



Squashing Stigma: The elephant in the room

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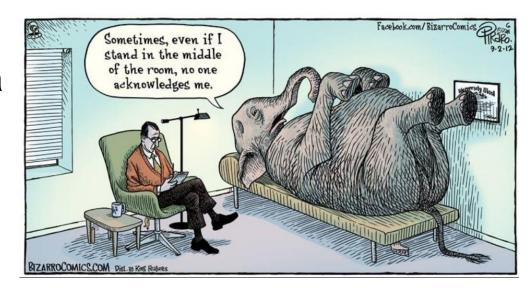
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Outline

- Definition of stigma
- Types of stigma
- Reasons for dementia stigma
- Effects of dementia stigma
- Stigma reduction
- Dementia stigma interventions
- Conclusion







What is stigma?

 Stigma is a complex social phenomenon where a socially salient group difference is identified, devalued and discriminated against.





Types of stigma

- Public stigma: reaction the general public has to those with a particular stigmatised condition.
- Courtesy stigma: stigma of those associated with a stigmatised person (e.g. family members and professionals).
- Self-stigma: prejudice people with the condition turn against themselves by internalising the negative attitudes they perceive from society.





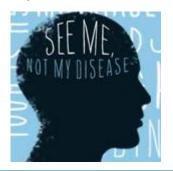
Dementia

- Assumed to be a natural part of ageing
- Due to its effects on memory, judgement and behavior – dementia is perceived as a mental illness
- 2nd most feared condition in Australia
- Fear and lack of understanding lead to stigma





- "No one wants to spend time with me now that I have a diagnosis. It is like they think I no longer count and I am not a person anymore. It makes me so sad and I end up sitting at home wishing life was different"
- "I have lost almost all of my friends and the few I have I see once a year or even once every 2 years."
- "Sometimes people ignore me completely, sometimes they talk down to me."



Source: Alzheimer's Australia





Effects of dementia stigma

- Affects self-esteem
- Causes distress in people with dementia and carers
- Impacts social inclusion
- Reduces quality of life of people with dementia and carers
- Prevent people from accessing health services
- Delays the diagnosis and timely treatment of dementia





Stigma reduction

- Protest (Corrigan & Penn, 1999)
 - where organisations protest against inequalities, or object to negative or inaccurate portrayals of people with stigmatising condition in the media.







Anger over Fin Review's 'feral' dementia story

By Darragh O'Keeffe on June 24, 2015 in Consumers, Industry

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Advocates and care providers are outraged over a newspaper article that labelled seniors experiencing severe behavioural and psychological symptoms of dementia (BPSD) as "mad, bad and dangerous to know", sparking a new focus on media representations of dementia.

Prominent dementia experts have described as "misleading, offensive" and "scurrilous" the Australian Financial Review article on the government's Severe Behaviour Response Teams that appeared under the headline 'Teams to deal with feral patients'.

The article by veteran Fairfax reporter Christopher Jay, which discussed the tender for the teams that will assist with the care of seniors experiencing BPSD, said that aged care providers were "bracing themselves" for a "surge of feral geriatrics with severe and often violent behaviour problems stemming from dementia."

Mr Jay wrote that while seniors with various forms of dementia were typically seen as being "vaguely harmless", a proportion were "turning out to be a menace to themselves and other retirement home inmates – mad, bad and dangerous to know."

The article has been met with fierce criticism from consumer groups such as Alzheimer's Australia, as well as leading dementia advocates and researchers.





Stigma reduction

- Education
 - where factual information is provided on stigmatising conditions to replace inaccurate stereotypes and beliefs, and to increase affirming attitudes.



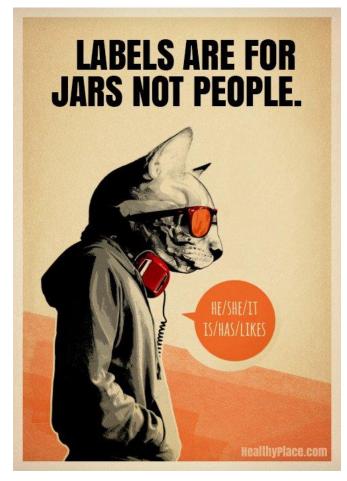






Appropriate Language

- Accurate
- Respectful
- Inclusive
- Empowering (sufferers, victims)
- Non stigmatising



https://fightdementia.org.au/sites/default/files/NATIONAL/documents/language-guidelines-full.pdf





Stigma reduction

- Contact
 - involves direct or indirect contact with people with stigmatising conditions.





Dementia stigma reduction interventions

- RCT (Cheng, et al., 2011)
 - A brief exposure to information about dementia led to a significant reduction in stigma in adults aged 18-92.
- No other intervention studies





Conclusion

- Dementia is a stigmatised condition.
- It prevents help seeking, delaying the diagnosis and treatments.
- One RCT using education approach has been conducted in dementia stigma reduction.
- Need to evaluate different aspects of anti-stigma programs.