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Exploring Self-neglect in Older Adults: Preliminary Findings of the Self-Neglect Severity Scale and Next Steps

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Abstract

Despite the public health implications of self-neglect, no tool exists for characterizing this condition. Self-neglecters often have no caregivers or surrogates to interview regarding the neglect, and are often too cognitively impaired to provide valid self-reports. In response to this need, researchers from the Consortium for Research in Elder Self-neglect of Texas (CREST), collaborated with other experts in the field of elder self-neglect to design the Self-neglect Severity Scale (SSS). The SSS assesses three domains of self-neglect: hygiene, functioning, and environment and relies on observational ratings assigned by trained observers. Following pilot testing and revision, the SSS was field tested in the homes of subjects who had been reported to and substantiated by Texas Adult Protective Services (APS) as self-neglecting, and compared to subjects recruited from a local geriatric clinic who were reported to APS and who had no history of self-neglect.

The first field test demonstrated that the SSS could distinguish elder self-neglecters from community dwellers that do not self-neglect. The SSS exhibited adequate scale reliability (Cronbach's alpha) and correlation with case status. Interrater reliability also appeared adequate although sensitivity and specificity fell below the conventional acceptable range. Future methods are proposed for refining the SSS to improve its use as the benchmark for identifying elder self-neglect.

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Keywords

screening; self-neglect; environment

BACKGROUND

Self-neglect

Aging potentiates the likelihood of a host of health related problems including multiple co-morbidities, loss of functional status, reduced life space and cognitive impairment. All of these increase vulnerability. Elders who self-neglect often live in squalor, suffer from untreated medical conditions, have multiple co-morbidities and are incapable of or refuse to provide themselves with basic care and protection¹. Consequently, these individuals experience an increased risk of early mortality when compared to community dwellers that do not self-neglect. As the current population ages and a greater number of individuals reach the age of 65 years and older, the prevalence of elder self-neglect is only expected to increase. Despite the severe public health implications of self-neglect, no standard assessment procedure or instrument exists for characterizing this condition.

Cataloging Elder Self-neglect

Like any important issue related to human health and survival, the time comes when accurate assessments are needed to determine the incidence and prevalence of a problem so that it can be addressed effectively. The demographic shift in the population endorses the need for a tool to detect elder self-neglect. Unfortunately, problems such as elder self-neglect that develop from multiple pathways often require comprehensive approaches for detection and prevention and thus provide numerous methodological challenges.

Currently, there are several tools that measure neglect of a person by others although these tools do not assess self-neglect. The current tools lack the precision to detect elder self-neglect because they mostly rely on reports by caregivers, surrogates, or victims themselves whereas persons who neglect themselves often have no caregivers or surrogates to provide collateral information. Moreover, cognitive impairment is prevalent among the elder self-neglecting population and thus individual self-report may not be accurate enough to accurately identify self-neglecting behavior. Also, many of these tools are standardized in an institutional setting such as hospital rooms and emergency rooms. These tools only provide objective data on the person's physical appearance at the time of assessment. Older persons, however, may neglect themselves in multiple ways that may not be discernible by physical examination or examination outside of the home environment.

Designing a Scale

Geriatric academicians, elder mistreatment experts and members from Texas Adult Protective Services (APS) collaborated to design a scale that would detect specific domains of self-neglect as well as the severity of neglect within each domain. This scale was designed specifically for the purpose of observing self-neglect in a home setting. Development began in 2002 when the group developed the concept for such an instrument and structured interviews were also completed with 25 APS professionals throughout the Houston metropolitan area who were trained to detect elder self-neglect.² From this initial work, three domains of self-neglect indicators were identified:

1. Personal Hygiene — Dirty hair and clothing, poor condition of nails and skin;
2. Impaired Function — Decline in cognitive function and activity of daily living, as measured by one or more short-form tests

3. Environment Neglect — Visual evidence of subject's inability to make necessary household repairs, clean the household and yard, as well as manage the material goods acquired over the years.

The impaired function domain was noted by the APS professionals to be particularly important in influencing their decision to classify a case as self-neglect.

Developing the Self-neglect Severity Scale (SSS)

Drawing upon this initial work, an item pool was developed and circulated to an expert panel consisting of three APS administrators, a civil attorney with expertise in elder mistreatment, an epidemiologist, a psychologist, and a geriatrician.³ In addition to agreeing with the three domains listed above, the expert panel members cited failure to maintain adequate nutritional status, lack of use of medical care and medications, and failure to maintain utilities as important indicators of self-neglect. Next, a subsequent research workgroup, consisting of an epidemiologist, clinicians who frequently care for elders who self-neglect, and APS workers convened to revise the items and assemble the initial version of the SSS.

A psychometrician joined the research team, and a pilot study of the SSS was begun. A "field team" consisting of a nurse practitioner and a research assistant was charged with administering the SSS in the field. These highly qualified individuals completed over 24 hours of extensive training which included field safety training, subject comfort training, and data accuracy training prior to starting the pilot study. In particular, for this portion of the pilot study, pre-testing and training to ensure interrater reliability were stressed since the SSS is based heavily on observation. Therefore, field team members were trained by the psychometrician and PI of the project on what to assess in the field and how to judge what they assessed. This training was facilitated by having the field team members complete the SSS at the homes of 14 volunteers prior to the pilot study. The psychometrician accompanied the field team on several of these home visits to ensure proper administration of the tool. During the actual funded pilot study, both field team members completed the SSS for the first 15 subjects enrolled and every tenth subject thereafter, for a total of 23 subjects. The SSS was scored by a single evaluator on the remainder of the study participants. The psychometrician used these data to assess interrater reliability and also to provide periodic performance feedback and suggestions to the field team members. The details of this initial phase are described in detail in another manuscript.³

Preliminary Findings

The initial version of the SSS consisted of 50 items; removal of redundant items during the pilot study reduced this number to 37. Most items are scored either on a 0 – 4 scale, with "0" meaning "no problem" to "4" meaning "among the worst I've ever seen," or dichotomously as "0" or "4". "N/A," for "not applicable," is also an option. Most items on the SSS are completed by direct observation, except for the items in the impaired function domain. These items are scored with inputs from the ¹Wolf-Klein Clock Test⁴, the APS data extraction sheet (a comprehensive social history form), and a physical examination of the subject. One item requires a verbal response from the subject. A global, 0 – 10 scale "overall risk assessment" item is also included. Lastly, three individual domain summation scores and a composite summation score are calculated and recorded on the SSS. Table 1 lists the items, domains, scoring scale and source of each SSS item.

¹The Wolf-Klein clock test was completed as part of the in-home Comprehensive Geriatric Assessment. It is a 10-point easily administered evaluative tool which screens for dysfunction in the area of spatial orientation associated with Alzheimer's Disease. Scores >6 are considered within the normal functioning range. Normal clock test scores contributed a 0 to the SSS and abnormal scores contributed a 4 to the SSS for each individual.

To date, the SSS has empirically exhibited several key strengths. First, at the group level the SSS distinguished APS cases from geriatric comparison subjects on all three domains plus the composite score. The mean score differences are positive, large and statistically significant; however, the clinical interpretation of these differences across groups has yet to be determined. Importantly, the existence of these group-wise mean score differences in SSS scores does not necessarily translate to good differentiation at the individual level (i.e., sensitivity and specificity of the tool, discussed below). Correlations of SSS domain and composite scores with case status were also statistically significant, although moderate in size. Internal consistency, as expressed by coefficient Alpha, is acceptable for the environment domain and the composite score. The sensitivity and specificity for the scale fell below the conventional range of acceptability using most cut scores. However, when using a cut score of 4 in each domain, the sensitivity reached a level of .86. Lastly, interrater reliability appeared high, indicating that the field team members tended to assign the same score for a given item and subject.

Proposed Methods for Subsequent Study

Proposed Research Goals—The primary goal is to reduce the number of items on the SSS, if possible, to create a more feasible and time efficient scale. This revised scale should maintain or improve upon the psychometric properties of the current scale, such as the sensitivity and specificity ranges, the interrater reliability, face validity, and construct validity for detecting elder self-neglect. This goal will be achieved by re-assessing the new reduced SSS scale in a valid population of elders who self-neglect.

Proposed Recruitment—The population that will be used to re-assess the SSS will be community-dwelling individuals 65 years of age or older who have been identified by APS as substantiated cases of elder self-neglect. Each individual will be referred to the research team by APS caseworkers and will meet specific inclusion criteria used in previous successful studies of elder self-neglect. Accordingly, each individual will undergo an Institutional Review Board approved consent procedure. A group of design-matched elders who do not self-neglect will also be enrolled as the comparison group. They will be subjected to the same enrollment and consent criteria.

Proposed Procedures—Similar to the pilot study, the reduced SSS will be performed by two independent raters who will complete the scale at the participant's home. The two rater's scores will be stored separately. The SSS will be completed by both raters on 30 self-neglect participants, and 30 comparisons who do not self-neglect. This will provide sufficient data to determine the new scales psychometric values.

Proposed Statistical Analyses—The SSS will be assessed for its psychometric properties using a variety of statistical techniques. Similar to previous techniques, the raters' observations will be considered "in agreement" when they both provide a score of 4 for the same participant in the same domain. Inter-rater reliability will be assessed using this strategy and the significance will be determined using the chance adjusted Kappa statistic. Contingency tables will be produced to provide a classification table so that sensitivity and specificity calculations can be performed. Internal-item consistency will be determined using the Alpha coefficient.

DISCUSSION

Limitations of the Proposed Study

There are a number of limitations to the SSS that remain unresolved; the three of the most prominent were presented here. First, the score correlations among the three domains of the

SSS were low. Interpretation of this finding is impeded by the fact that the research team has not yet determined whether the three domains are independent or interdependent from a theoretical standpoint. If, as the clinicians on the research team believe, the domains are independent, one would expect score correlations among the domains to be low. Alternatively, if the domains are interdependent (and consequently, summing them to obtain a composite score made sense), high, or at least medium, score correlations among domains would be expected. In such a case, low correlations may mean that the SSS as presently designed misperforms in measuring the three domains. As work with the SSS moves forward, the research team must address this important measurement issue.

Second, a common practice in “diagnosing” misperformance of an instrument is to examine the effect on coefficient Alpha when a given item is deleted from the instrument. Typically, during the early development of an instrument, one expects to find a number of items that empirically improve internal consistency of the instrument by being removed. Because the initial item pool is usually much larger than the anticipated final instrument, some items are simply not as “good” as others for assessing the condition. Therefore, some degree of item culling is normal. However, only a few SSS items produced change in coefficient Alpha upon their removal, and of these, only the Wolf-Klein Clock score produced an appreciable change. In short, little empirical evidence exists to show that deleting items from the existing version of the SSS would improve its performance.

Third, sensitivity and specificity of the SSS to the presence of self-neglect did not fall within the conventional range of acceptability of 0.80 – 0.90. Since no a priori cut score for the SSS has yet been determined, sensitivity and specificity were modeled for hypothetical cut scores of 2, 4, 8 and 10 on the composite score scale. None of these hypothetical cut scores exhibited sensitivity and specificity within the range of 0.80 – 0.90. The sensitivity and specificity closest to this acceptable range were produced from a cut score of composite score = 4 (0.86 and 0.53, respectively). Further study of sensitivity and specificity will be necessary in order to develop the SSS for use as a screening tool. For example, it is possible that individual domains require different cut scores, or that application of a domain-weighting factor may be necessary for generating the composite score.

An underlying cause for the current limitations of the SSS is that an overall sparseness of item scores other than “0” is seen. In particular, few scores of “3” or “4” were recorded on any item except items “Wolf-Klein Clock Score;” “Response to Emergency;” “Untreated Conditions;” and, “Clutter in the Bedroom”. The disproportion of “3”s and “4”s for these items was statistically significant ($p = .001$). Moreover, no apparent pattern of 4s — or any other scores — was observed across cases or comparison subjects. One plausible reason for the lack of reporting 3’s and 4’s by the observers is because severe self-neglecters are known to refuse any type of outside interference and thus, the most extreme self-neglecters may not be represented in the pilot study.

Significance

It is the belief of the researchers that there is an unequivocal need for the kind of tool that the SSS represents. The development of a tool that performs well in identifying elder self-neglect in the home setting has tremendous implications. For instance, this measure will advance the epidemiological approach to this public health problem by facilitating incidence and prevalence studies. Clinical trials aimed at prevention and intervention will have a quantifiable and evaluative outcome measure. Moreover, vulnerable persons suffering from the self-neglect syndrome will be more readily identified and possibly at an earlier juncture, thus potentially increasing the chance of successful remediation and ultimately reducing the risk of early mortality.

Summary

So far, this team has developed a tool that correlates adequately with case status, which seems face-valid to professionals who perform these assessments, and that exhibits adequate internal consistency in most of its domains. As the researchers further develop the SSS, a number of key issues must be addressed. First, the number of items must be reduced in order to make the SSS practical for field use. Second, the researchers must decide whether the SSS should be strictly an observation-based tool or whether administering additional formal tests such as the Kohlman Evaluation of Living Skills⁶, asking the subject questions, and reviewing APS medical data on the subject should continue to be included. Third, the researchers must determine, and support with theory, whether indication of self-neglect is to be based on individual domain scores, the composite score, or both. The clinicians on the research team believe that extremely poor performance on any one domain should be enough to indicate self-neglect. However, since no theoretical basis for dividing items into three domains has been established to date, the domain structure serves essentially as an organizer: the field team completes the personal hygiene items as a set, then the cognitive function items as a set, and then the environmental items as a set.

Fourth, SSS scores should be examined after adjustment for the Mini-mental State Exam (MMSE)⁷ score to determine the impact that cognitive impairment has on the performance of the SSS. Fifth, the longitudinal measurement properties of the SSS should be assessed. There is a presumption that, as a subject's self-neglect progresses without intervention, the SSS score for that subject would increase over time accordingly. Alternatively, self-neglect may plateau over time. A longitudinal study would be the best way to assess this aspect of the instrument.

Lastly, and most importantly, the researchers must expand the test population to include the most severe APS cases. If one imagines the variability of severity of self-neglect cases as falling on a scale akin to the light spectrum, the SSS has been utilized to date with cases from the infrared end of the spectrum to the region of yellow or green, roughly the middle of the spectrum. In future work, the SSS must be employed with cases from the blue to violet region of the spectrum, metaphorically the more severe cases. Failure to include the most severe (or even somewhat severe) cases in further development of the SSS will undermine the validity of the instrument. Obtaining access to such cases is, of course, difficult, and therefore, a major focus should be to find strategies for accessing these cases more effectively and including these subjects in future research.

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Appendix

Self-neglect Severity Scale (without photos)

SECTION A

SECTION A							
Personal Appearance of Subject (Circle number that reflects severity of condition)					Not Assessed, Unable to Determine	Procedure	
Hair	Clean, Combed		Matted, Dirty			☐	Look at front and back of head. If the subject is bald then mark unable to determine.
	0	1	2	3	4		

Personal Appearance of Subject (Circle number that reflects severity of condition)					Not Assessed, Unable to Determine	Procedure
Nails	Clean, Trimmed		Long, Untrimmed, Dirty		☐	Look at hands and feet if possible.
	0	1	2	3	4	

Personal Appearance of Subject (Circle number that reflects severity of condition)					Not Assessed, Unable to Determine	Procedure
Skin	Normal/No sores Or injuries		Multiple or severe open pressure ulcers or other injuries		☐	First check what's visible, Nurse Practitioner to point out skin lesions during exam.
	0	1	2	3	4	

Personal Appearance of Subject (Circle number that reflects severity of condition)					Not Assessed, Unable to Determine	Procedure	
Clothing	Clean, Neat				Very Soiled	☐	Examine just the clothes the subject is wearing.
	0	1	2	3	4		

Personal Appearance of Subject (Circle number that reflects severity of condition)						Not Assessed, Unable to Determine	Procedure
Insect Infestation	No Apparent Infestations	Fleas	Lice or Scabies	Maggots	Multiple Infestations	☐	Assess subject for any number or combination of these infestations.
	0	1	2	3	4		

SECTION B

Functional Status of Subject			Not Assessed, Unable to Determine	Procedure
Mental Status				
Cognitive test performance (if measured)	Clock Drawing Test Score _____	WK Clock Score: 1-6= 4 7-10= 0	☐	Obtain score from assessment protocol.
Evidence of delusional state	☐ Yes (4) ☐ No (0)		☐	If client speaks to people not present, seems overly paranoid about imagined risks & problems, or reports hallucinations of auditory and or visual type signals delusion.
Response to emergency	☐ Subject demonstrates ability to call for help "if he/she is in danger" (0) ☐ Subject is unable to respond appropriately to emergencies (4)		☐	Obtain from KELS

Functional Status of Subject						Not Assessed, Unable to Determine	Procedure
Medical Need							
Has usual source of care	☐ Yes (name of usual provider can be documented from medical bills, prescriptions, or other written records (0)) ☐ No (No documentation of health care provider available (4))					☐	Obtain from data abstraction sheet
Time since last visit to physician	0–3 mths 0	6 mths 1	12 mths 2	18 mths 3	24mths & up 4	☐	Ask the subject and look for documentation.
Untreated conditions	☐ Yes (Subject reports pain/discomfort or other health complaints that need attention) ☐ Yes (Subject denies medical problems, but appears ill and/or in pain) ☐ No					☐	Obtain from physical exam.
Functional Status Score							

SECTION C

Environment Status of Subject (Circle number that reflects severity of condition)						Not Assessed, Unable to Determine	Procedure
Exterior Condition	Neat, Well Kept No trash or other Debris		Poorly Maintained Trash and/or other Debris			☐	Assess the front and back yard including the entrances to the home.
Yard/ Sidewalk	0	1	2	3	4		

Environment Status of Subject (Circle number that reflects severity of condition)						Not Assessed, Unable to Determine	Procedure
Exterior Condition	Intact, No Structural Damage		Dilapidated, Poorly Maintained, Holes etc			☐	Assess the roof of the home.
Roof	0	1	2	3	4		

Environment Status of Subject (Circle number that reflects severity of condition)						Not Assessed, Unable to Determine	Procedure
Exterior Condition	Intact, Not Broken Or Missing		Multiple Sections Broken or Missing			☐	Assess the windows on the perimeter of the home.
Windows	0	1	2	3	4		

Environment Status of Subject (Circle number that reflects severity of condition)						Not Assessed, Unable to Determine	Procedure
Exterior Condition	Intact, No Structural Damage		Dilapidated, Fallen or Missing			☐	Assess all the walls on the perimeter of the home
Walls	0	1	2	3	4		

Environment Status of Subject (Circle number that reflects severity of condition)						Not Assessed, Unable to Determine	Procedure
Interior Condition	Normal Household Odors		Pungent unpleasant odor (may be mixture of human or animal waste, Rotting food etc.)			☐	Assess the odor of the house.
Odor	0	1	2	3	4		

Environment Status of Subject (Circle number that reflects severity of condition)						Not Assessed, Unable to Determine	Procedure
Interior Condition	Clean, No evidence of unsanitary conditions		Very dirty, Unwashed dishes, trash, litter			☐	Assess the four following areas:
Cleanliness	0	1	2	3	4		☐ Kitchen _____ ☐ Bathroom _____ ☐ Bedroom _____ ☐ Living room _____

Environment Status of Subject (Circle number that reflects severity of condition)		Not Assessed, Unable to Determine	Procedure
Interior Condition	Neat, Orderly	☐	Assess the following four areas: ☐ Kitchen _____ ☐ Bathroom _____ ☐ Bedroom _____ ☐ Living room _____
Clutter	Very cluttered, Difficult to move around or find things		
	0 1 2 3 4		

Environment Status of Subject (Circle number that reflects severity of condition)		Not Assessed, Unable to Determine	Procedure
Interior Condition	No structural Problems	☐	Assess the four following areas: ☐ Kitchen _____ ☐ Bathroom _____ ☐ Bedroom _____ ☐ Living room _____
Structure	Severe structural damage (e.g. holes in sheet-rock or floor, leaking ceiling)		
	0 1 2 3 4		

Environment Status of Subject (Circle number that reflects severity of condition)		Not Assessed, Unable to Determine	Procedure
Multiple Pets	0 – 3 dogs 1-2 uncared for animals 3-4 uncared for animals 5-6 uncared for animals 6 or more uncared for animals	☐	Assess the overall number of animals and their conditions for indications of malnourishment, matted hair, excessive fleas, and untreated wounds.
	0 1 2 3 4		
Total Number of Pets:

Note: If interested in receiving a full copy of the SSS, please contact the authors.

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Table 1

Self-Neglect Severity Scale (SSS), revised item set (37 Items).

Variable Name	Domain	Scoring Scale	Source
A1 — Hair	Hygiene	0-4 plus N/A	Rater Observation
A2 — Nails	Hygiene	0-4 plus N/A	Rater Observation
A3 — Skin	Hygiene	0-4 plus N/A	Rater Observation
A4 — Clothing	Hygiene	0-4 plus N/A	Rater Observation
A5 - Insect Infestation	Hygiene	0-4 plus N/A	Rater Observation
Clock Test Score	Functioning	Raw Score	Clock Test in Protocol
B1 - WK Clock Score	Functioning	dichotomous 4 or 0 plus N/A	Rater, from Clock Test Score
B2 - Evidence of Delusional State	Functioning	dichotomous 4 or 0 plus N/A	Rater Observation
B3 - Response to Emergency	Functioning	dichotomous 4 or 0 plus N/A	KELS in Protocol
B4 — Usual Source of Care	Functioning	dichotomous 4 or 0 plus N/A	Data Abstraction Sheet
B5 - Time Since Last MD Visit	Functioning	0-4 plus N/A	Rater Asking Subject
B6 - Untreated Conditions	Functioning	0-4 plus N/A	Physical Examination
C1_1 - Condition of Exterior - Yard	Environment	0-4 plus N/A	Rater Observation
C1_2 - Condition of Exterior - Roof	Environment	0-4 plus N/A	Rater Observation
C1_3 - Condition of Exterior - Windows	Environment	0-4 plus N/A	Rater Observation
C1_4 - Condition of Exterior - Walls	Environment	0-4 plus N/A	Rater Observation
C2 - Interior Odor	Environment	0-4 plus N/A	Rater Observation
C3_1 - Cleanliness, Kitchen	Environment	0-4	Rater Observation
C3_2 - Cleanliness, Bathroom	Environment	0-4	Rater Observation
C3_3 - Cleanliness, Bedroom	Environment	0-4	Rater Observation
C3_4 - Cleanliness, Living Room	Environment	0-4	Rater Observation
C4_1 - Clutter, Kitchen	Environment	0-4	Rater Observation
C4_2 - Clutter, Bathroom	Environment	0-4	Rater Observation
C4_3 - Clutter, Bedroom	Environment	0-4	Rater Observation
C4_4 - Clutter, Living Room	Environment	0-4	Rater Observation
C5_1 - Structure, Kitchen	Environment	0-4	Rater Observation
C5_2 - Structure, Bathroom	Environment	0-4	Rater Observation
C5_3 - Structure, Bedroom	Environment	0-4	Rater Observation
C5_4 - Structure, Living Room	Environment	0-4	Rater Observation
C6 - Condition of Pets	Environment	0-4 plus N/A	Rater Observation
C7 — Utilities	Environment	0-4 plus N/A	Rater Observation
Overall Risk Assessment	N/A	0-10 plus N/A	Rater Observation
Hygiene Domain Score	Hygiene	Summation Score	Rater, from Domain Items
Functioning Domain Score	Functioning	Summation Score	Rater, from Domain Items
Environment Domain Score	Environment	Summation Score	Rater, from Domain Items
Composite Score	N/A	Summation Score	Rater, from Domain Scores