ACADEMIC TERMINOLOGIES AND STIGMA IN LATER LIFE

A linguagem acadêmica e o estigma na longevidade

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RESUMO

É comum encontrarmos na literatura científica brasileira termos potencialmente estigmatizantes sendo utilizados para descrever pessoas com demência e pessoas vivendo em residenciais de cuidado, tais como os termos pessoa demenciada, paciente asilado ou idoso institucionalizado. Historicamente, transtornos mentais e longo termo care settings for older people have had negative connotations in society. The use of terms that historically refer to social segregation, institutionalization, or that reduce the individual to their disease can therefore contribute to the perpetuation of the stigma, prejudice, depersonalization and discrimination experienced by these people. This opinion paper aims to stimulate discussions about the use of such terms by the Brazilian scientific community and the media, as well as to foster reflections on the impact of the use of such language as part of current academic and clinical environments. The author mentions examples of stigmatizing phrases and words that are commonly found in the literature and mentions some of the consequences of stigma for people with dementia and those living in care homes. The author also refers to international documents which can be used as references for more inclusive and ethical writing.

PALAVRAS-CHAVE: estigma social; demência; doença de Alzheimer; idosos; empatia; cuidados paliativos.

ABSTRACT

It is common to find stigmatising terms being used to describe older people with dementia and / or living in care homes in the Brazilian literature, such as ‘demented person’, ‘patient in asylum’, or ‘institutionalised elderly’. Historically, both mental illnesses and long-term care settings for older people have had negative connotations in society. The use of terms that historically refer to social segregation, institutionalization, or that reduce the individual to their disease can therefore contribute to the perpetuation of the stigma, prejudice, depersonalization and discrimination experienced by these people. This opinion paper aims to stimulate discussions about the use of such terms by the Brazilian scientific community and the media, as well as to foster reflections on the impact of the use of such language as part of current academic and clinical environments. The author mentions examples of stigmatising phrases and words that are commonly found in the literature and mentions some of the consequences of stigma for people with dementia and those living in care homes. The author also refers to international documents which can be used as references for more inclusive and ethical writing.

KEYWORDS: social stigma; dementia; Alzheimer disease; aged; empathy; palliative care.
The use of negative language is the face of social stigma, so that the way we refer to people or phenomena not only represents our perceptions of the world but also shapes identities and ways of life. Language therefore plays a key role both in practices that stigmatize people and in those that can reduce the impact of stigma. Dementia and residential care homes for older people are the focus of many stigmatizing statements in Brazil. For example, dementia is commonly associated with terms such as senile, dependent, and demented, while people living in residential care homes are commonly considered lonely, abandoned, and fragile.

Although Brazilian studies on stigma in later life are virtually non-existent, international studies indicate that people who receive a diagnosis of dementia are often moved to a new lower social status group, resulting in social isolation because of not only the dementia itself but also the society’s responses to it. Stigma leads people with dementia to remain invisible and to withdraw from social contact, which not only influences the perception people have of themselves (self-stigmatization) but also encourages them to hide their illness from others. This contributes to creating barriers to accessing diagnosis, social isolation, depression, and worsening of quality of life in people with dementia.

Fear of discrimination may deter people with dementia and their families from seeking help, leading them into experiencing difficulties without receiving the support they need. By mistakenly believing that dementia is a natural part of aging and that nothing can be done to improve the quality of life of people with this syndrome, individuals, care managers, and health professionals may not invest the time and resources needed in prevention and early diagnosis strategies as well as in the quality of treatment and care for these individuals. Referring to someone as demented inevitably links a person's whole being and doing to a syndrome with negative social characteristics, denying the uniqueness of that individual. Conversely, using the term person with dementia may reinforce a sense of personal identity by placing dementia as only a part of the individual’s life.

Negative social connotations linked to residential care homes may be transferred to the care-home residents when they are called patients, asylee, or institutionalized. These terms reflect power relations that can separate individuals into groups of “us” and “them” and may lead to distancing individuals from health professionals, making it less likely that an individual will initiate or accept care in a residential care facility. The negative image of residential care homes as an asylum may also affect the quality of care and contribute to a high turnover of staff in these facilities. Such terms reinforce the view that these people live in social isolation and are ill, depersonalizing them and considering them passive rather than active members of society with individual personality, history, interests, aspirations and desires, regardless of their cognitive status or place of residence. Not calling someone asylees or institutionalized does not mean denying the use of residential care facilities as a place of residence and care for older people, but rather prevents using the term institution or a place historically known for social segregation as part of the social characterization placed upon individuals. The use of alternative terms, such as individuals living in residential care homes, not only separates the place of residence from the person's being and doing but also stops characterizing the individual's home as an institution.

The use of stereotyping or stigmatizing terms may have severe consequences for individuals and societies, especially for people living with neurodegenerative diseases and/or in long-term care homes for older people. Given its importance, Alzheimer’s Disease International chose ‘attitudes to dementia’ as the theme of the World Alzheimer Report 2019. In addition, several documents have been published internationally on how to refer to older people and people with dementia in a way that stigma can be mitigated. In the annual conference of Alzheimer Europe, abstracts can be rejected outright if the use of stigmatizing language is detected by the event committee. International journals are also in line with this trend by refusing to publish manuscripts that use pejorative language, such as aged, elderly, older, senile, dementia person, sufferer, institutionalized, and demented. Moreover, ageism, which is the stereotyping, prejudice, and discrimination against people based on their age, is also an important item in policies by the World Health Organization intended to increase the social inclusion of older people and reduce the prejudice experienced by these people.

We, health professionals and researchers, must be careful and responsible for the messages we convey. As researchers, our discourses reach out to our peers, students, care providers, study participants, and society as a whole, with potential impact on a number of social spheres. We can be perpetuators of misrepresented and negative views of the people for whom we care or with whom we conduct research, or we can be agents of social change. Although not published in Brazilian Portuguese, several materials have been recently published to inform researchers, health professionals and members of the public of more respectful ways to refer to people with dementia and to older people. It is now up to us to do our part in reducing the propagation of stigmatizing messages in academic and clinical settings in Brazil.

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REFERENCES


