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Assessing Capacity in the Setting of Self-Neglect:

Development of a novel screening tool for decision making capacity

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Summary

Compared to older adults with disabilities and those who autonomously choose to live in squalor; self-neglect syndrome arises from a predicate state of vulnerability in frail older adults. This state of vulnerability is characteristically associated with a decline in decision-making capacity regarding the ability to care for and protect oneself. We developed the COMP Screen to evaluate vulnerable older adults to identify potential gaps in decision-making capacity using a screening tool. A total of 182 older adults were evaluated and consistent declines in cognitive ability and decision-making processes were present in this population. However, there were no significant differences between elders referred for self-neglect and matched older adults. These findings suggest that declines in decision-making processes are not uncommon in vulnerable older adults but traditional conceptualizations of decision-making capacity may be inadequate for differentiating the capacity for self care and protection in elders who self-neglect.

Keywords

Self-Neglect; Capacity; Decision-making; Self Care and Protection

Introduction

As persons age, they face a variety of functional, psychological, and physical challenges. The cumulative burden of these ailments can adversely affect the ability to live safely and independently. Without appropriate social and clinical supports, vulnerable older adults are at-risk for the geriatric syndrome of self-neglect (Pavlou & Lachs, 2006). Self-neglect can be defined as the failure to 1) engage in self-care acts which adequately regulate independent living or 2) take actions to prevent conditions or situations which adversely affect the health and safety of oneself or others (Clark, Mankikar, & Gray, 1975; Lauder, 2001; Orem, 1995). Thus, a predicate state of vulnerability from diminished ability to care for and protect oneself may be a common denominator among various clinical phenotypes of self-neglect (Dyer et al., 2006).

The unique aspect of elder self-neglect is that the predicate state of vulnerability often manifests as an inability and/or unwillingness to access potentially remedial services (Pavlou & Lachs, 2006). In the context of self-neglect; social services professionals, e.g. Adult Protective Services (APS), usually intervene if a vulnerable adult lacks decision-making capacity. APS professionals, in turn, must therefore be equipped to render judgments about decision-making capacity on a regular basis and for a variety of decision-making scenarios. Failure to accurately assess capacity may result in at least two adverse outcomes. First, overestimating an individual's decision-making capacity may cause persons to be left in harmful environments without appropriate resources. On the other hand, underestimating an individual's capacity may inadvertently limit a person's rights when, in fact, his or her decision-making ability remains preserved. In healthcare settings, clinicians may consult experts to determine capacity prior to the rendering of care. For APS professionals in the field, this expertise is not available. Instead, they must assess clients in the absence of valid and reliable methods for measuring decision-making capacity, and without the formalized training needed to perform these crucial evaluations. As a consequence, there is an over reliance on unverified verbal claims in the evaluation of older adults. This unfortunately has been a key source of criticism regarding capacity assessments from clinicians and ethicists (Agich, 1993; Collopy, 1988; Lidz, Fischer, & Arnold, 1992; Strang, Molloy, & Harrison, 1998).

Frontline clinical and social service providers (APS professional, paramedic, police officer, social worker, home health care nurse, etc.) who evaluate older adults in non-clinical settings need valid and reliable tools that screen capacity in vulnerable older adults. To be consistent with and implement the legal presumption of competence, a positive screening test result should not be understood as definitive evidence that a client has significant, irreversible loss of capacity, but rather as providing reliable clinical grounds for seeking a more in-depth assessment of capacity. Screening tools do not provide diagnoses, and formal evaluation by trained clinicians with appropriate training and experience in capacity assessment should occur as a consequence of a positive screening test. Screening tools do, however, provide justification for further work-up of a vulnerable elder's condition. If the older adult is judged to have intact capacity, he or she then

participates in the informed consent process to authorize or refuse further clinical evaluation and management.

To address this important clinical and public health need, we developed the COMP Screen, a pilot instrument to screen for decision-making capacity in the context of self-neglect. The COMP Screen is a concise 4-item tool that was designed for use in the field by clinical and social services professionals. The current study was designed to evaluate the decision-making abilities, using the COMP Screen, of two known groups: 1) older adults referred by a State Adult Protective Services agency for self-neglect (using state mandated criteria) and 2) matched comparison group of older adults seen in a geriatrics clinic. A secondary analysis included an examination of the participants' comprehension of each of the four items in the screening tool and their willingness to complete them. Lastly, this study evaluated the feasibility of the use of the COMP screen in the field, integrated with a battery of comprehensive home-based assessments.

Methods

Study Population

The study sample consisted of a portion of the participants from the Consortium for Research in Elder Self Neglect of Texas (CREST) pilot study. The complete pilot study consists of 100 older adults reported to Adult Protective Services (APS) Region VI of Harris County in Houston, Texas and designated as having "self-neglect" syndrome and an additional 100 older adults recruited from the geriatrics clinic at the Harris County Hospital District. In Texas, the definition of self-neglect is mandated in Probate Law as, "the failure to provide for one's self the goods or services, including medical services, which are necessary to avoid physical or emotional harm or pain or the failure of a caretaker to provide the goods or services ("Texas Probate," 1993). APS professionals translate this statute into three distinct types of self-neglect allegations: medical, physical, and mental health. Medical and mental health neglect both include the failure to provide for or obtain medical (or mental health) care or needs (e.g., lack of medications, inappropriate medical self-care, or failure to seek appropriate medical care). Physical neglect is the failure to provide goods or services that may be vital to one's health and well-being, including the lack of material items, care services, or inappropriate financial management.

Vulnerable elders who meet one or more of the APS criteria for self-neglect and who voluntarily released their names to the CREST research team were approached. Prior to obtaining consent, the research team ensured that each potential participant meet the following inclusion criteria: (1) Substantiated case of self-neglect, (2) 65 years of age and older, (3) English speaking, and (4) residents of Harris County, Texas. The study participants were contacted by telephone to schedule a home visit. While at the participant's home, a consent form was administered according to a preset protocol where the document is read in its entirety and then the clients are required to state the purpose of the study including the risks and benefits of the study prior to signing the consent form. All study participants were given a copy of the consent form. The comparison group was recruited from the Baylor College of Medicine Geriatrics Program at the Harris County Hospital District and matched to the self-neglect group by age, race, gender, and zip

code (as a measure of socioeconomic status). Potential comparison group participants were contacted by telephone to schedule a home visit. Consent to participate involved the same procedures as performed for participants referred by APS and the identical battery of assessments was performed.

Study Design and Procedures

The current study is a cross-sectional analysis of CREST pilot participants enrolled between March 2005 and June 2006. Prior to enrollment, Institutional Review Board approval was obtained from Baylor College of Medicine and Harris County Hospital District in Houston, Texas. The research team conducted a comprehensive geriatric assessment on all study participants including some of the following tools: physical examination, social and medical history, Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975), Activities of Daily Living Efficacy scale (Reid, Williams, & Gill, 2003), Physical Performance Test (Reuben, Greendale, & Harrison, 1995), Kohlman Evaluation of Living Skills (Kohlman-Thomson, 1992), and the 15-Item Geriatric Depression Scale (Yesavage et al., 1982). All assessments were conducted in the client's home by a geriatric nurse practitioner and research assistant trained in the appropriate methodology for each of the assessment test. Statistical comparisons between the self-neglect cases and the comparison group were made using chi-square tests and Student's T-tests. Significant differences are reported using 2 sided P-values.

The COMP Screen

Assessments of capacity are not universal and should be circumscribed to particular domains of judgment or ability. In the setting of self-neglect, this would involve the capacity to make decisions relevant to safe and independent living. Even within a single domain, capacity is typically defined by an array of standards. Assessments of capacity, therefore, involve measurements of one or more of these standards. One widely cited set of standards (Grisso & Appelbaum, 1998) describe the necessary components of capacity as the abilities to *comprehend* information relevant to treatment decision-making, *appreciate* the significance of that information for one's own situation, have a *rational process* of comparing the outcomes of different alternatives, and the ability to *articulate* a single choice (Appelbaum & Grisso, 1988). Marson and colleagues based their legal standards in part on these classic standards and have used a series of standard neuropsychological tests to assess capacity for decision-making in patients with dementia (Marson, Cody, Ingram, & Harrell, 1995). Building from this conceptual foundation, our team designed the COMP Screen to address the domains of capacity for making decisions regarding one's safe and independent living. The COMP screen tests three cognitive domains that assess an older adult's ability to *comprehend* information: attention, expressive language, and delayed recall. A fourth conceptual domain, awareness, tests the *rational process* of comparing different alternatives and *articulating* a single choice using a standardized case scenario requiring the subject to evaluate a medical problem, consider two options for handling that problem and make one definitive choice.

We used the acronym COMP to serve as a mnemonic to help field personnel remember the components of the instrument (see Figure 1). The COMP Screen was designed to take 10 minutes to administer with dichotomous

(pass/fail) scoring for each of the four measurement items. The domain of attention was assessed by asking the patient to count forward from 1 to 20 then backwards from 20 to 1 in twenty seconds. Language is assessed by asking the subject to identify three common items that the questioner can point to in the room (e.g., watch, lamp, and pen). The third domain of delayed recall would be tested by asking the participant to repeat three standard items and after question 4 to recall the three items again. To test awareness, the team developed a sample scenario involving the case of a 68 year-old patient with abdominal pain and fever:

A 68 year-old man (or woman) complains of pain near his (her) belly button. Several hours later he (she) notes that the pain has moved into the lower right abdomen. The pain continues for six hours and his (her) spouse becomes concerned and calls 911. The paramedics arrive and evaluate him (her). They suspect that he (she) might have appendicitis. They request to take him (her) to the hospital for possible surgery. He (She) wants to know the risks and benefits of going to the hospital.

Study subjects were asked to give the potential risks and benefits of going to the hospital in the sample scenario. In order to pass this portion of the COMP Screen, subjects would have to articulate the potential risks of not seeking treatment, the potential risks of seeking treatment, and articulate one clear choice based on a weighing of those risks. A medical scenario was chosen to evaluate judgment in the context of self care and self protection. All three elements are required for a passing score, based on a dichotomous assessment of each item. A neuropsychologist, experienced in teaching these methods, trained the members of our research team to conduct the COMP screen in a standardized manner.

Results

The characteristics of the study population are described in Table 1. Over 90% (182 of 200) of the planned enrollment of the CREST pilot study is included in the current study. The matching process was appropriate as there are no significant differences between the self-neglect cases and the comparison group for the four baseline demographic characteristics. Most participants were female, non-white, seventy to eighty years old, had some high school education, and an income less than \$1000 per month.

There were significant differences in other baseline characteristics and among some of the tests included in the comprehensive geriatric assessment. Elders who self-neglect were significantly more likely to live alone and take fewer medications. Cognitive impairment, defined as an MMSE score < 24, was not more common among self-neglect cases. However, depression and functional impairment were both more likely to be present among the self-neglect cases.

COMP Screen Findings

The results of the COMP Screen tests are presented in Table 2 and stratified by elder self-neglect cases and the comparison group of older adults. No significant differences were found between the two groups for each of the four test domains. For both the attention and language domains, the pass rate was at or above 90% for both groups. For the delayed recall domain,

55% of self-neglect cases compared to 45% of the comparison group failed the test item ($p=0.26$). The percentage of failing scores for the awareness domain, using the *a priori* passing score of 3 of 3 criteria, was nearly identical between the two groups (57% versus 60%).

Additional results for the awareness domain are presented in the bottom portion of table 2. Using a modified passing score of 2 out of 3 criteria, there was a small non-significant difference in the percentage of failing scores between self-neglect cases and the comparison group (13% versus 6%, $p=0.12$). The criterion asking participants to cite the risks of accepting treatment had the highest failure rate in both groups (55% and 59%). The other two criteria demonstrated failing scores of <15% for both groups.

The COMP Screen was easily integrated among the battery of tests included in the comprehensive geriatric assessment. Research study personnel reported no significant difficulty conducting each of the test items. Over 98% of all study subjects completed each of the fourth items in the COMP Screen and all but one in each group completed the awareness domain.

Discussion

As part of the Consortium for Research in Elder Self-Neglect of Texas (CREST), the current study attempted to assess the known groups validity of the COMP Screen between older adults referred by APS for self-neglect and a comparison group of older adults cared for in a community based geriatrics clinic. The results of the current study demonstrate that clinicians can use the COMP Screen as part of a comprehensive battery of geriatric assessment tests and vulnerable older adults can respond to each of the items of the screening tool without significant difficulty. Unfortunately, the findings of the current study do not support the validity of the COMP Screen as a screening tool for decision-making capacity in the setting of self-neglect. There were no significant differences in the scores of any of the four items between cases of self-neglect and the comparison group of older adults. Furthermore, the items for the attention and language domain may represent a measurement ceiling given the exceptionally high rate of passing scores for both groups. The scores for the delayed recall and awareness domains offer a more robust distribution across the total population but without significant intergroup differences.

There are several potential reasons for the findings of the current study. First, it is possible that a diminished decision-making capacity is not a distinguishing feature of self-neglect among older adults. The behaviors of elders who self-neglect, however, are distinct from adults with disabilities and those who refuse to conform to social norms. Autonomous nonconformers acknowledge their refusal to live by community norms of health and hygiene and their actions are consistent with those choices (Agich, 1993). Adults with significant disabilities are often unable to fulfill their health and social needs, but actively seek and receive clinical interventions and social support to maintain a robust standard of health and safety (Collopy, 1988). In both cases, individuals make autonomous choices and perform actions in accordance with their decisions, despite eccentric preferences or physical limitations. In contrast, the actions of older adults who self-neglect do not appear consistent with the decisions they make,

bolstering the hypothesis that underlying deficits with the decision-making process are characteristic of this condition.

Second, the negative results may suggest that the items of the COMP Screen do not accurately measure the conceptual standards of decision-making capacity. Although the COMP screen evaluates abilities related to comprehension, reasoning, and articulating a choice, it does not consider a person's ability to *appreciate* (Appelbaum & Grisso, 1988; Marson et al., 1995) — the ability to recognize how a problem pertains to him or herself. The omission of the *appreciation* standard may be noteworthy given the nearly universal concordance of this standard as a key component of decision-making capacity among experts (Volicer & Ganzini, 2003), and its importance in interpreting how patients weigh the risks and benefits of a choice. The fact that a patient is able to simply state the risks and benefits of an intervention does not necessarily mean that he or she believes they apply to their own situation. The COMP screen is limited in this regard, as the case scenario used in the instrument is hypothetical.

The third and more likely explanation is that the capacity to make decisions is a constituent but insufficient element of the predicate state of vulnerability in older adults who self-neglect. Self-neglect is defined as the failure to 1) engage in self-care acts which adequately regulate independent living or 2) take actions to prevent conditions or situations which adversely affect the health and safety of oneself or others (Clark et al., 1975; Lauder, 2001; Orem, 1995). The predicate state of vulnerability in at-risk older adults arises from diminished capacity to care for and protect oneself (Dyer et al., 2006). Consistent with the legal requirements for guardianship in most State Probate courts ("Texas Probate," 1993), the conceptualization of capacity as the ability to make and effect decisions regarding one's self care and protection is the more appropriate standard for capacity in the setting of self-neglect.

As evidenced by the results of the current study, many older adults who self-neglect can fulfill the criteria for making some informed decisions about their health, but characteristically do not perform the actions necessary for implementing their choices (Lai & Karlawish, 2006). Unlike those with disabilities, they often cannot utilize or even refuse necessary assistance and supports. In contrast to non-conformists, their actions are typically not consistent with their stated preferences, goals, or intentions. Elder self-neglect creates the conceptual challenge for clinicians and social services of recognizing that older adults who self-neglect lack the capacity to make decisions (decisional capacity) *and* the capacity to execute decisions regarding their health, safety and independent living (executive capacity) (Collopy, 1988; McCullough, et al. 2001). Future research is needed to better understand deficits in decisional and executive capacity as they manifest in the safe and independent living of vulnerable older adults. Screening tools and more comprehensive assessments are needed in the field and laboratory settings to better characterize the lack of capacity for self-care and protection that is central to the clinical phenomenon and pathology of elder self-neglect. The lack of capacity for self-care and protection is what differentiates older adults who self-neglect from adults who are autonomous nonconformers to social norms and those with significant physical disabilities but intact capacity to seek and obtain aid. Clinical and

social services professionals working in non-clinical settings must rely on more than simple verbal declarations when evaluating capacity to live safely and independently.

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	Instrument Task	Conceptual Domain	Measurement Item
C	Count to 20 forwards and backwards to 1	Attention	Counting backwards from 20
O	Name three objects in the room	Language	Naming to visual confrontation
M	Test recall and recent memory using three words (e.g., watch, lamp, and pen).	Delayed Recall	Immediate and Delayed Recall from the Mini Mental State Examination
P	Perceptions of the diagnosis of an illness and the risks & benefits of treatment	Awareness	Read and recite relevant details of a case scenario involving fever and abdominal pain in an older adult. Based on the design of Hopkins Competency Assessment Test (HCAT)
<p>Scoring of Measurement Items:</p> <ol style="list-style-type: none"> 1.) Attention is the patient's ability to attend to a task or to recognize what is being told. Scoring: subject completes 17/20 numbers correctly (Wechsler, 2001). 2.) Language is the ability to express a choice. Scoring: subject must correctly identify three objects (Goodglass, Kaplan, & Barresi, 2000). 3.) Recall is the ability to absorb, retain and on cue, remember and repeat the information. Scoring: subject remembers 2/3 items without cueing at delayed recall (Folstein, Folstein, & McHugh, 1975). 4.) Awareness includes "acquiring and grasping" the presence of a medical condition, the nature and course of the disorder, and the risks and benefits of the intervention or the alternatives to intervention. Scoring: 3 of 3 criteria correct for passing score: Describes the disorder, potential treatments, and the benefits and risks of treatment (Janofsky, McCarthy, & Folstein, 1992). 			

Figure 1. Conceptual Domains and Measurement Items of the COMP Screen

Table 1
Baseline Characteristics of the Study Population

Patient Characteristics	Self-Neglect Cases, N=91	Control Group, N=91	P value
Female Gender, n (%)	61 (67)	61 (67)	
Age in yrs, mean $\pm$ standard deviation	76.1 $\pm$ 7	75.9 $\pm$ 6.9	
Non white race, n (%)	56 (62)	58 (65)	
Education in yrs, mean $\pm$ standard deviation	10.86 $\pm$ 3.3	10.66 $\pm$ 4.5	
Monthly Income (\$), mean $\pm$ standard deviation	879 $\pm$ 531	875 $\pm$ 430	
Living Alone, n (%)	47 (52)	31 (34)	.014
Currently Married, n (%)	22 (24)	28 (31)	
Kohlman Evaluation of Living Skills, passing score, n (%)	43 (49)	66 (73)	.001
Total medications, mean $\pm$ standard deviation	6.7 $\pm$ 4.6	8.5 $\pm$ 4.5	.01
Mini Mental State Examination, mean $\pm$ standard deviation	24.19 $\pm$ 4.3	24.95 $\pm$ 4.1	
Geriatric Depression Score, mean $\pm$ standard deviation	5.09 $\pm$ 3.4	3.37 $\pm$ 3.2	.001

COMP screen for decision-making capacity: results from cases with elder self-neglect and comparison group of older adults

Table 2

Test domains and items	Self-neglect Cases N=91			Comparison Group N=91		
	Item Score, N (%)			Item Score, N (%)		
	Pass	Fail	Missing	Pass	Fail	Missing
Attention	77 (89)	10 (11)	4(4)	80 (91)	8 (9)	3 (3)
Language	86 (98)	2 (2)	3 (3)	89 (100)	0 (0)	2 (2)
Delayed Recall	40 (45)	48 (55)	3 (3)	50 (55)	41 (45)	0 (0)
Awareness (3 of 3)	39 (43)	51 (57)	1 (1)	36 (40)	54 (60)	1 (1)
Awareness (2 of 3)	78 (87)	12 (13)	1 (1)	85 (94)	5 (6)	1 (1)
Articulate a choice	79 (87)	11 (12)	1 (1)	87 (96)	3 (3)	1 (1)
Risks of refusing	79 (87)	11(12)	1 (1)	85 (93)	5 (5)	1 (1)
Risks of accepting	40 (44)	50 (55)	1 (1)	36 (40)	54 (59)	1 (1)