRACT

**Aim:** As the population ages, the problem of dementia increases and affects a growing number of people. People with mental illness are known to be stigmatised and this has been the subject of numerous studies. There have been contradictory studies assessing the stigma attached to dementia, and the majority focus on stigma at a social level and the public perception of people with dementia. There have been a number of projects that included a study group of people with dementia. However, to date, this topic has not been discussed in Poland. Hence, the aim of this paper is to carry out a literature review addressing this issue. **Perspective:** The problem of stigma attached to dementia is particularly significant as it affects not only the subject, but also their family, friends and health professionals. As people with dementia develop cognitive impairment and lose their independence, stigmatisation leads to their social isolation, despite their need for care. Stigma has emotional, behavioural and social implications, including diminished self-esteem, a feeling of anxiety and the development of a sense of shame and a fear of the judgement of others. Family members also deal with the stigma, which manifests itself as embarrassment and anxiety and causes their circle of friends and acquaintances to decrease. Current studies show that professionals can also play a negative role in the process of labelling and stigmatisation of patients. **Conclusion:** Stigma is a serious and common problem in dementia. It seems necessary to target this issue in research and social discourse.

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\* Corresponding author at: Zakład Psychiatrii Konsultacyjnej i Badań Neurobiologicznych, Katedra Psychiatrii, Uniwersytet Medyczny im. Piastów Śląskich we Wrocławiu, Wybrzeże Pasteura 10, 50-367 Wrocław, Poland. Tel.: +48 71 784 16 28.

E-mail address: [k.urbanska@hotmail.com](mailto:k.urbanska@hotmail.com) (K. Urbańska).

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## Introduction

The issue of the stigmatisation of patients with mental disorders has been the subject of theoretical analyses and scientific research. The stigma of mental illness attached to patients suffering from schizophrenia, depression and other serious mental illnesses (SMI) has been discussed in numerous foreign [1, 2] and Polish [3-8] research articles. The results of these studies suggest that both society in general, and health professionals who work with people suffering from mental disorders, display stigmatising behaviour. The authors attempt to identify the causes of stigma and determine possible ways to reduce this phenomenon. Recent literature has shown an increasing stigmatisation of people with dementia and their families. However, to date, this issue has not been studied in Poland.

There are between 15 and 21 million people suffering from Alzheimer's disease worldwide, with 500,000 of them living in Poland, where this disease comprises more than 50% of all diagnosed dementias [9-13]. It is estimated that people with dementias account for 5-7% of the general population and over 10% of the population over 65 years old [14, 15]. This figure is likely to increase in the coming years according to the report issued by the World Health Organization [16].

## Stigmatisation of people with dementia

In the available literature, the terms 'stigmatisation' and 'stigma' are not clearly defined, which causes methodological difficulties when it comes to operationalisation. It also impedes the comparison of the results of studies on the subject [17, 18]. Stigma (from the Greek *stigma*) is defined as a "prick mark; stigma of slaves and criminals, metaphorically known as shame; also tattoo, associated with stigmatisation, tattooing" [19]. Goffman [20] was the first to introduce the term 'stigma' in social sciences, in 1963. In the context used by Goffman, rather than being a carrier trait, it is a relationship between a given trait and the stereotype and can occur in social situations. He distinguished five types of stigma, relating to body deformation, mental illness, personality flaws, belonging to a religious group or certain nationality [3, 20]. According to Link and Phelan, stigmatisation is understood to be a multistage process, which combines labelling, stereotyping, alienation, a loss of social status, discrimination and emotional reactions [3]. Stigmatisation refers to the relationship between the knowledge of the topic of stigmatisation (stereotypes), the attitudes (prejudice) towards a stigmatised individual and the expression of the discriminatory behaviour [21, 22]. Labelling consists of providing names for certain significantly different categories, which have some social significance. These names do not necessarily describe the qualities or characteristics of a person, but are attributed to this person (sometimes unjustifiably). Therefore, the meaning of certain labels may differ at different times, places and among different groups of people [1, 3]. The use of diagnostic labels by medical professionals is one such example. The

labels aid in the systematisation of large amounts of medical information, facilitate the selection of an appropriate treatment plan and allow the prognosis to be made [3, 23]. They may, however, be a source of stigmatisation, especially if they are strongly associated with stereotypes, in other words general, usually negative beliefs concerning the characteristics or behaviour of a certain social group [1, 22]. One can be labelled as suffering a mental disorder not only after being diagnosed with an illness, but also through being seen exiting a psychiatric ward or a counsellor's office [1].

There are numerous classifications of stigma in literature. Public stigma, self-stigma and internalised stigma are distinguished most commonly. Public stigma refers to all those people in the society who are prejudiced against a given person or social group. Internalised stigma refers to the feeling of a stigmatised person, or possibly a member of a group which experiences prejudice. It can be considered as an intermediary between social stigma and its psychological consequences [2]. The other kinds of stigma mentioned in the literature are stigma by association, courtesy stigma and family stigma – the terms used to describe the attitude towards the families and professionals taking care of stigmatised people [1, 3, 18]. The *Alzheimer's Society of Ireland* suggests stigmatisation should be divided into an external issue, where the stigmatised person (suffering from dementia) is discriminated against, and an internal one, associated with a feeling of inferiority and shame caused by the development of symptoms [24]. The Link and colleagues' concept takes into account both the perception and experience of stigma, and is composed of four elements: financial insecurity, social rejection, internalised shame and social isolation [25-27]. Based on this theory, the *Stigma Impact Scale* was created by Burgener and Berger to study stigmatisation in dementia [25-27].

People with dementia and other mental disorders suffer psychological, behavioural and social consequences of the diagnosis. People with mental illness and neuropsychiatric disorders are thought to be incompetent, dangerous and unpredictable. The people closest to the patient feel these consequences. Therefore, dementia is associated not only with memory impairment, language difficulties and the deterioration of spatial orientation, but it also has social consequences [24]. A person diagnosed with a mental disorder experiences negative emotions, low self-esteem, lack of independence, insecurity and embarrassment. Typically, this person will also expect to be rejected by society and will behave elusively in order to protect himself/herself from exclusion [23]. Moreover, stigma may lead to a rejection or termination of treatment, as well as a failure to inform others of one's diagnosis [1]. People with mental disorders experience stress factors associated with coping with the disease, isolation and public stigmatisation, which reduces their social functioning [2]. People labelled as having a 'mental disorder' have difficulty with finding and keeping a job, renting an apartment, keeping in touch with a health professional, and avoid seeking help in institutions which may be perceived as stigmatising. The diagnosis reduces the status of the family, or immediate social environment [1, 17]. People with dementia face social inequality, loss of identity and discrimination. They are

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