

Stigma and Alzheimer's disease

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ABSTRACT

Alzheimer's disease (AD) is a brain ailment that contains psychiatric and cognitive abnormalities. Stigma is the use of unwanted labels to categorize a person with a disability or illness. Stigma about AD exists. Three types of stigma affect persons with AD dementia; public stigma, self-stigma and spillover stigma. Stigma is often a major cause of distress to family members and care partners. Both persons with AD and their family members are influenced by disinhibition and challenging social behaviours caused by AD. Younger age, higher education, and familiarity with a person with AD were linked to lower levels of stigmatizing approaches. The National Alzheimer's Association Early Stage Advisory Group in US provided advice to persons with dementia to help them in overcoming the stigma of dementia: be part of the solution, stay open and direct, talk the truths, seek support and join in, do not lose hope.

Public awareness and understanding of the disease is important for preventing people from stigmatizing AD. Education and public policy might be able to lessen that stigma by creating more understanding.

Keywords: Alzheimer disease (AD), Stigma, Dementia, Discrimination, Prejudices

INTRODUCTION

Alzheimer's disease (AD) is a multispectral brain disorder that includes psychiatric, movement, and cognitive abnormalities [1]. The latest epidemiological studies have projected that the global prevalence of AD will increase from 27 million worldwide in 2006 to 135 million in 2050 [2]. The incidence of AD doubles every 5 years from the age of 65, so probably after the age of 85, every one of the three people will have AD-type dementia [3].

Older adults with AD face three problems. Firstly, they are bothered by age itself. Secondly, they fight with the disabilities and symptoms that are caused by the disease. Lastly, they are challenged by the labels, prejudice, and discrimination that result from misconception about AD [4]. Stigmatizing of elderly people with AD occurs in many cultures [5].

Stigma

Stigma happens when a person notices that he/she is overlooked and has been subjected to a process whereby certain persons and groups are unreasonably shunned, considered shameful, and differentiated against [6]. As said by Goffman, stigma is "an attribute that is deeply discrediting." For him, stigma is a general

aspect of social life where one person is labelled different, while the other is reflected normal [7]. Stigma is a manifestation of people's reactions to persons who have some disagreeable features [8]. Goffman advocated the perception of stigma to be caused by many conditions such as epilepsy, mental disorders and acquired immune deficiency syndrome (AIDS), but he never related it to AD [9]. Later studies, conversely stated the stigmatization of AD patients [10].

Alzheimer's Disease and Stigma

Both persons with AD and their family members are influenced by disinhibition and challenging social behaviours caused by AD [11]. In a broad literature evaluation to ascertain factors which affect the affliction of dementia caregivers, Eters et al., described negative consequences such as depression and decreased quality of life [12]. Werner et al., showed family stigma as another destructive side of caring for a family member with AD [10].

"Feeling of shame due to the strange behaviour and speech of the person with AD" revealed the family stigma [13]. Family

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stigma is depicted as the stigma practiced by individuals as a consequence of having a relative with the stigmatic mark [14].

Caregivers of persons with AD may have feelings of blame and shame due to the behaviour or speech of the patient. This feeling is named "internal stigma" or "felt stigma" and defined as a sense of shame when the person avoids trying to find help from others [13].

Family stigma follows a process characterized by three main components; 1. Cognitive features (comprising the severity of the disease, the aesthetic looks of the person with AD and perceptions of abnormality); 2. Emotional reactions, including positive emotions (such as kindness and sadness) and negative emotions (such as blame, shame, and guilt); 3. Behavioural reactions (such as suppression and diminished caregiving).

Also, family stigma was found to be accompanied with significant bad consequences such as intensified caregiver burden and caregiving stress [15].

In recent years, public stigma has brought attention to AD. Individuals with AD are considered as unpredictable and difficult to communicate with by lay people [16]. They frequently evoke common feelings of shame and fear [17]. Lay people frequently consider that persons with AD should be institutionalized [18].

Public stigma refers to the stereotypes, prejudices, and discriminatory behaviours held by lay people toward a person or group with a stigmatized form [19]. Public stigma is of the greatest significance, especially since it has been accepted as essential in the realization of other types of stigma, such as self-stigma and courtesy stigma [20] and is the main obstacle to help-seeking [21]. Current observed studies on public stigma with regard to AD, showed that persons with AD are victims of a substantial amount of stigma and discrimination, particularly in developed countries. Generally, these studies show that biological opinions about causality are accompanied by less negative reactions [4]. Younger age, higher education, and familiarity with a person with AD were linked with lower levels of stigmatizing approaches. Little awareness about the disease was established as accompanying bigger levels of stigma to persons with AD. Cultural values might have a stronger association with the establishment of stereotypes and through them with the emotional and behavioural reactions to the stigmatized subject. This is tremendously significant, as it recommends the modification of cultural stereotypes as a first stage in the controlling of public stigma [22].

Courtesy or affiliate stigma is defined as stigma practiced by a person because of their near relationship with another person with a stigmatizing feature [23].

Besides the above mentioned stigma types, Corrigan et al., recognized that prejudice and discrimination are practised on people without the visible marks of stigmatized features because of their connection to a person with the stigmatized mark [24]. This kind of stigma surrounded by family members, known as courtesy stigma, is named affiliate stigma when it is internalized [25]. The stigma of the caregivers of persons with dementia is only caused by the relationship with their family member who has dementia. The stigma of the caregivers is not just as a result

of the physical problem of caregiving, although the caregivers may meet with extra care problems if the stigma has an effect [26].

As indicated by Blum's results, stigma controlling by AD caregivers changes through two periods. In the initial period, the caregiver gets together with the ill family member as they collaborate in the organization of facts and problematic circumstances. As Blum describes, 'as the stigma becomes noticeable in collaboration, the caregiver makes efforts to minimize its remarkable feature'. When the capability of the person with Alzheimer's weakens and he/she 'can no longer play the deceitful game', the second period starts. Information control is no longer the key concern: the main concern now is to prevent or direct the difficult situations that occur as a consequence of the ill family member's wrong behaviour [27].

Some claim that persons with preclinical AD diagnoses will be subject to "stigma and discrimination"; others worry that the diagnosis may be "distressing, alarming, and stigmatizing"; the strategy, designed to reduce the burden of disability, may create spillover stigma. Should spillover stigma happen in Alzheimer's, the stigma of Alzheimer's clinical form will include a community of people who are apparently healthy, many of them working and or else involved in social, cultural and political spaces. Should it not, the practice of stigma might split the Alzheimer's patient public into groups: those with clinical AD who experience both poorer symptoms and bigger stigma and those with a preclinical AD. If the Alzheimer's brand itself is the primary supplier to stigma, then those with preclinical Alzheimer's may be subject to stigma even in the lack of symptoms. In contrast, if symptoms are the main supplier to stigma, then persons who are branded but asymptomatic may not practice stigma. Additionally, if stigma is related to views that the person's cognitive difficulties will get poorer, communicating that the path of preclinical AD differs among patients will be vital [28.]

Decreasing the stigma

Educational policies might be an encouraging attitude for decreasing the stigma of AD. Community education has been shown as one of the vital implements for altering approaches linked to mental disease. The consequences revealed that individual or family practice was unconnected to stigma, thus showing that such practices were variables that were mostly unable to clarify the occurrence [29]. Educating families and caregivers of patients with AD on stigma management and the correct method in treating the patient are important factors in coping with stigma [13]. Although, damaging messages about AD may underwrite to stigma, family and caregivers are advised to empathize and establish an emotional connection with AD patients in order to make them happy and not to feel labelled [30]. Therefore, public information campaigns may be essential as an effort to lessen the stigma, more so than emotional requests. One capable key is to emphasize spreading information about precise stigmatizing beliefs, attitudes, and actions [31].

The National Alzheimer's Association Early Stage Advisory Group in the US provided advice to persons with dementia to

help them in overcoming the stigma of dementia: Be part of the solution, stay open and direct, talk the truths, seek support and join in, do not lose hope [32].

Overall advice to support overcoming the stigma of dementia as fixed by the US National Alzheimer's Association Early Stage Advisory Group is as follows:

1. Inform the community
2. Diminish loneliness of the person with dementia
3. Give people with dementia a voice
4. Be aware of the rights of persons with dementia and their caregivers
5. Include persons with dementia in their original societies
6. Backing and teaching informal and formal caregivers
7. Improve the quality of care at home and in care homes
8. Develop dementia training of primary care contractors
9. Request governments to produce national dementia policies
10. Increase research into how to address stigma in persons with dementia [32].

The Centers for Disease Control and Prevention (CDC) and the Alzheimer's Association have established The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018. This Road Map offers 35 actions to raise the quality of life for people with cognitive impairment. Two action suggestions in the "Educate and Empower the Nation" area are:

1. Identify and promote culturally appropriate strategies designed to increase public awareness about dementia, including AD, to reduce conflicting messages, decrease stigma, and promote early diagnosis.
2. Identify and promote strategies for the public about how to communicate effectively and sensitively with people suffering from dementia, including AD, and their families [33].

Conclusion

Public awareness and understanding of the disease is important to preventing people from the stigma on AD. Education and public policy might be able to lessen that stigma to create more understanding.

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REFERENCES

- [1] Devi G, Williamson J, Massoud F, et al. A comparison of family history of psychiatric disorders among patients with early- and late onset Alzheimer's disease. *J Neuropsychiatry Clin Neurosci* 2004; 16: 57-62. doi: 10.1176/jnp.16.1.57
- [2] Prince M, Albanese E, Guerchet M, Prina M. World Alzheimer Report 2014: Dementia and risk reduction: An analysis of protective and modifiable risk factors. London: Alzheimer's Disease International, 2014:104.
- [3] World Alzheimer Report 2015 the Global Impact of Dementia. An analysis of prevalence, incidence, cost and trends. 2015:23-24. <https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf> Accessed: 23.10.2020
- [4] Blay SL, Pisa Peluso ET. Public stigma: The community's tolerance of Alzheimer disease. *Am J Geriatr Psychiatry* 2010;18:163-171. doi: 10.1097/JGP.0b013e3181bea900
- [5] Mahoney DF. Vigilance. Evolution and definition for caregivers of family members with Alzheimer's disease. *J Gerontol Nurs* 2003;29: 24-30. doi: 10.3928/0098-9134.2003.0801-07
- [6] World Health Organization and World Psychiatric Association, Reducing Stigma and Discrimination against Older People with Mental Disorders. Geneva, Switzerland: WHO, 2002. http://apps.who.int/iris/bitstream/handle/10665/67380/WHO_MSD_MBD_02.3_eng.pdf?sequence=1&isAllowed=y Accessed: 23.10.2020
- [7] Goffman E. Stigma: Notes on the management of spoiled identity. London, UK: Penguin Books, 1990:31.
- [8] Joachim G, Acorn S. Stigma of visible and invisible chronic conditions. *J Adv Nurs* 2000;32:243-8. doi: 10.1046/j.1365-2648.2000.01466.x
- [9] Goffman E. Stigma: Notes on the management of spoiled identity. Englewood Cliffs, NJ: Prentice-Hall, 1963.
- [10] Werner P, Goldstein D, Buchbinder E. Subjective experience of family stigma as reported by children of Alzheimer's disease patients. *Qual Health Res* 2010; 20: 159-69. doi: 10.1177/104.973.2309358330
- [11] Chang E, Easterbrook S, Hancock K, Johnson A, Davidson P. Evaluation of an information booklet for caregivers of people with dementia: an Australian perspective. *Nurs Health Sci* 2010; 12: 45-51. doi: 10.1111/j.1442-2018.2009.00486.x
- [12] Eters L, Goodall D, Harrison B. Caregiver burden among dementia patient caregivers: a review of the literature. *J Am Acad Nurse Pract* 2008; 20: 423-8. doi: 10.1111/j.1745-7599.2008.00342.x
- [13] Navab E, Negarandeh R, Hamid P, Navad P. Stigma among Iranian family caregivers of patients with Alzheimer's disease: A hermeneutic study. *Nurs Health Sci* 2013;15:201-6. doi: 10.1111/nhs.12017
- [14] Larson JE, Corrigan P. The stigma of families with mental illness. *Acad Psychiatry* 2008; 32(2):87-91. doi: 10.1176/appi.ap.32.2.87
- [15] Werner P, Mittelman MS, Goldstein D, Heinik J. Family stigma and caregiver burden in Alzheimer's disease. *Gerontologist* 2012; 52:89-97. doi: 10.1093/geront/gnr117
- [16] Woo B K P, Chung J OP. Public stigma associated with dementia in a Chinese-American immigrant population. *J Am Geriatr Soc* 2013; 61:1832-3. doi:10.1111/jgs.12472
- [17] Adebisi A O, Fagbola, MA, Olakehinde O, et al. Enacted and implied stigma for dementia in a community in south-west Nigeria. *Psychogeriatric: the Official Journal of the Japanese Psychogeriatric Society* 2010; 16: 268-73. doi:10.1111/psyg.12156

- [18] Werner P. Discriminatory behaviour towards a person with Alzheimer's disease: Examining the effects of being in a nursing home. *Aging Ment Health* 2008; 12: 786-94. doi:10.1080/136.078.60802380649
- [19] Corrigan PW, Rao S. On the self – stigma of mental illness: Stages, disclosure, and strategies for change. *Can J Psychiatry* 2012; 57:464-9. doi: 10.1177/070.674.371205700804
- [20] Mak WW, Cheung R. Affiliate stigma among caregivers of people within intellectual disability or mental illness. *J Appl Res Intellect Disabil* 2008; 21:532-45. doi:10.1111/j.1468 – 3148.2008.00426.x
- [21] Werner P, Goldstein D, Karpas DS, et al. Help-seeking for dementia: A systematic review of the literature. *Alzheimer Dis Assoc Disord* 2014; 28: 299-310. doi:10.1097/WAD.000.000.00000000065
- [22] Werner P, Jabel H.A, Reuveni Y, et al. Stigmatic beliefs toward a person with Alzheimer's disease among high-school students: Does majority-minority status make a difference? *Educ Gerontol* 2017; 43: 609-18. doi: 10.1080/03601.277.2017.1376461
- [23] Birenbaum A. Courtesy stigma revisited. *Ment Retard* 1992; 30:265-8.
- [24] Corrigan PW, Watson AC, Miller RE. Blame, shame, and contamination: the impact of mental illness and drug dependence stigma on family members. *J Fam Psychol* 2006; 20:239-46. doi: 10.1037/0893-3200.20.2.239
- [25] Chang C-C, Su J-A, Lin C-Y. Using the Affiliate Stigma Scale with caregivers of people with dementia: psychometric evaluation. *Alzheimers Res Ther* 2016; 8: 45. doi: 10.1186/s13195.016.0213-y
- [26] Lin C-Y, Wang J-D, Pai M-C, et al. Measuring burden in dementia caregivers: confirmatory factor analysis for short forms of the Zarit Burden Interview. *Arch Gerontol Geriatr* 2017; 68:8-13. doi:10.1016/j.archger.2016.08.005
- [27] Rae HM. Managing courtesy stigma: the case of Alzheimer's disease. *Sociol Health Illn* 1999; 21 (1): 54-70.
- [28] Johnson R, Harkins K, Cary M, Sankar P, Karlawish J. The relative contributions of disease label and disease prognosis to Alzheimer's stigma: A vignette-based experiment. *Soc Sci Med* 2015; 143:117-27. doi: 10.1016/j.socscimed.2015.08.031
- [29] Prince M, Livingston G, Katona C. Mental health care for the elderly in low-income countries: a health systems approach. *World Psychiatry* 2007; 6: 5-13.
- [30] Van Gorp B, Vercruyse T. Frames and counter-frames giving meaning to dementia: A framing analysis of media content. *Soc Sci Med* 2012; 74:1274-81. doi:10.1016/j.socscimed.2011.12.045,
- [31] Vaala S E, Bleakley A, Hennessy M, Jordan AB. Weight stigmatization moderates the effects of sugar-sweetened beverage related PSAs among U.S. parents. *Media Psychol* 2016; 19:534-60. doi:10.1080/15213.269.2015.1121826.
- [32] Batsch NL, Mittelman MS, (editors). *World Alzheimer Report 2012, overcoming the stigma of dementia*. London: Alzheimer's Disease International (ADI), 2012.
- [33] CDC Brief (<https://www.cdc.gov/aging/pdf/stigma-and-AD-brief-july-2015.pdf>) Accessed: 5.09.2020