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
- **Existential loneliness**: 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

Cons:
- 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: 0-6 points

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

Cons:
- Some dimensions are less clear
- Only negative questions

*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

Cons:
- Longer
- Less frequently used

How do we define Social Isolation?

- Social isolation refers to a complete or near-complete 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

<table>
<thead>
<tr>
<th>Index</th>
<th>Pros</th>
<th>Cons</th>
</tr>
</thead>
</table>
|Berkman-Syme Social Network Index (12 items)| - 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)|
|Duke Social Support Index (10-items)| | |

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

1. 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-Lunstad, PhD