# Social Isolation and Engagement Aging in Place with Dementia: A Workshop

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## Disclosures

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#### **A Workshop**

Maybe more questions than answers



### **Objectives**

- Stories
- Agreement\*
- Research
- Reflection



#### Personal Story- Grandparents with dementia

#### Community, Environment and Transitions

- Moving my grandparents to my home (USA)
- Family to my grandparents home (West African-Ghana)

Place & Culture Matter



#### Personal Story- More than the rent

- Renting Rooms to medical students
- Financial supplement
- Constant change
- Ongoing social connection

#### **Bidirectional Benefits**





#### Patient Stories- Flammable Hoard

#### Homebased primary care

- Homebound older adults
- Aging in place as a couple in a row home
- Safety challenges
- Impact on neighbors

Balancing Autonomy & Safety





## **Social Isolation**

Objectively having few social relationships, social roles, group memberships, and infrequent social interaction.

#### **Distinctions**

Social Isolation	Loneliness
Objective: being isolated— like quarantine	Subjective: feeling isolated
Low levels of social contact	Mismatch between actual and desired social relationships
Not necessarily unpleasant, possibly preferred	Emotionally distressing and unpleasant
May be chosen: "solitude"	Low sense of control or choice



### **Social Connection framing**

#### Social connection

The extent to which an individual is socially connected depends on multiple factors, including:

- 1. Connections to others via the existence of relationships and their roles
- 2. A sense of connection that results from actual or perceived support or inclusion
- 3. The sense of connection to others that is based on positive and negative qualities

#### Structural

The existence of and interconnections among different social relationships and roles

- · Marital status
- Social networks
- Social integration
- Living alone
- Social isolation

#### **Functional**

Functions provided by or perceived to be available because of social relationships

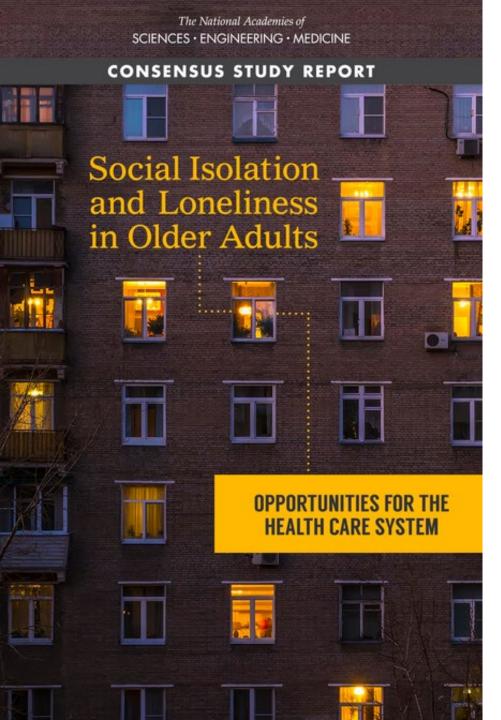
- Received support
- Perceptions of social support
- Perceived loneliness

#### Quality

The positive and negative aspects of social relationships

- Marital quality
- Relationship strain
- Social inclusion or exclusion





**Develop a More Robust Evidence Base** 

**Translate Research into Healthcare Practice** 

**Improve Awareness** 

**Strengthen Education & Training** 

Optimize ties b/w Health Syst. & Community Networks/Resources

# Our Epidemic of Loneliness and Isolation



The U.S. Surgeon General's Advisory on the Healing Effects of Social Connection and Community



**Strengthen Social Infrastructure** 

**Enact Pro-Connection Public Policies** 

**Mobilize the Health Sector** 

**Reform Digital Environments** 

**Deepen Our Knowledge** 

**Cultivate a Culture of Connection** 

#### Measurement

#### nature aging

https://doi.org/10.1038/s43587-023-00472-4

#### Reflections on measures of social isolation among older adults

Check for updates

n 2020, the National Academies of Science, Engineering, and Medicine reported on opportunities for the healthcare system to address social isolation and loneliness, which are risk factors for morbidity and mortality1. Shortly after the report was released, the COVID-19 pandemic ensued which pushed social isolation up the research and public health agendas as broad swathes of the population experienced this phenomenon. Studies demonstrate social isolation as a key risk factor for adverse physical, mental and cognitive health outcomes1,2. Despite these implications, the research community lacks consensus on how to measure social isolation. which hinders progress toward solutions to combat this challenge.

Social isolation affects 15-25% of community-dwelling older adults, but estimates vary

widely owing to the lack of a uniform metric3. Literature reviews identify more than fifty measures related to social isolation4. The lack of measurement consensus and use of instruments that vary in their content, rigor and uptake inhibits progress toward building knowledge on social isolation and its consequences. Standardized measurement is crucial to assess and address the health risks of social isolation, as highlighted in a 2023 advisory from the US Surgeon General.

Among the measurement issues is the problem of single-item metrics. Proxy variables such as 'living alone' or 'not married' are easy to administer but do not capture key aspects of social isolation, such as social connection at the group (for example, network size or frequency of contact) or community (for example, volunteering) level\*, Social

isolation measures should capture objective and quantitative components of relationships. Although some researchers have used multidomain metrics, single-item indicators persist and may confound estimates.

Furthermore, many studies interchange social isolation with loneliness4, Social isolation is the lack of social contact and relationships, whereas loneliness is subjective and characterized by feeling isolated1 (Fig. 1). These interrelated concepts are moderately correlated and associated with distinct health outcomes1,2, There is also a need to disentangle the effects of social isolation from other aspects of social connection on health4. Refined and well-validated measures of social isolation would help to achieve this goal.

Measures that capture both objective and subjective aspects of social connection are

Duke social support index Measures social networks, social interaction, subjective support, instrumental support

Berkman-Syme social network index Validated scale measuring

Measures frequency and quality of social support, social participation and social contact isolation and social support

Cornwell perceived isolation scale

Validated scale measuring social disconnectedness and perceived isolation Measures living arrangement,

Nicholson social isolation index core discussion network and Validated index measuring frequency of community participation contact, closeness, fulfillment, belonging and relationship engagement Shaw objective isolation scale

De Jong Gierveld loneliness scale

social isolation

Validated scale measuring emotional and social loneliness

Steptoe social isolation index

Measures social connectedness including living arrangement, marital status, frequency of contact and community participation

Lubben social network

social networks, social

scale

Measures social connectedness including network size, range, number of

friends and frequency of contact

Loneliness Perceived isolation or

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Fig. 1| Common measures of social connection. Various measures are used to evaluate social isolation and related concepts that fall under social connection a multifactorial construct that encompasses distinct but related aspects (including social support (functional aspect), social isolation (structural aspect) and loneliness (quality aspect))4.5.

feeling of being alone

Actual or perceived availability of resources from others

UCLA loneliness scale

subjective feelings of

Validated scale measuring

loneliness and feelings of

Social support

Pomeroy et al 2023, Nature Aging

Social isolation

Objective lack of

Cudjoe social

isolation typology

social contact



Older people living with dementia are at greater risk than others for social isolation and having little or no support can have serious consequences for their ability to remain in the community over time.

## Social isolation is prevalent among older adults





# Social Isolation prevalent and changes



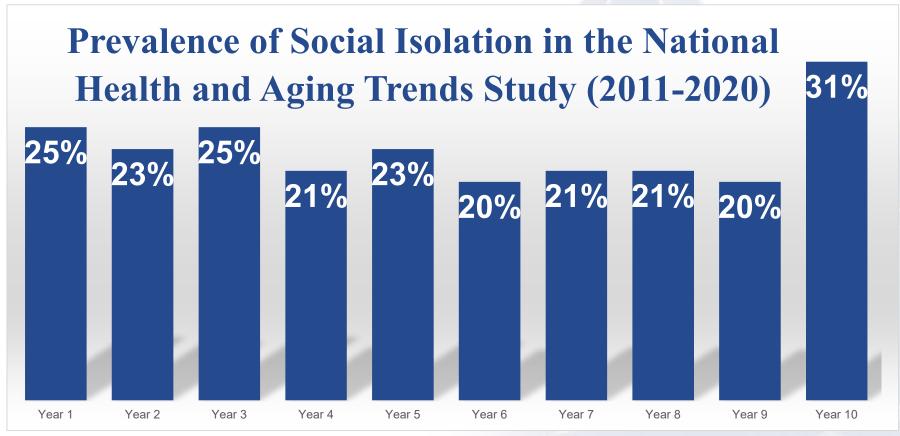


## LONELINESS AND SOCIAL ISOLATION IN OLD AGE

CORRELATES AND IMPLICATIONS

Edited by André Hajek, Steffi Riedel-Heller and Hans-Helmut König





#### Social isolation matters at the cellular level

American Geriatrics Society

Received: 7 June 2021 Revised: 13 September 2021 Accepted: 1 October 2021

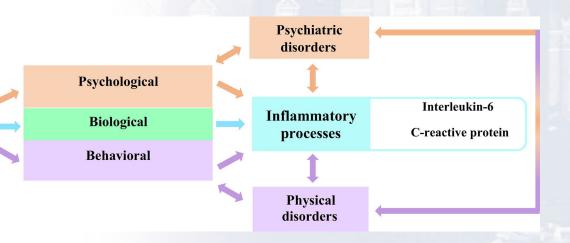
DOI: 10.1111/jgs.17518

Journal of the

Getting under the skin: Social isolation and biological markers in the National Health and Aging Trends Study

Thomas K. M. Cudjoe MD, MPH¹ □ □ | Sruthi Selvakumar MS¹ □ |
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Roland J. Thorpe Jr PhD² | Cynthia M. Boyd MD, MPH¹

# JOURNAL OF THE AMERICAN GERIATRICS SOCIETY



Social

isolation

#### Social Isolation increases dementia risk

Received: 10 June 2022 Revised: 26 September 2022 Accepted: 26 October 2022

DOI: 10.1111/jgs.18140

Journal of the American Geriatrics Society

#### Social isolation and 9-year dementia risk in community-dwelling Medicare beneficiaries in the United States

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#### JOURNAL

Socially isolated older adults have a 27% higher chance of developing dementia than older adults



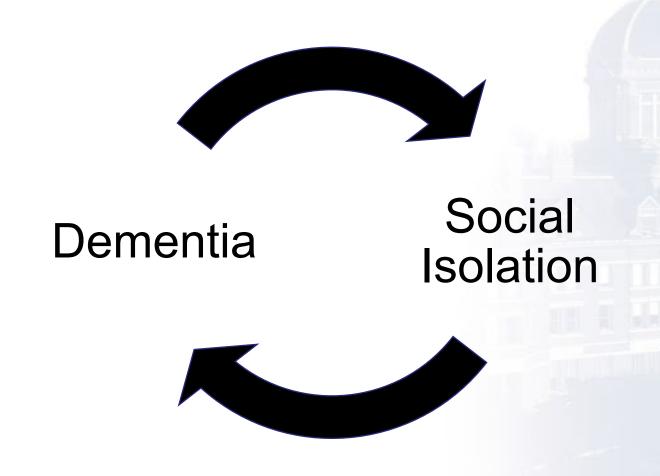
#### Is there sufficient evidence?

## Older people living with dementia are:

(a) at greater risk than others for social isolation and

(b) having little or no support can have serious consequences for their ability to remain in the community over time.

#### What comes first...



# More research is needed on the social connections of people living with dementia.

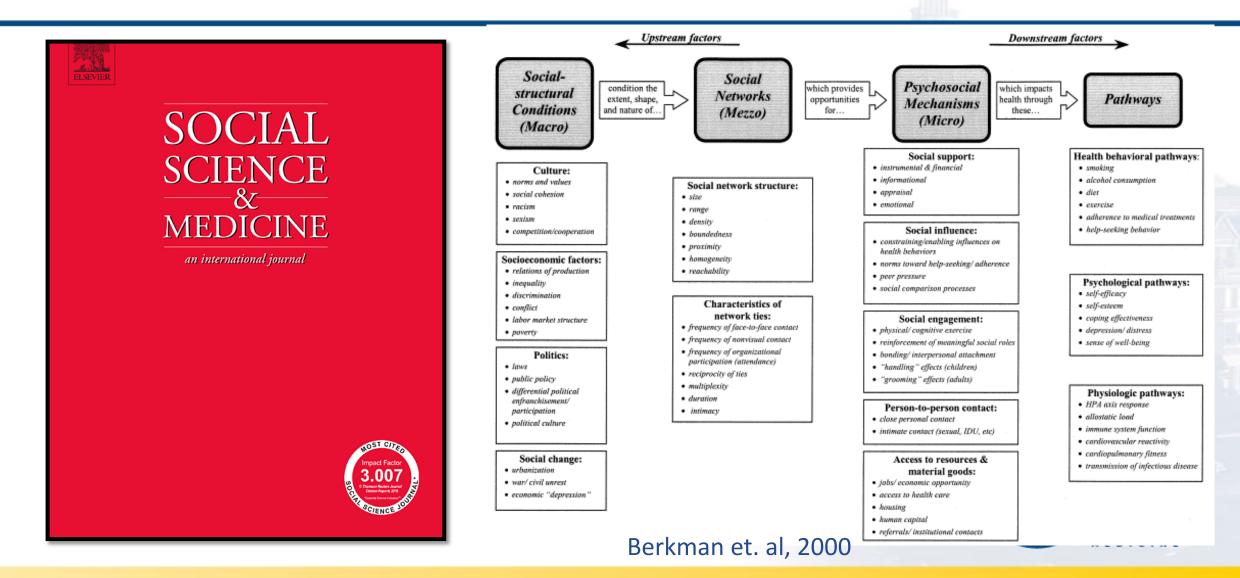
- Many studies indicate that social isolation increases risk for dementia (Evans et al 2019, NASEM 2020)
- Are individuals with dementia at greater risk for social isolation? <u>Fewer studies examine reverse causation</u>
  - Heterogeneity of individual and community resources
  - Challenges in diagnosis and care of people living with dementia
  - Evolution and change in cognition with time



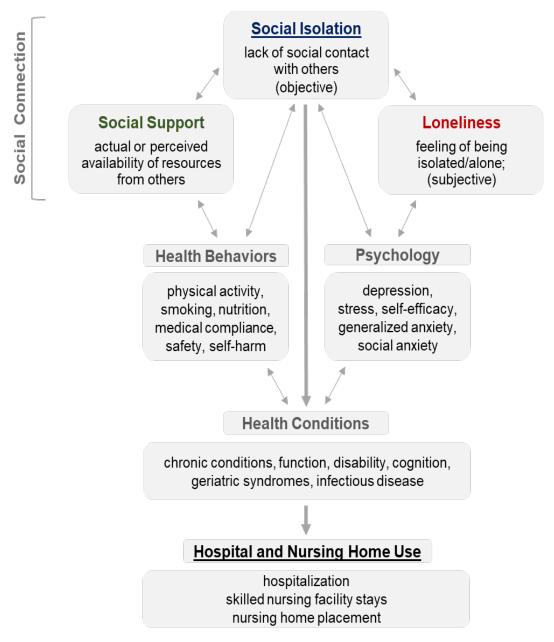
#### **Decades\* of Research**

#### From social integration to health: Durkheim in the new millennium

Lisa F. Berkman<sup>a,\*</sup>, Thomas Glass<sup>b</sup>, Ian Brissette<sup>c</sup>, Teresa E. Seeman<sup>d</sup>



# Conceptual Framework Modeling Bidirectional Pathways between Social Isolation and Healthcare Utilization



### How does dementia influence social connection? Different responses

#### Increased connection

- Utilization of clinical and community based services
- Family/Friend/Community supports amid increased needs

#### **Decreased connection**

- Memory challenges in maintaining connection
- Compounding risk of poor health/function
- Stigma, Stress,
   Misunderstanding, Fear,
   Anxiety
- Communication impact



#### **Driving Questions**

- How are people living with dementia vulnerable to risks of isolation?
- What individual and community level factors improve or worsen the consequences of isolation for people living with dementia?
- What interventions are available that might be useful to support those without family or friends available?

## How are people living with dementia vulnerable to risks of isolation?

- Memory challenges –living alone and overall safety
- Performing ADLs/IADLs
- Accomplishing health/medical task (i.e taking meds, going to appointments)
- Maintaining basic needs- food+ water/shelter/clothing
- Risk for elder mistreatment



#### What individual and community level factors improve or worsen the consequences of isolation for people living with dementia?

#### **Factors That** Individual · Chronic disease **Can Shape** · Sensory and functional impairments · Physical health Social · Personality · Race · Gender Connection Socioeconomic status · Life stage Relationships · Structure, function, and quality · Household size · Characteristics and behaviors of others Community · Outdoor space · Housing · Schools Workplace Local government Local business Community organizations · Health care Transportation Society · Norms and values · Public policies Tech environment and use Civic engagement Democratic norms · Historical inequities Office of the

#### Individual

- Life course matters
- Demographics (Race, sex/gender, income, education, zip code)
- Personality & Preferences

#### Community

- Housing & Living arrangements
- **Transportation**
- Networks of support (family, friends, neighbors)
- Social infrastructure (libraries, senior centers, café)

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# What interventions are available that might be useful to support those without family or friends available?

- Lot of activity in intervention development, differing outcome measures
- Before the intervention –how to identify those in need
- Think upstream before dementia or MCI
- Menu or platform of solutions

   person/place focus
- Group based and purpose orientation



## **Addressing Social isolation**

- Educate, Assess, Respond- EAR Framework<sup>1</sup>
- Solutions Easy, Adaptable, Sustainable
- Starting Proximal
- Sawubona- "I see you"



# **Social Isolation and Engagement**Aging in Place with Dementia

- Balancing Perspectives: Personal, Clinical, Population
- Expand Awareness
- Improve Measurement—Identifying
- Investment in Research & Intervention Development
- Equity & Justice at the core of efforts
- Realize Assets

#### Thank you!

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