

Measuring Loneliness and Social Isolation and Collecting Data among Older Adults

Ashwin Kotwal, MD, MS
Assistant Professor
Division of Geriatrics, UCSF
@AshwinKotwalMD



### We will discuss...

1. Definitions and Measurements

1. Primary Data Collection among older adults and populations at risk



### We will discuss...

1. Definitions and Measurements

1. Primary Data Collection among older adults and populations at risk



# Social Isolation and Loneliness In Older Adults: Opportunities for the Health Care System

## Recommendations





Develop a more robust evidence base



Translate current research into **health care practices** 



Improve awareness



Strengthen ongoing education and training



Strengthen **ties** between the health care system and community-based networks and resources



# Loneliness

"Subjective" assessment that social relationships are lacking

# Social isolation

"Objective" measure of connections to family, friends, or the community



#### Dimensions of Loneliness

- Intimate/emotional loneliness: Lack of a close partner or confidante
- Relational loneliness: Lack of friendships and support
- Collective loneliness: Lack of community or group with shared purpose
- <u>Existential loneliness</u>: Loss of identity and meaning in the world



## Key Measurement Considerations

- Length of questionnaire
- Avoiding stigma associated with self-identifying as lonely
- Positive and negative questions
- Frequency of measurement
- Standardized measures (to aid in comparison)



## Single item:

"In the last month, how often have you felt lonely?"

Responses: Hardly Ever, Sometimes, Often

#### **Pros:**

- Short
- Broad measure of all loneliness dimensions

- Possibility of stigma
- Unclear which dimension you are measuring
- "Ceiling/Floor effects"



## **Indirect Measure: 3-item UCLA**

In the last month, how often have you:

- 1. Felt left out
- 2. Felt isolated
- 3. Felt like you lack companionship

Responses: Hardly Ever, Sometimes, Often Scale: o-6 points

#### **Pros:**

- Short
- Avoids stigma
- Intimate/relational loneliness
- Gold-standard in clinical literature
- Less Ceiling/Floor effects

- Some dimensions are less clear
- Only negative questions



<sup>\*</sup>Taken from a 20-item questionnaire

## **De-Jong Gierveld Scale**

- 1. I experience a general sense of emptiness
- 2. There are plenty of people I can rely on when I have problems
- 3. There are many people I can trust completely
- 4. I miss having people around
- 5. There are enough people I feel close to
- 6. I often feel rejected

Responses: None of the time, Rarely, Some of the time, Often, All of the Time

\*Taken from an 11-item questionnaire

#### Pros:

- Short
- Avoids stigma
- Intimate/relational loneliness
- Mixed Positive and Negative Questions

- Longer
- Less frequently used



### How do we define Social Isolation?

- Social isolation refers to a complete or nearcomplete lack of contact with society
- Relates to a *quantifiable* number of relationships and *frequency* of interaction
  - Spouse or partner
  - Children
  - Family, Friends, Neighbors
  - Community organizations





# Single item: Confidantes

"Looking back over the last year, who are the people you talked with most often about important things?"

#### **Pros:**

- Short
- Can list out important confidantes

#### Cons:

 Does not assess other dimensions of social isolation



# Berkman-Syme Social Network Index (12 items)

# Duke Social Support Index (10-items)

#### Pros:

- Relatively short 10-11 items
- Assesses multiple dimensions
- Publicly available and widely used in research

- Can be long if embedded in other surveys
- Have not been updated (religious activities, no tech questions)



We will discuss...

1. Definitions and Measurements

1. Primary Data Collection among older adults and populations at risk



## Why collect data?

- Strategic Planning
- Make the case to decision-makers
- Ensure quality and that you're meeting client needs
- Can enhance partnerships with other organizations or health systems



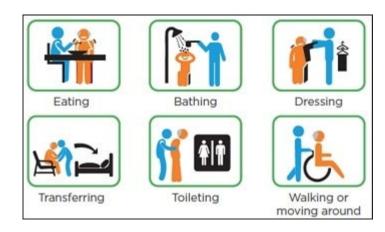
## Surveys: Sociodemographic Measures

- Think about your community and important measurement concerns
- Sociodemographics:
  - Demographics: Age, Gender, Sexual Orientation, Race/Ethnicity
  - Social subgroups: Immigrants, Veterans
  - Socioeconomic status: Education, Homelessness, Wealth/Assets
  - Social situation: Living Alone, Marital Status, Children
  - Technology: Access to devices/internet, Comfort using devices



## Surveys: Clinical Measures

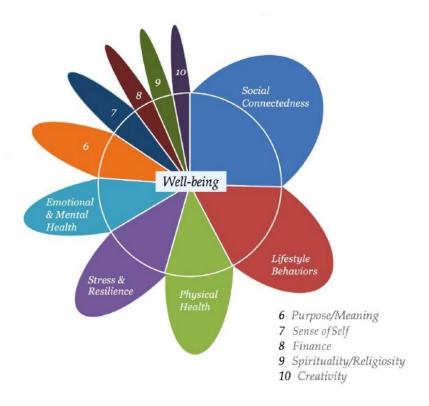
- Think about your community and important measurement concerns
- Clinical:
  - Medical conditions: Psychiatric or Chronic
     Illnesses
  - Function: ADL or IADL impairment
  - Sensory deficits: Hearing or Vision impairment
  - Access to health care





## Survey: Additional Social Measures

- Loneliness and Social Isolation are broad measures
- Consider inclusion of other social measures:
  - Availability of social support or caregiver support
  - Elder mistreatment
  - Neighborhood safety and support





## Logistics of primary data collection

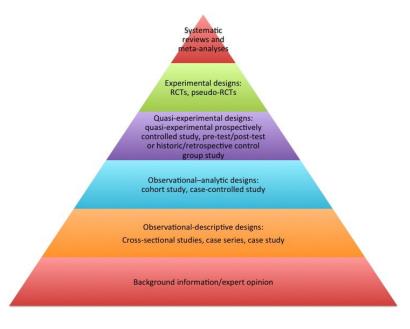
- Institutional Review Board Review
- Secure Data Storage and Management
  - Example: RedCap
- Available Data vs Conducting Interviews
  - Think about sample sizes early





## Frequency and Timing of Data Collection

- If testing the effect of an intervention:
  - Randomized trials
  - Pre-post studies
  - Pilot or observational studies
- Can include structured surveys and qualitative interviews
- Multiple time points can help





## In Summary

- We defined loneliness and social isolation
- 2. We examined how loneliness and isolation are linked to serious illness, cognitive impairment, and the COVID-19 pandemic
- 3. We applied a general framework for interventions to address social needs, which can guide how we support patients while we await higher quality evidence for interventions tailored individual needs



# Thank You!



Alex Smith, MD, MS, MPH
Carla Perissinotto, MD, MSHS
Louise Hawkley, PhD
Linda Waite, PhD
Julianne Holt-Lunstadt, PhD

