

# Suffering in People with dementia.....

how does society, policy  
and our own behavior add to  
the suffering of persons with  
dementia?

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# Faculty/Presenter Disclosure

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Faculty: **Romayne Gallagher**

## Relationships with financial sponsors:

- **Any direct financial relationships including receipt of honoraria: No**
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**This program has received financial support NO**

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**Potential for conflict(s) of interest:**

- **None**

# Mitigating Potential Bias

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Not applicable

# LEARNING OBJECTIVES

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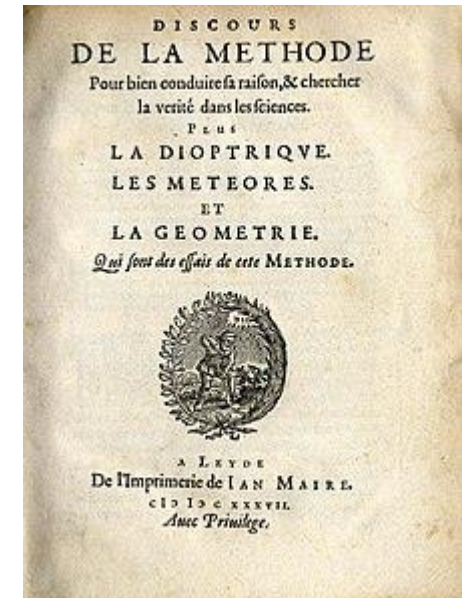
- Identify key themes of the suffering in persons with dementia
  - Identify stigma involved in having a diagnosis of dementia
  - Understand the rôle palliative care can play in maintaining quality of life for those with dementia and/or frailty
  - Making change in the way we view those with dementia and how we can improve their quality of life
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# Cogito, ergo sum – I think therefore, I am

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Rene Descartes 1637

Discourse on the Method of Rightly  
Conducting One's Reason and of  
Seeking Truth in the Sciences

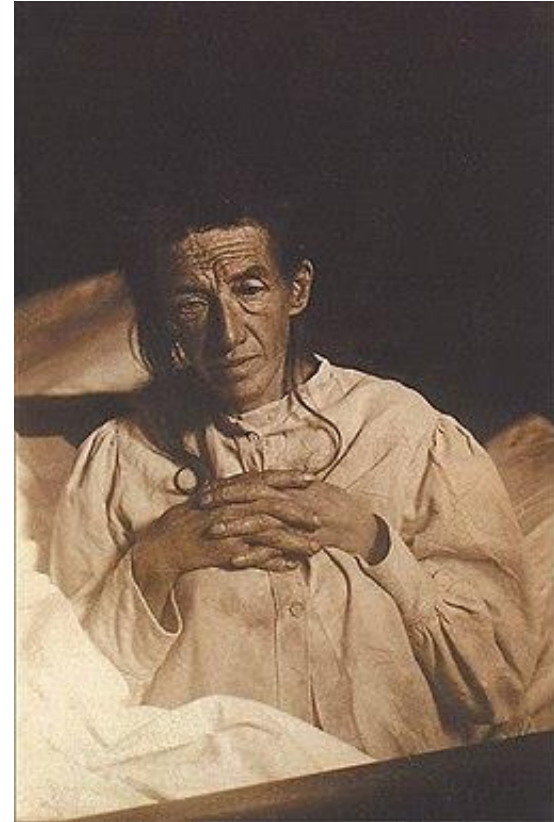


# The history of Alzheimer's Disease

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Alois Alzheimer



Auguste Deter

# Alzheimer's becomes a disease – late 1970s

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## Editorial

### The Prevalence and Malignancy of Alzheimer Disease

A Major Killer

An accompanying letter to the editor (p 304) provides another illustration of the malignancy of Alzheimer disease, a phenomenon well known to neurologists. Katzman and Karasu<sup>1</sup> estimate that the senile form of Alzheimer disease may rank as the fourth or fifth most common cause of death in the United States. Yet the US vital statistics tables do not list "Alzheimer disease," "senile dementia," or "senility" as a cause of death, even in the extended list of 263

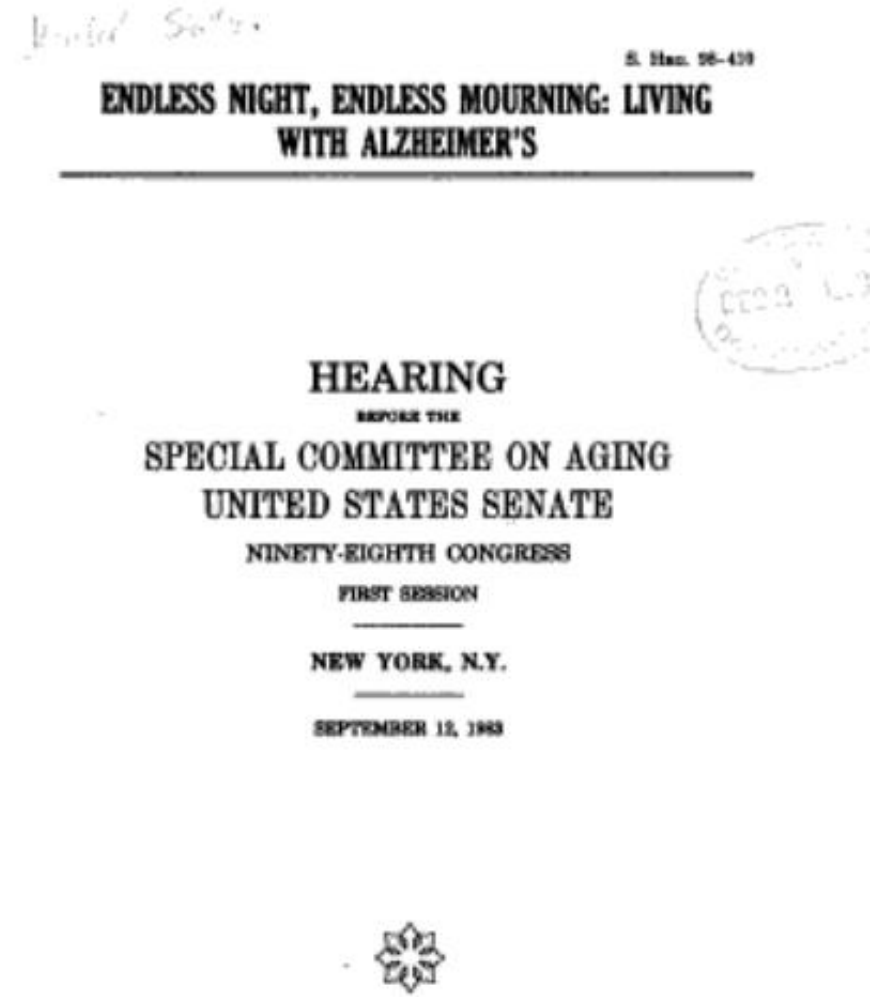
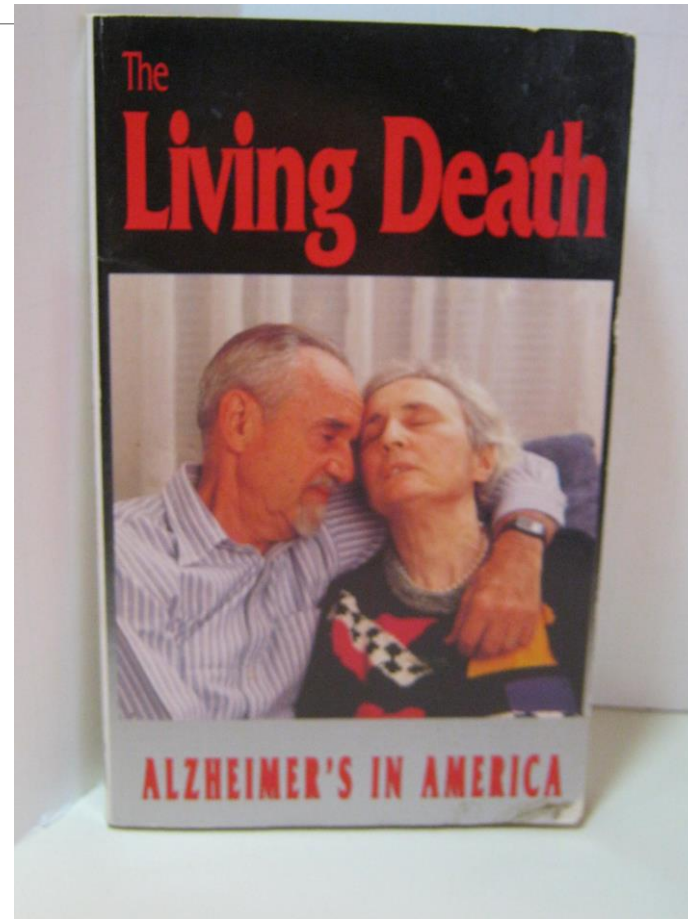
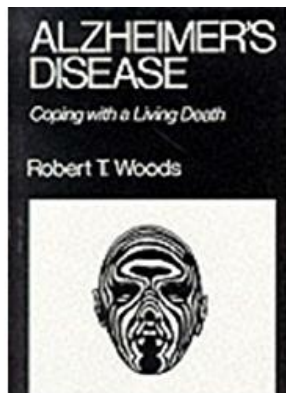
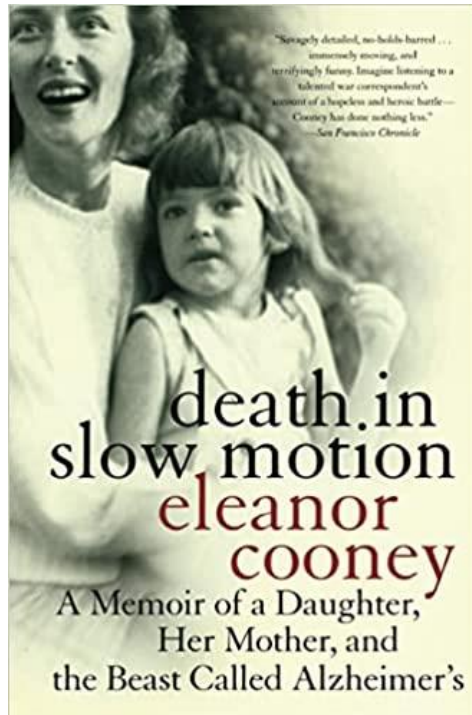
studies indicate that the neurofibrillary tangle in both disorders is characterized by the twisted tubule that represents two neurofilaments joined together in a helical fashion with a period of 800 Angstroms. The studies of Tomlinson et al<sup>4</sup> and Blessed et al<sup>5</sup> have established a quantitative correlation between the degree of dementia and the number of neurofibrillary tangles and senile plaques in the cerebral cortex. The evidence on which a distinction between senile dementia and Alzheimer disease can

the two disorders, except by the age of the patient. Today, the majority of workers in the field accept the identity of the two disease.<sup>6</sup> We believe that it is time to drop the arbitrary age distinction and adopt the single designation, Alzheimer disease.

Precise epidemiological information is not available concerning the prevalence of Alzheimer disease in the United States. However, several excellent community surveys of the prevalence of organic dementias in persons over age 65 have been carried



# Apocalyptic demography





# Person Theory

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Self 1: personal identity/point of view, beliefs, values, narratives of our life

Self 2 : traits, skills, and our beliefs regarding these attributes, includes deficits from neuropathology and attempts to cope with it

Self 3 : how we perceive ourself to be seen by others.

- Sabat et al. Dementia 2002 <http://dx.doi.org/10.1177/147130120200100101>

# Advancing Dementia

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- selfhood is an embodied dimension of human existence:
  - persists with advanced dementia
  - preserved abilities despite losses of cognitive functions
  - being able to assess internal state of being such as feeling cold/hot, pain
  - listening/responding to music
  - communicating about these assessments to others may be impaired

# Landscape of suffering in dementia

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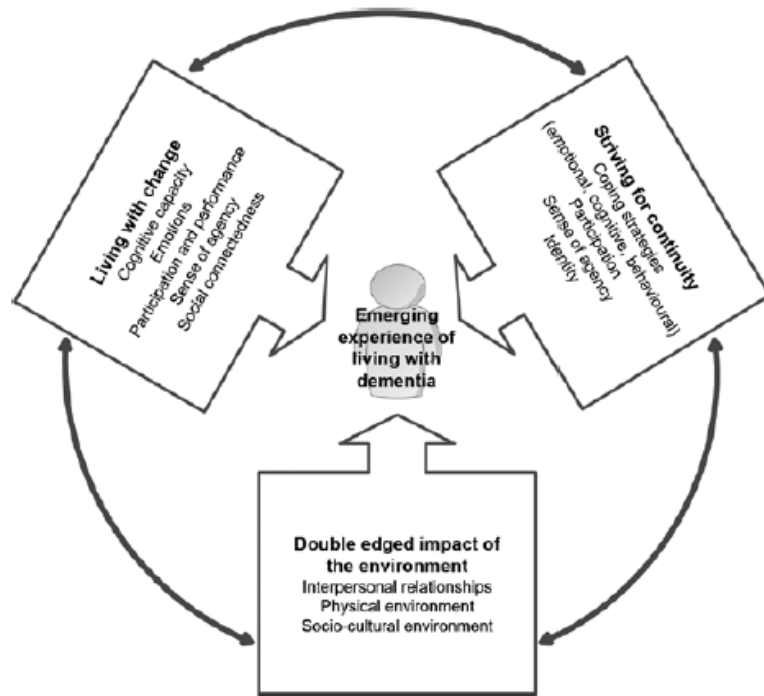


Figure 2. Experience of living with dementia: transactional relationships between identified themes.

Living with Dementia: A Meta-synthesis of Qualitative Research on the Lived Experience

Gorska et al. Gerontologist 2017

# Double-edge impact of the environment

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The environment is both the physical and the relational

Interpersonal relationships can be enabling or disempowering.

Malignant social psychology

# Personhood vs Citizenship

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- ‘Personhood is a standing or status that is bestowed on one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust....’ Kitwood
- Citizenship is a ‘status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties which the status bestows’... Marshall

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“the very reputation of this illness has added to the suffering of those who have it”

Susan Sontag Illness as Metaphor 1978





# Policy effects on PWD

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Safety over ability to exercise or be in nature

Walling out the community to keep people safe –  
nursing home design

Falls recorded as a sign of neglect vs the ability to  
explore environment

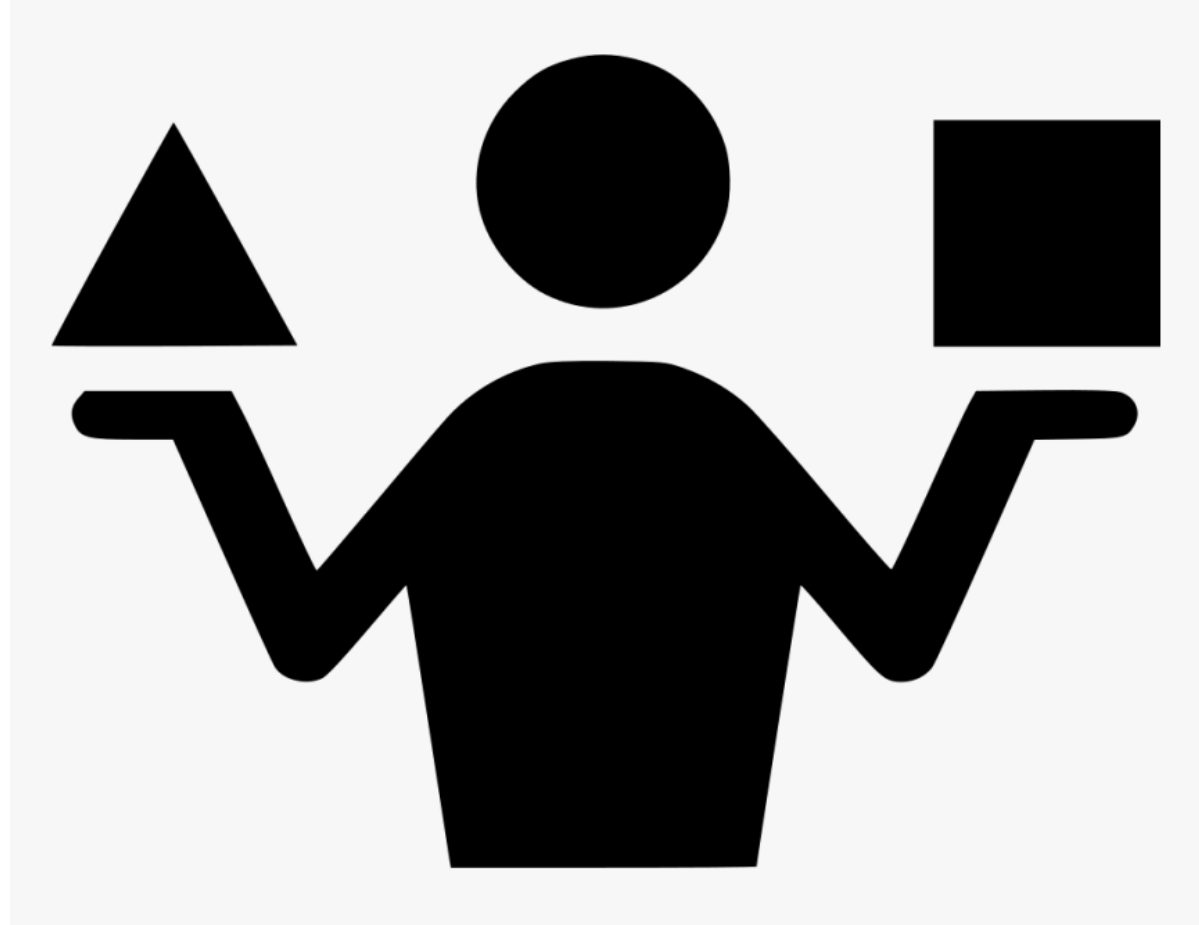
Our indicators do not measure quality of life – safety

# Quality of Life in those with dementia

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PWD self report

Proxy reports



# Living well with dementia

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## Moderate

- Social engagement and good relationship with family carer
- Religious beliefs/spirituality
- Carers self-rated health

## Lesser but important

- Better functional abilities
- PWD self-rated health
- Having a spouse carer & living in community
- Living in a specialized dementia unit

## Negligible

- Cognitive test scores
- Self-rated memory function

Martyr et al. 2018. Psychological Medicine

# Environment

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Dementia friendly communities

Dementia villages



# Palliative care's greatest impact on persons with dementia

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Maintaining quality of life through prevention and treatment of symptoms and illness burden that impair function and reduce quality of life



**Table F1** Proportion of people who received palliative care in the last year of life, 2016–2017, by cancer diagnosis and care setting

Diagnosis	Home care	Long-term care	Complex continuing care	Acute care
Cancer	50%	13%	79%	41%
Non-cancer (all others combined)	19%	9%	50%	14%

**Notes**

Excludes Quebec.

The numerator is those who received palliative care in the last year of life in the setting of care where they died.

The denominator is all those with a record of death by stated setting of care (e.g., home care clients with a home death, long-term care residents with a long-term care death).

**Sources**

Discharge Abstract Database, Continuing Care Reporting System and Home Care Reporting System, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

**Table F2** Proportion of people with selected chronic conditions who received palliative care in the last year of life, 2016–2017, by diagnosis and care setting

Diagnosis	Home care	Long-term care	Complex continuing care	Acute care
Heart failure	25%	10%	59%	11%
Dementia	20%	7%	51%	22%
COPD	28%*	10%	63%	20%
Renal failure	26%	12%	64%	14%

**Notes**

\* Includes asthma.

COPD: Chronic obstructive pulmonary disease.

**Sources**

Discharge Abstract Database, Continuing Care Reporting System and Home Care Reporting System, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

# Factors impairing quality of life

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Depression

High disease burden

Loss of function

Pain

Burks et al. Dement Geriatr Cogn Disord 2021



# Dementia is life shortening

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Comparison of 1818 PWD and 7235 age and sex matched persons without dementia who were followed for 5 years

Cumulative five-year mortality was 53.5% in PWD and 31.1% in the control group

Even after adjusting for comorbidities, the mortality risk was 1.5 times higher for PWD

- Koller et al. Int Psychogeriatr 2012



# Neuroinflammation

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activation of microglia and astrocytes, release of cytokines and chemokines, production of reactive oxygen species, infiltration of peripheral leukocytes into the central nervous system (CNS).

prolonged or maladaptive neuroinflammation is likely **a key pathological driver of many neurological diseases**, including neurodegenerative diseases, psychiatric illnesses, pain syndromes, stroke, and traumatic brain injury.

# Pain's impact on quality of life

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Pain and depression were associated with each other

People with lower levels of pain had lower depression scores

Neuropsychiatric symptoms are associated with pain

Symptoms, such as depression, agitation and challenging behavior can be indicators for present or not adequately treated pain as in people with dementia

Adequate pain management improved symptoms of depression, apathy, and night time behavior

- Eisenmann et al. Front Psychiatry 2020

# Prevalence of symptoms in dementia

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Focus on neuropsychiatric symptoms: agitation, depression, apathy, hallucinations, sleep impairment

These are symptoms in their own right, but may indicate underlying/unmet physical and social needs

pain in dementia related to behavioural symptoms: depression, verbal abuse, wandering, agitation, and aggression

- van Dalen-Kok et al. BMC Geriatr 2015

Pain related to functional impairment

- Lin et al. J Clin Nurs 2011

## 12 indicators of relative well-being in dementia:

The assertion of desire or will

The ability to experience and express a range of emotions;

Initiation of social contact

Affectional warmth

Social sensitivity

Self-respect

Acceptance of other dementia sufferers

Humor

Creativity and self-expression

Showing evident pleasure

Helpfulness

Relaxation

sense of  
personal worth

sense of agency

social confidence

sense of  
hope.

- Kitwood and Bredin Aging and Society 1992 Sabat Am. J of Alz. Care & Rel. Disorder Res 1994

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What needs to change in our society and long term care?



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Special Article

# The Rights of Persons With Dementia and Their Meanings



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[https://www.jamda.com/article/S1525-8610\(21\)00303-0/fulltext](https://www.jamda.com/article/S1525-8610(21)00303-0/fulltext)