

# Stigma and Dementia

Ruth Palan Lopez, PhD, FAAN  
Professor of Nursing



THE UNIVERSITY OF  
TENNESSEE  
KNOXVILLE



THE UNIVERSITY OF  
TENNESSEE  
KNOXVILLE

# Objectives

- Define stigma
- Impact of stigma
- Stigma among family caregivers
- Stigma among healthcare providers
- Combatting stigma

# Background

- ADRD
  - Irreversible, progressive brain disorder
  - Destroys memory, language, problem-solving and cognition
  - Begins with mild impairment and progresses to severe, end-stage disease

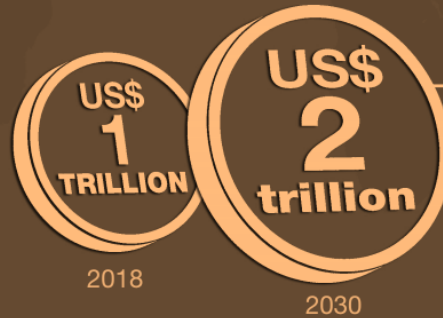
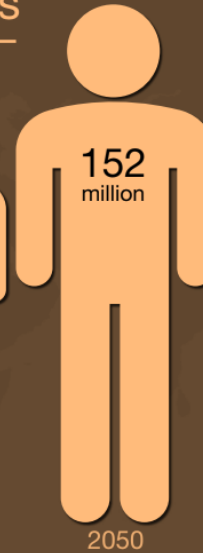
INFOGRAPHIC

# The global impact of dementia



Around the world,  
there will be one new case  
of dementia  
**every  
3 seconds**

50 million people worldwide are  
living with dementia in 2018.  
This number will more than  
**triple to 152  
million by 2050**



The total estimated  
worldwide cost of dementia  
in 2018 is US\$1 trillion.  
This figure will rise to  
**US\$ 2 trillion  
by 2030**

# Stigma

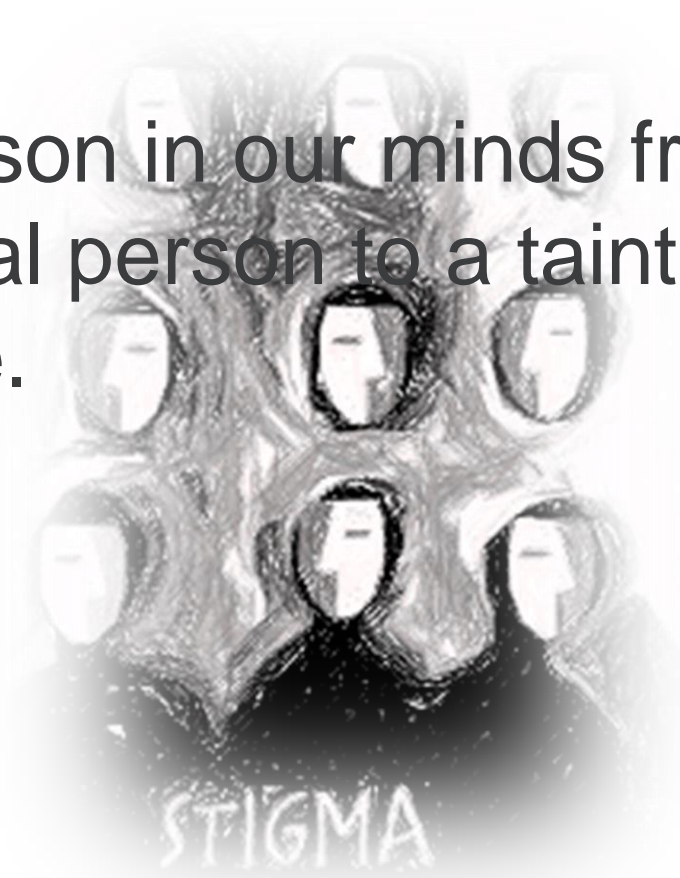
- A mark of disgrace associated with a circumstance that sets a person apart from others as part of a stereotyped group



(Goffman, 1963) (Link & Phelan, 2001)

# Stigma

- Reduces a person in our minds from a whole and usual person to a tainted and discounted one.



(Goffman, 1963)

# Stigma

- Leads to negative attitudes, actions, and discrimination
- Limits material, social, and cultural resources
- Source of health inequalities

(Goffman, 1963) (Link & Phelan, 2001)



# Stigma Worldwide

- 60% lack of public awareness
- 75% negative assoc. people with dementia
- 25% of people hide their diagnosis
- 40% withdraw from everyday activities

(Alzheimer's Disease International: World Report 2012)

# Stigma Worldwide

- 50% of 317 randomly selected adults in US
  - Expected discrimination
  - Excluded from decision making
  - Limited health insurance

(Sites, Rubright, & Karlawish, 2018)

# Stigma Worldwide

- Worse among those with
  - Limited disease knowledge
  - Little contact
  - Men
  - Younger individuals
  - Context of ethnicity and culture

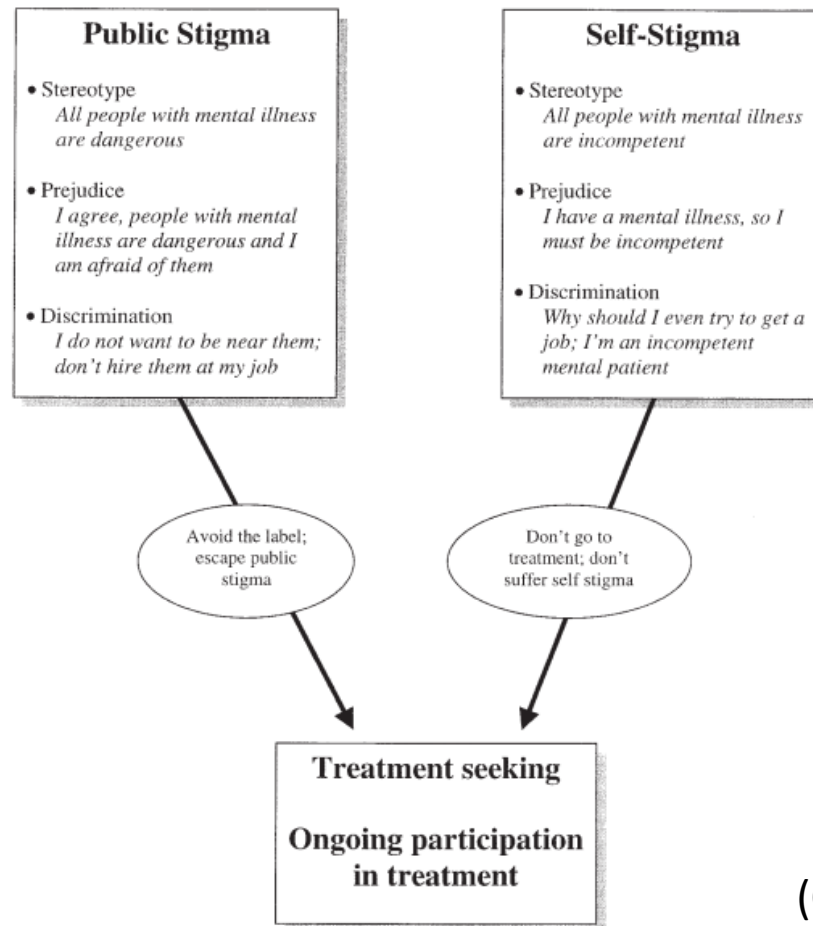
(Herrmann et al, 2018)

# Stigma: How it works

- Public stigma
  - Created when society labels and ascribes negative stereotypes
- Self-stigma
  - Created when person internalizes negative stereotypes

(Corrigan, 2002)

# Effects of Stigma



(Corrigan, 2004)

# Dementia Stereotypes

- Normal part of aging
- Second childhood
- Nothing can be done
- Complete dependence
- Cannot communicate their preferences
- Fail to contribute or burden society
- Dangerous

# Stigma Impact

- Social rejection
- Financial insecurity
- Internal shame
- Social isolation



(Burgener & Berger, 2008)

# Consequences

- Prevents early accurate diagnosis
- Prevents treatment
- Prevents access to support and services
  - Associated with anxiety, behavioral symptoms, depression, self esteem health and activity participation

(Burgener & Buckwalter, 2018)



# Caregiver Stereotypes

- Undervalued
- Responsible for appearances or behaviors
- Seeking help demonstrates weakness
- NH placement is failure or abandonment

# Family Stigma

- Stigma “spill over” to caregivers
- Prevents caregivers from seeking help
- Increases caregiver burden
- Poor quality of life



(Werner & Heinik, 2008) (Werner, Mittelman, Goldstein, & Heinik, 2012)

# Importance: Family Caregiving

- Family caregivers are the backbone of health and long-term care system
  - 15.7 million care for someone with dementia
  - 90% of unpaid help to people with dementia
  - \$217.7 billion economic value

(Alzheimer's Association, 2015)

# It Can Take a Toll

- Many caregivers are not well prepared
- Emotional, mental, and physical problems may arise
  - Depression and anxiety
  - Stress and frustration
  - Exhaustion
  - Lower immune response
  - Physical strain
  - Less self-care activities
  - Higher mortality than non-caregivers

# Purpose

- To use qualitative methods to explore how stigma manifests within families from the perspective of family caregivers of people with dementia

(Lopez, Rose, Kenney, Sanborn, & Davis, 2019)

# Method

- Grounded theory
- Recruited from memory clinics
- Semi-structured interviews
  - Audio recorded
  - Transcribed
  - NVivo
- Analyzed 3 levels of coding

# Sample

- 13 participants
- 10 female
- 5 spouse 6 adult children 2 other
- Age range 35-89 years
- 9 White non-Hispanic
- 4 White Hispanic
- Most care recipients moderate level dementia

# Results

- Central Theme: Managing Shame
- Produced 3 categories of responses
  - Silencing
  - Concealing
  - Shunning





# Shame

- Sense of disgrace and humiliation
  - *A shell of themselves*
  - *Losing control, mindset, becoming childlike*
  - *Not the same person*
  - *Diminished person*
  - *Better off passing*

# Responses

- Silencing
- Concealing
- Shunning

# Silencing



- To protect from shame
  - Silenced talk about symptoms
    - *Adult children feel disloyal when they start saying he's very forgetful*

# Silencing



- Created a code of silence
  - Avoiding telling family and friends
  - Healthcare providers
    - *I didn't get any kind of help*
    - *Nobody gave me any information*
    - *Continued in their computers*

# Concealing

- The person with dementia from others
  - *My mom didn't want people to know*
  - *...she was a social person...for her it was very embarrassing*
  - *...she's losing touch with people...but I don't believe its our place to tell people*

# Shunning



- Social rejection
  - *Only the strong ones engage*
  - *They don't visit...They do nothing*
  - *...now no one really inquires...now that she's got dementia*
  - *There's a different social standing*

# Limitations

- Sample drawn from memory clinic
- Limited to geographic region
- Did not include persons with dementia



# Conclusions

- Family stigma is present
- Stigma is co-created
- Healthcare providers were not seen as supportive
  - Participated in creation of stigma



# Dementia Stigma Carers

- Implicit biases and beliefs affect healthcare decision-making and are associated with lower quality care
- People with dementia report that biases were a barrier to receiving care

# Purpose

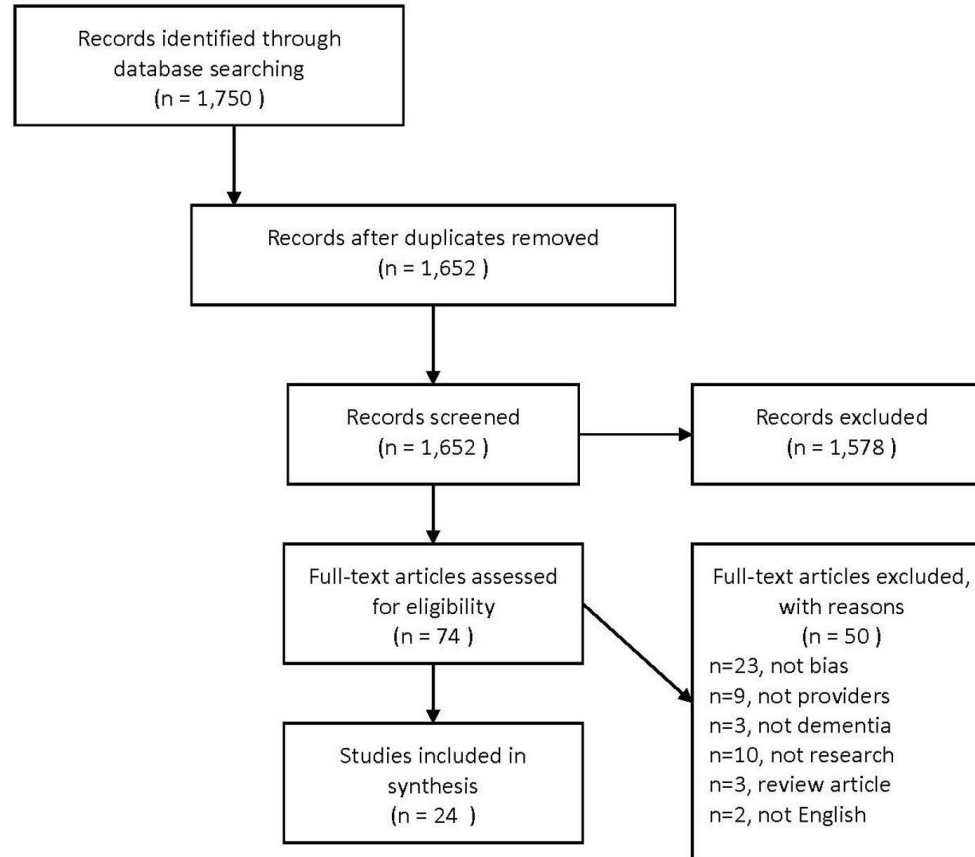
- To identify what is known about dementia-related biases and beliefs among healthcare providers

(Auerbach, Lopez, Gruss, & Lorenz, 2018)

# Method

- Search Pubmed, Scopus, PsychINFO, CINAHL, and Cochrane
- Key words: healthcare providers AND (biases OR discrimination) AND dementia
- Excluded: commentaries, case studies, non-peer reviewed articles
- Created a synthesis matrix
- Identified themes

## Literature Search Flow Diagram



# Results

- N = 24 studies
  - n = 8 quantitative
  - n = 13 qualitative
  - n = 3 mixed

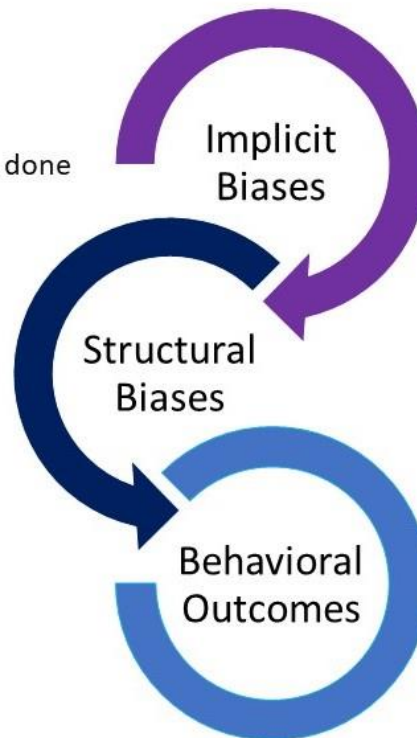
# Results

- Settings
  - 7 UK
  - 3 USA
  - 3 Sweden
  - 2 Netherlands
  - 2 Australia
  - 1 each Finland, Belgium, France, Japan, China, Nepal, Israel



# Findings

1. Implicit Biases
  - Ageism: Dementia is normal
  - Therapeutic nihilism: Nothing can be done
2. Structural Biases
  - Inadequate dementia education
  - Insufficient time for patient care
  - Not enough staff to provide care
3. Behavioral Outcomes
  - Lack of dementia screening
  - Lack of dementia diagnosis
  - Problems with communication
  - Using physical restraints
  - Using chemical restraints



# Conclusion

- There is a lot of work that needs to be done



# Changing Public Attitudes

- Removing blame
  - Contradict stereotypes
- Drawing equivalences
  - Underscore commonalities

(Clair, Daniel, & Lamont, 2016)

# Changing Attitudes

- Public health and medical experts
- Legal experts
- Social science and policy experts
- Media and journalists
- Social movement activists
- Firms and workplaces

(Clair, Daniel, & Lamont, 2016)

# Research

- World Alzheimer's Report 2019 Survey
  - Alzheimer's Disease International
  - The London School of Economics and Political Science
  - World's largest survey of people's attitudes around dementia
  - <https://www.alz.co.uk/research/world-report-2019>

# Education

- Awareness raising campaigns
  - The First Survivor
    - <https://youtu.be/IreMiiJefWA>
  - Time to Forget
    - <https://youtu.be/jjnHcyl0XPU>
  - Alzheimer's Research UK
    - <https://youtu.be/TQe1bWltMHs>

# Stereotypes in Language

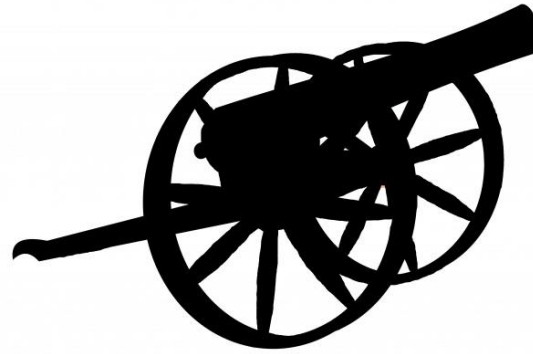
- Epidemic metaphor
  - Plague
  - Afflicted
  - Affected



(Young, Lind, Organge, & Savundranayagam, 2019) (Johnstone, 2011)

# Stereotypes in Language

- Military metaphor
  - Strikes
  - Attacks
  - Enemy
  - Battle

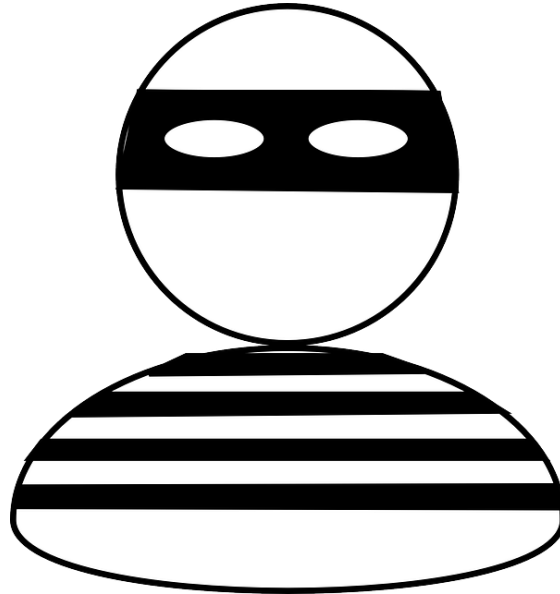


(Young, Lind, Organge, & Savundranayagam, 2019) (Johnstone, 2011)



# Stereotypes in Language

- Predatory metaphor
  - Robs
  - Steals
  - Destroys



(Young, Lind, Organge, & Savundranayagam, 2019) (Johnstone, 2011)

# Stereotypes in Language

- Zombie metaphor
  - Shell of oneself
  - Loss of mind
  - Living dead



(Young, Lind, Organge, & Savundranayagam, 2019) (Johnstone, 2011)

# Make Implicit Bias Explicit

- Recognize how dementia stigma and ageism impacts
  - Education
  - Resources
  - Policies
  - Practices

# Conclusion

- Humble
- Inspire
- Empower

# More Questions than Answers

- How does stigma differ
- What role do HCPs have
- How does stigma impact workforce
- What strategies diminish stigma