Observational Measure of Elder Self-Neglect: Development, Testing and Program Outcomes

Madelyn Iris , PhD
CJE SeniorLife

Kendon J. Conrad, PhD
University of Illinois at Chicago (Emeritus)
Chestnut Health Systems

Objectives

1. Describe results of the conceptual development/concept mapping phase of the project and ESNA item generation
2. Describe results of the field test of the ESNA and psychometrics of the instrument
3. Discuss applications of these findings

Self-Neglect Project Research Questions

- What constitutes self-neglecting behaviors?
- How do practitioners and other experts conceptualize elder self-neglect, based on these behaviors?
- Can a standardized measure of elder self-neglect be used by practitioners?
- What are the psychometric properties of the standardized measure?
- How can these findings contribute to theory of the nature of self-neglect?

Importance of Assessing ESN

- Elder self-neglect (ESN) represents half or more of all cases reported to adult protective services.
  - National Center on Elder Abuse (2006) reported 84,767 cases of ESN (FY2003) in 21 states
  - Estimated there are more than 1 million cases of ESN each year in the United States (Dong, Tang, Gorbien, and Evans, 2008)
- ESN is associated with higher than expected mortality rates, increased hospitalizations and long-term care placements, localized environmental and safety hazards

What is Elder Self-Neglect?

" …the inability (intentional or non-intentional) to maintain a socially and culturally accepted standard of self-care with the potential for serious consequences to the health and well-being of the self-neglecter and perhaps even to their community. "

Gibbons, S., Lauder, W., & Ludwick, R. (2006). Self-neglect: A proposed new NANDA diagnosis. *International Journal of Nursing Terminologies and Classifications*, *17*(1), p.16.

Assessment Content Development

- Conducted 2 face-to-face brainstorming sessions to elicit indicators of ESN
  - 20 participants (senior services program supervisors, geriatricians, local policy analysts, program planners, elder law practitioners, and university-based researchers)

- Prompt: " Generate a short statement that describes an item that should be included in an elder self-neglect measure. "

- Results: Several hundred items were generated; consolidated into final list of 78 indicators

Conceptual Development

Used Concept Systems software:

- Participants sorted items into groupings based on similarity
- Rated each item for importance for the concept of self-neglect and feasibility of assessing (1-5, least to most)

Results:

- 50 participants: case managers and supervisors from local agencies, social workers specializing in working with older adults, elder abuse investigators, lawyers, program planners, researchers, etc.
- 36 completed the sorting exercise
- 33 completed the rating exercise.

Analysis and Interpretation

Multidimensional scaling and hierarchical cluster analysis used to construct conceptual domains (clusters) based on aggregated sortings

Multiple cluster maps generated using Concepts Systems software; 7 cluster map selected

- Illinois Interdisciplinary Research Consortium for Self-Neglect reviewed cluster map for face validity
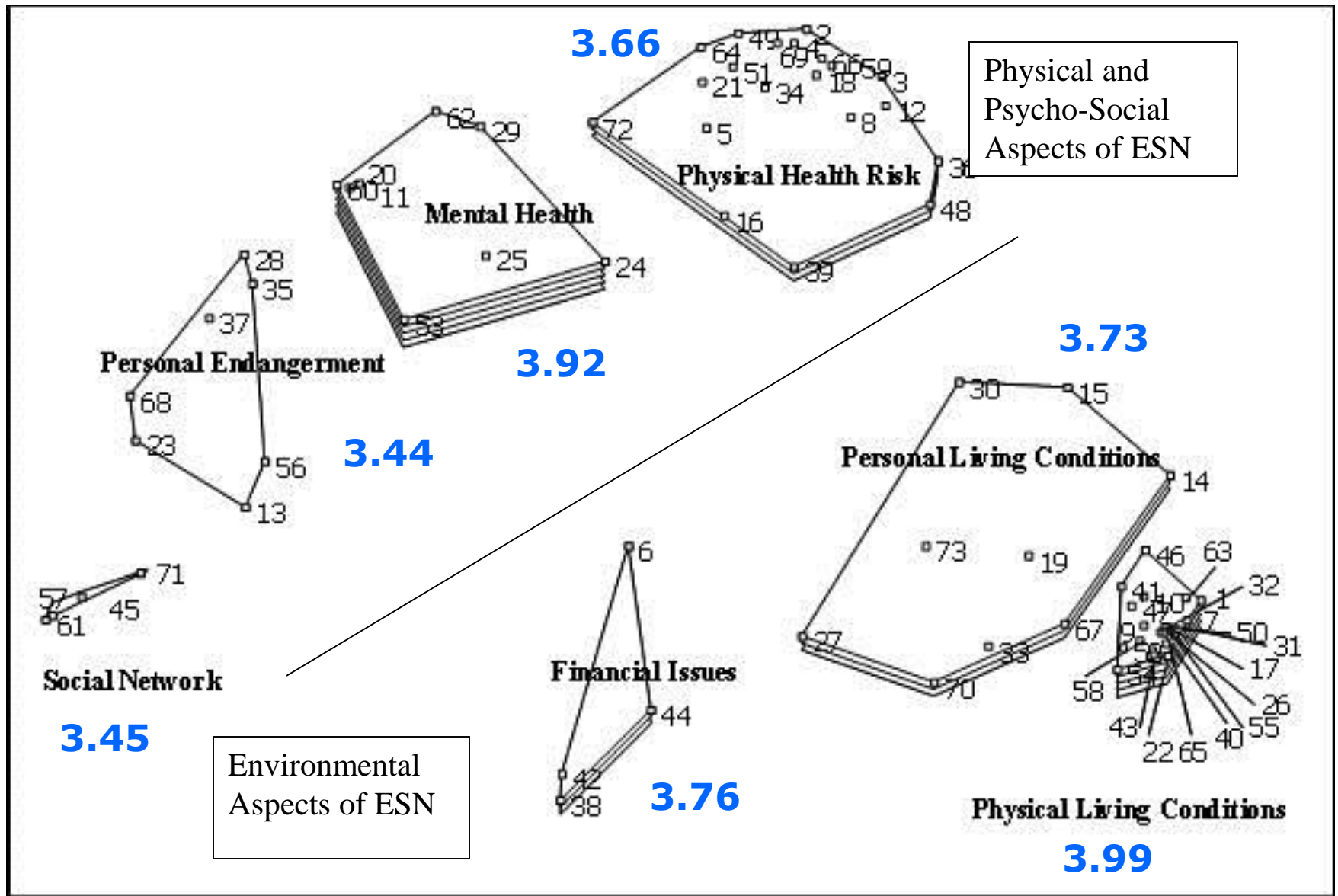
The consortium was sponsored by the Department of Geriatrics at Rush Medical Center and CJE SeniorLife in Chicago, as an informal interdisciplinary group of 16 members, including physicians, social workers, academics, and policy analysts, all of whom had an expressed interest in improving care for persons suffering from self-neglect.

How to Interpret the Map

- Numbers refer to item list
- Points represent placement of item relative to other items
- Proximity of points is based on the frequency with which items are placed in the same pile by each sorter
- HCA groups items into clusters that represent unique conceptual units
- The placement of clusters on the map represents the relationship of one set (or cluster) of ideas to another.
- Clusters in the middle of the map may contain ideas that are linked to multiple regions on the map.
- Clusters that are conceptually distinct may appear near the boundaries of the map.
- A larger cluster often represents a concept that is quite broad or that bridges two other specific ideas on the map, but size is not an indication of importance or relevance
- Numbers in Blue represent mean importance rating for all items in that cluster

7 Cluster map with items, Importance Rating and 2 regions of meaning.

3.66

3.92

3.44

3.45

Physical and Psycho-Social Aspects of ESN

Physical Health Risk

Mental Health

Personal Endangerment

Social Network

Environmental Aspects of ESN

Financial Issues

3.76

Personal Living Conditions

3.73

Physical Living Conditions

3.99

Clusters, Example Items, and Mean Importance Ratings

Item	Mean Importance rating
Physical Living Conditions Cluster	*3.99*
46. Are there human or animal feces/urine on the floor or walls	4.70
47. Does the condition of the home/apartment appear unsafe?	4.64
65. Is there an accumulation of garbage?	4.12
Mental Health Cluster	*3.92*
25. Are the older person's behaviors likely to cause physical harm to themselves?	4.64
11. Does the older person appear to be confused?	4.15
29. Is the older person abusing substances?	3.67
Financial Issues Cluster	*3.76*
42. Are essential bills overdue or unpaid (rent/mortgage, utilities, etc.)?	4.15
44 Are bills unpaid, despite adequate income to pay them?	4.06
Personal Living Conditions Cluster	*3.73*
30. Is there any evidence that the older person is eating spoiled food?	4.67
67. Does the older person have an accumulation of stuff that presents a safety hazard?	4.12
33. Does the older person have an excessive amount of pets?	3.48
Physical Health Risk Cluster	*3.66*
66. Does the older person present with signs of malnourishment, dehydration, skin rashes, lice, etc.?	4.91
5. Does the older person ignore signs and symptoms of disease?	3.64
Social Network Cluster	*3.45*
71. If the older person is isolated, is the isolation putting them at risk?	3.97
45. Does the older person have someone they can turn to in an emergency	3.73
Personal Endangerment Cluster	3.44
56. Is the older person willing to accept needed assistance	3.76
28. Does the older person show signs of agitation?	3.55

Implications
of the Findings

- 2 "Regions of Meaning" emerged, based on orientation of the clusters vis-à-vis one another: Physical and Psycho-social aspects of ESN and Physical and Psycho-Social Aspects of ESN and Environmental aspects of ESN

- Proximity of the Physical Living Conditions cluster and the Personal Living Conditions cluster suggests that indicators of the physical environment and personal living situation are closely related; may constitute a single area of interest.

- "Tightness" of the physical Living Conditions cluster indicates that this grouping has high integrity as a distinct domain of ESN.

- High importance attributed to the Mental Health cluster suggests that mental health issues may represent underlying or predisposing factors related to self-neglect.

- Financial Issues cluster rated high in importance, suggesting that lack of financial security may influence an elder's ability to care for self and/or home.
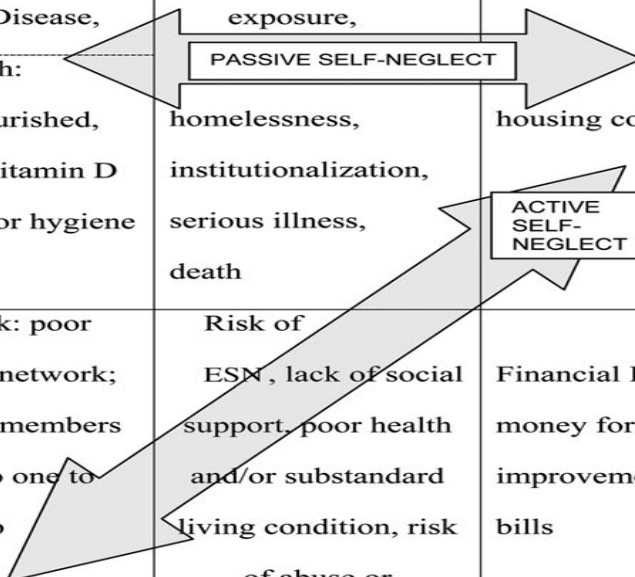
Implications (cont.)

- Supports the contention that cognitive impairment and depressive symptoms are associated with ESN

- Favors the self-care deficit explanatory model

- Given the close proximity of the Mental Health cluster and the Physical Health Risks cluster, may be that mental health and physical health interact in situations of self-neglect, but cannot infer any type of causality

- Model suggests ESN is related to declines in personal care that as well as decline in the personal environment, challenging the characterization of ESN as a medical syndrome

Theoretical Model of ESN

Physical and Psycho-Social Region of Meaning	Consequences for Older Adult	Environmental Region of Meaning	
ESN			
Mental Health: may abuse substances, experiences cognitive deficits such as Alzheimer's' Disease,	Life-altering or life-threatening conditions, including eviction, relocation, exposure,	Physical Living Conditions; appliances not working, utilities turned off,	**High Importance**
Physical Health: may be malnourished, suffers from Vitamin D deficiency; poor hygiene	homelessness, institutionalization, serious illness, death	housing code violations	
Social Network: poor social support network; lack of family members and friends; no one to turn to for help	Risk of ESN, lack of social support, poor health and/or substandard living condition, risk of abuse or exploitation	Financial Issues: no money for home improvement, unpaid bills	
Personal Endangerment: refuse to accept help; non-compliant with medical directives		Personal Living Conditions: hoarding (pets, newspapers, etc.), blocked pathways	**Low Importance**
Normal Aging			

PASSIVE SELF-NEGLECT

ACTIVE SELF-NEGLECT

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Field Test of the Measure

- Refined items into an assessment format
- Field tested the ESNA with cooperation of 12 CCUs and 1 social service organization in Illinois serving rural, suburban, urban populations
- 215 assessments received
- Data entered into SPSS database
- Analyzed using Rasch methdology, Winsteps software

Characteristics of the Sample

Variable	Valid Percent	Number
Gender	56.8% female	121
	42.3% male	91
	1.4 Missing Data	3
Location	33.8% Urban	72
	31.0% Rural	66
	35.2% Suburban	75
	.9% Missing Data	2
Age	Average age 75.37	
	Std. dev. 8.79	
	Range: 60-99	
	28.5% 60-69	57
	36.5% 70-79	73
	28.8% 80-89	62
	3.7% 9 0-100+	8
	7% Missing Data	15
Latino Origin	1.5% Yes	3
	98.5% No	201
	5.1% Missing Data	11
Race	85.8% White	181
	13.5% Black	29
	.5% Asian/Pacific Islander	1
	1.9% Missing Data	4
Suspicion of Elder Abuse	17.8% Yes	34
	81.2% No	155
	12.0 % Missing Data	26

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Rasch Measurement Model

- Scaling properties of linear, interval measurement are used to establish item hierarchy and distances between items to support theory building and test construct validity. Used to test the theoretical hierarchy.

- Item hierarchy created by the item difficulty estimates provides an indication of construct validity, with low severity symptoms on the bottom and high severity symptoms on the top.

```
   MEASURE     PERSON - MAP - ITEM
                         |T REFRIG-E
                         |
      2                  +  COMBAT-B    PARASITE-E
                         |
                  .  |  HOARDMED-B
                  .  |  UTILOFF-E
                  .  |  ALCOHOL-B   COOKAPP-E   PERSINFO-B  SMOKE-B     TOILETS-E
                  . T|  PETCARE-E
                  .  |S INAPDRSS-B  MEDEQUIP-B
      1          .#  +  MEDOUTDT-B  POORFURN-E  TEMP-E
                 #   |  BADFOOD-E   DRUGABS-B   KITCHAPP-E  NOPHONE-E   VERBABS-B
                 #   |  WGHTLOSS-B
               .###  |  HEATCOOL-E
                .#   |  MALNOUR-B   NOACCESS-E  NOEXIT-E    SINKS-E
                 #   |  ASSTDEV-B   FECES-E     HELPSEEK-B
                ##   |  SMKDECT-E
      0        ### S+M VERMIN-E
              ####   |  MEALS-B     NOPCMD-B    SENSRIMP-B
              .###   |  LEGPROB-B   NOSEE-E
             .####   |  UNCOOP-B
             #####   |  AGITATE-B   BATHFAC-E   GARBAGE-E   MAIL-E
              .###   |  LIVCOND-E
             .####   |  HOARDING-E
     -1      .####   +  EMERCONT-B  FIRERISK-E  HISTMI-B    SAFEHAZ-E
           #######  |S CAUSEHRM-B  DRTYCLOT-B  MHPRBLEM-B  PERSHYG-B
           ##### M|  ODORS-E
             .###   |
             .###   |  IGNRSYMP-B
              .#    |  ISOLARIS-B  ISOLATED-B  NOPREVNT-B
           ######   |  ABILITY-B   HOMECOND-E  LACKCARE-B
     -2     .###   +
           ####   |  NOFLWTHR-B  NOSOCIAL-B
```

Findings

- ESNA is unidimensional
- 62 item measure produced
  - Rasch person reliability =.89, Alpha = .91
  - Cronbach's Alpha = .91
- Statistically significant (at .01) correlation with Illinois' Determination of Need assessment – Unmet Need Scale
- Confirms our two regions of meaning
  - ➢ Environmental Conditions
  - ➢ Behavioral Characteristics

ESNA Short Form

25 Item Short Form

- Selected items from across the hierarchy of the 62 item version
  - Unidimensional
  - Person reliability of .83
  - Cronbach's Alpha = .87

  62 item and 25 item correlation = .922

```
                    |T PARASITE-E
   1            XXX  +   TOILETS-E
                 XX  |   MEDOUTDT-B   TEMP-E
               XXXX  |   BADFOOD-E
               XXXX  |   SINKS-E
               XXXX  |   MALNOUR-B    NOACCESS-E
             XXXXXX  |   FECES-E
             XXXXXX  |   VERMIN-E
             XXXXXX  |   NOPCMD-B
             XXXXXX  |   UNCOOP_B
   0          XXXXX  +M
             XXXXXX  |   GARBAGE-E
             XXXXXX  |   BATHFAC-E
              XXXXX  |   FIRERISK-E   PERSHYG-B
                XXX  |   CAUSEHRM-B
              XXXXX M|   DRTYCLOT-B  ODORS-E
      XXXXXXXXXXX    |
              XXXXX  |S  IGNRSYMP-B
        XXXXXXXX     |
            XXXXXXX  |   ISOLARIS-B  NOPREVNT-B
               XXXX  |   HOMECOND-E
      XXXXXXXXXXX    |   LACKCARE-B
        XXXXXXXX     |   NOFLWTHR-B
  -1             XX  +
```

Item Endorsement

- All 215 people in our sample were assessed as exhibiting at least one indicator of Personal/Behavioral characteristics related to SN and one related to Environmental SN.

- Supports conclusion that ESNA is unidimensional. Although Behavioral items are lower on the scale, they form a hierarchy with Environmental items that tend to be higher.

- Strongly indicates need to assess both behavioral and environmental aspects of ESN.

Discussion

- Placement of SN indicators on the severity hierarchy suggests that behavioral indicators occur more frequently than environmental indicators, suggesting they tend to be more common but less severe.

- Hypothesis: Behavioral characteristics of ESN are precursors or risk factors for more severe environmental ESN.

- Early intervention with persons exhibiting SN associated with behavioral indicators could forestall later and more severe environmental harm.

Study Limitations

- Sample of 215

- Predominantly white

- Community-based sample, not clinical

- Sample limited to individuals assessed by Case Managers for eligibility for home/community based Medicaid waiver program in Illinois

Applications

- ESNA is appropriate for use by case managers, APS workers, clinicians, social workers, and researchers
  - ❖ ESNA is being used by the Chicago Area Agency on Aging's ICAS program (Intensive Case Advocacy and Support) with pre/post intervention assessments used to determine effectiveness of the intervention

- ESNA has been adapted as a neglect assessment as part of the Adult Abuse Decision Support System (AADSS) used in 6 APS agencies in Illinois as part of a demonstration project

DIRECTIONS: Please mark all responses with an X or use the space provided to enter a written response where applicable.

ID #: _____
Date of first contact: _____
Date of completion: _____

Has this client been assessed previously? ☐ Yes = 1 ☐ No = 2

Assessor's Information

Assessor (Last Name Only): _____

Title/Department: _____

Name of agency: _____

Is agency an Elder Abuse Provider Agency? ☐ Yes ☐ No

Is agency a Case Coordination Unit? ☐ Yes ☐ No

Demographics of Older Adult

Age of older adult: _____   Gender: ☐ Female ☐ Male ☐ Unknown

Address: _____

_____

Does the older adult own or rent his/her home or apartment?

☐ Owns   ☐ Rents   ☐ Someone else owns/rents

Is older adult of Hispanic / Latino origin?   ☐ Yes = 1   ☐ No = 2

Race or ethnicity?   *(If bi-racial, circle all that apply)*

☐ White = 1

☐ Black = 2

☐ American Indian / Alaskan Native = 3

☐ Asian/Pacific Islander = 4

☐ Don't Know / Refused = 5

☐ Other = 6   Please describe: _____

What language(s) are spoken, if not English? _____   Is an interpreter needed? ☐ Yes ☐ No

Risk Assessment

Is elder abuse also suspected?   ☐ Yes ☐ No

Please indicate the overall risk level for this older adult: ☐ High   ☐ Moderate   ☐ Low

Action

☐ Refer to elder abuse   ☐ Refer to Case Management ☐ Needs assistance but not case management

Elder Self Neglect Assessment (ESNA)

cJe SeniorLife ❀

Instructions: Please answer each question based upon your professional judgment, reports from the older adult directly, or from a 3rd party. Please complete the following sections as best you can, using currently available information. If you have questions about a specific diagnostic description of a mental illness, please refer to the Diagnostic Statistical Manual. There is a comment box at the end of each section. Please write your comments there, and indicate which question they relate to.

Note that items are arranged in order of severity, from low to high. Clustering of items at the low, middle or high end of the assessment should help you determine the overall severity of the self neglect.

ESN Rating Scale

Circle the appropriate number for each question. If completing this electronically, insert an X in front of the correct response.
1 = Yes 2 – No 3 – Suspected Problem (SusP) 4 = Don't know (DK) 5 = Not applicable (N/A)

No.	Elder Self Neglect Indicator	Yes	No	SusP	DK	N/A
1	Does older adult have a lack of follow-through with preventive or diagnostic testing related to health conditions?	☐	☐	☐	☐	☐
2	Does the condition of older adult's house, apartment or yard appear unsafe or unsanitary?	☐	☐	☐	☐	☐
3	Does older adult lack sufficient care to meet his/her needs?	☐	☐	☐	☐	☐
4	Does older adult fail to engage in adequate preventive practices (e.g., diet, exercise, smoking cessation)?	☐	☐	☐	☐	☐
5	Is older adult's isolation putting them at risk?	☐	☐	☐	☐	☐
6	Does older adult ignore signs and symptoms of disease?	☐	☐	☐	☐	☐
7	Are there odors in older adult's home that raise concerns (urine, feces garbage)?	☐	☐	☐	☐	☐
8	Does older adult wear dirty clothes?	☐	☐	☐	☐	☐
9	Does the older adult exhibit poor personal hygiene as evidenced by a noticeable odor, long and dirty fingernails, etc.?	☐	☐	☐	☐	☐
10	Are older adult's behaviors likely to cause him/her imminent physical harm?	☐	☐	☐	☐	☐
11	Is older adult's home at risk for fire hazards?	☐	☐	☐	☐	☐
12	Is older adult generally uncooperative?	☐	☐	☐	☐	☐
13	Does the older adult lack a primary care physician?	☐	☐	☐	☐	☐

No.	Elder Self Neglect Indicator	Yes	No	SusP	DK	N/A
14	Are the bathing facilities unsafe, unsanitary or inoperable?	☐	☐	☐	☐	☐
15	Is there an accumulation of garbage in older adult's house/apartment?	☐	☐	☐	☐	☐
16	Is there evidence of vermin (e.g. rodents or insects) in older adult's home?	☐	☐	☐	☐	☐
17	Is there human/animal feces/urine on the floors/walls in older adult's home?	☐	☐	☐	☐	☐
18	Does the older adult show signs of malnourishment or dehydration?	☐	☐	☐	☐	☐
19	Does older adult lack access to needed areas of the home (bathtub, sinks, bed)?	☐	☐	☐	☐	☐
20	Are the sinks in the older adult's home in poor or non-working condition?	☐	☐	☐	☐	☐
21	Is there evidence the older adult is eating spoiled food?	☐	☐	☐	☐	☐
22	Are the majority of the older adult's medications out of date?	☐	☐	☐	☐	☐
23	Is temperature in older adult's home not appropriate for summer/winter conditions? (If older adult is not responsible for the temperature of the home, please indicate this in the comment box at the end of the form.)	☐	☐	☐	☐	☐
24	Is the older adult's toilet not in working order?	☐	☐	☐	☐	☐
25	Does the older adult have lice or other parasites?	☐	☐	☐	☐	☐

Comments

Contact Information

Madelyn Iris, Ph.D.

micki.iris@cje.net

Kendon J. Conrad, Ph.D.

kjconrad@uic.edu

Publications

- Iris, M., Ridings, R., Conrad, K. The Development of a Conceptual Model for Understanding Elder Self-Neglect**. *The Gerontologist*. 2010; 50(3): 303-315

- Iris, M., Conrad, K.J. & Ridings, J. (2014). Observational measure of elder self-neglect. *Journal of Elder Abuse and Neglect* 26, 1-33.