Feasibility and reliability of the elderly version of the Camberwell Assessment of Needs (CANE): results from the São Paulo Ageing & Health Study

Aplicabilidade e confiabilidade da versão para idosos da escala Camberwell de Avaliação de Necessidades (CANE): resultados do São Paulo Ageing & Health Study

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Abstract

Objective: *We set out to assess the feasibility, reliability and convergent validity of the Camberwell Assessment of Needs for the Elderly Scale in older residents of a Brazilian urban elderly population of low socioeconomic status.* ***Method:*** *We identified 32 older users of community health services from a population-based catchment area survey. We administered the Brazilian version of the Camberwell Assessment of Needs for the Elderly Scale to the older person and to an informal caregiver, and tape-recorded the assessments. Interviewers made a rating. Tape-recordings were independently co-rated.* ***Results:*** *Items contributing to older person and caregiver reports of needs and unmet needs had a high internal consistency. Inter-rater reliability was excellent for all needs, and fair to good for unmet needs. Older person and caregiver's reports, and interviewer ratings were highly mutually consistent. Convergent validity was supported by associations, as hypothesized, between needs and disability, and needs and dementia.* ***Conclusions:*** *The Brazilian version of the Camberwell Assessment of Needs for the Elderly Scale is a feasible, reliable and, to the extent assessed, valid assessment of unmet needs in a disadvantaged low and middle income countries setting. Its practical utility as a clinical tool remains to be assessed.*

Descriptors: *Needs assessment; Elderly; Mental disorders; Reproducibility of results; Developing countries*

Resumo

Objetivo: *O objetivo deste estudo foi o de avaliar a aplicabilidade, a confiabilidade e a validação convergente da Escala Camberwell de Avaliação de Necessidades em Idosos em uma população de baixa renda residente na cidade de São Paulo.* ***Método:*** *O estudo incluiu 32 participantes com 65 anos ou mais, usuários de serviços de saúde local que fizeram parte do estudo de levantamento de base populacional. A Escala Camberwell de Avaliação de Necessidades em Idosos foi administrada ao participante e ao seu cuidador, todas as entrevistas foram gravadas. Assistentes de pesquisa pontuaram as entrevistas. As gravações foram pontuadas por um pesquisador independente.* ***Resultados:*** *Itens que contribuíram para a pontuação positiva de necessidades atendidas ou não atendidas pelos participantes e seus cuidadores obtiveram alto coeficientes de consistência interna. Confiabilidade entre examinadores foi excelente para todas as necessidades, e para necessidades não atendidas oscilou entre razoável e boa. As respostas de participantes e cuidadores, e as pontuações dos entrevistadores foram mutuamente consistentes. Validade convergente foi mantida pelas associações entre necessidades e incapacidade, e necessidades e demência.* ***Conclusões:*** *O estudo de confiabilidade da versão brasileira da Escala Camberwell de Avaliação de Necessidades em Idosos mostrou que a mesma é um instrumento de pesquisa prático, confiável e válido para avaliar necessidades em países em desenvolvimento menos favorecidos.*

Descritores: *Determinação de necessidades de cuidados de saúde; Idoso; Transtornos mentais; Reprodutibilidade dos resultados; Países em desenvolvimento*

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Introduction

By 2050 it is estimated that those over 65 years of age will comprise 18% of the total Brazilian population[1]. In the accompanying health transition chronic diseases linked to disability, dependency and impaired quality of life will become more prominent[2]. Neuropsychiatric disorders account for almost 30% of years lost to disability worldwide[3]. The needs of elderly people with mental illness arise from their incapacity, comorbid physical illness and social disability. Assessment of needs of care is relevant to the planning and assessment of community services and the establishment of individualized treatment goals. The original Camberwell Assessment of Needs[4] has been translated into Portuguese, and its validity and reliability have been tested in a Brazilian sample of mentally ill adults[5]. The Camberwell Assessment of Needs for the Elderly (CANE)[6] has shown good psychometric properties in the United Kingdom and Spain[6-8]. We assessed its feasibility and reliability when administered to a Brazilian urban socioeconomically deprived setting.

Method

1. Setting and study design

The study was nested in the cross-sectional phase of the Sao Paulo Ageing and Health Study[9,10], an epidemiological population-based investigation of over 65-year-old residents of three catchment areas in São Paulo, Brazil. Inclusion criteria were: 1) participants had sought help from a healthcare provider for a mental health problem in the past 3 months; 2) participants should be able to answer the interview on needs of care.

2. Measurements

The CANE has 24 items on the needs of the older person, and two on the needs of caregivers. Each item has four elements – 1) whether a need exists; 2) help provided by family/friends; 3) help from statutory services; 4) whether the help provided meets the needs. These items identify needs and unmet needs within each of the 26 domains, and total number of needs and unmet needs, from the perspective of the older person, the caregiver and the interviewer. The CANE was translated into Portuguese and discussed with a bilingual multidisciplinary team of mental health professionals to assess consistency with the English version. The examples provided to illustrate "no need", "met need" and "unmet needs" had to be modified to ensure relevance to the Brazilian health system. For instance, in the 'Drugs' domain the English version includes as an example of moderate help 'supervision by district nurse/community psychiatric nurse/care facility administers drugs', services as such are not provided yet by the Brazilian public health system for those having problems with medication or drugs. Therefore we used in the Brazilian version 'attendance in a program regarding drug misuse or dependency'. A pilot with patients and caregivers confirmed its comprehensibility.

Adjustments were also made in the "Information" domain, where we included a more specific question asking if the person had understood the information given about their condition/treatment. This question does not exist in the English version and its importance emerged because of the sample's difficulty in understanding symptoms and treatment.

Data from the cross-sectional survey protocol was used on:

a) Sociodemographic characteristics (gender, age, marital status, education);

b) Automated Geriatric Examination for Computer Assisted Taxonomy (AGECAT) depression diagnosis from the Geriatric Mental State (GMS)[11];

c) Probable dementia, using the 10/66 Dementia Research Group's algorithm[12];

d) Disability ascertained through the World Health Organization Disability Assessment Schedule (WHODAS-II)[13].

The CANE was administered to the participant and a caregiver by four research assistants at their homes. Informed consent was obtained. All interviews were tape-recorded to assess inter-rater reliability. The second rater (RS) was trained to administer and rate the CANE, but did not conduct any of the field interviews. RS listened to the recorded interviews and rated them blind to the first interviewer ratings. The study had ethical approval from the Universidade de São Paulo Medical School (903/03) and from the King's College London Ethical Committees.

3. Analysis

Internal consistency for total needs and unmet needs scales was assessed using Cronbach's alpha. Inter-rater reliability was assessed using Cohen's *kappa* for individual items and intra-class correlation for total needs and total unmet needs. Kappa of less than 0.40 indicates poor agreement, 0.40 to 0.59 fair, 0.60 to 0.74 good, and 0.75 to 1.00 excellent agreement[14]. We used an analogous approach to assess agreement between the participant and caregiver for needs and unmet needs. Paired t-tests were calculated to compare means between the participant and caregiver's total needs and unmet needs. Convergent validity was assessed by estimating Pearson's correlations between the WHODAS II and total and unmet needs, and by comparing total and unmet needs between those with and without dementia and depression diagnoses, using an independent sample *t*-test.

Results

Thirty-two participants were included. Mean age was 72.8 years (65-88 years). Most (90%) were female, 14 (43.8%) were married/cohabitating and 12 (37.5%) widowed, 50% had no formal education. Only four (17%) had a paid caregiver. Most caregivers were adult children. Nineteen participants (59.4%) were current AGECAT depression cases, seven (21.9%) were probable 10/66 dementia cases, and four (12.5%) had had a stroke. Twenty-two (68.8%) had contacted primary care, 16 (50.0%) a hospital doctor, 17 (53.1%) another government health worker, and seven (21.9%) a private doctor in the last 3 months with a mental health complaint.

The mean total needs identified by participants, caregivers and interviewers were, respectively: 4.9 (sd 3.6), 4.7 (sd 4.0) and 3.8 (sd 2.7). The mean total of unmet needs identified by participants, caregivers and interviewers were, respectively: 1.5 (1.8), 1.5 (2.2) and 1.7 (2.1). Paired *t*-tests indicated no systematic differences between the reports of the participant, caregiver and interviewer, other than that participants rated more total needs than interviewers (paired mean difference 1.1, 0.2-1.9). The intra-class correlation coefficients (ICCs) for agreement between participant and caregiver's reports were 0.53 (0.23-0.74) for total needs, and 0.64 (0.39-0.81) for unmet needs.

According to participants, caregivers and interviewers, physical needs predominated (Table 1). Memory problems, psychological distress and psychotic symptoms were also important. Physical health needs were generally met, other than needs related to eyesight and hearing. Needs arising from psychological distress were generally unmet, while psychotic symptoms and memory needs were catered for better. Other outstanding unmet needs were in the social domain (daytime activities and company), and in caregiver's need for information.

1. Reliability

Internal scale consistency (Cronbach's alpha) was high for participant (0.79) and caregiver's ratings (0.83) of total needs, moderate for participant (0.57) and high for caregiver's reports (0.72) of unmet needs. Inter-rater reliability for participant and caregiver's responses was assessed with *kappa* coefficients for each

Table 1 - Number and proportion of older adults with needs and unmet needs in each of 26 CANE domains according to older person, caregiver's reports and interviewer ratings

	Older person's reports n = 32		Caregiver's reports n = 32		Interviewer ratings n = 32	
	Total needs	Unmet needs	Total needs	Unmet needs	Total needs	Unmet needs
Accommodation	3 (9.4%)	1	4 (25.0%)	1	2 (6.3%)	1
Household Skills	8 (25.0%)	2	9 (28.1%)	2	10 (31.3%)	2
Food	7 (21.9%)	0	6 (18.8%)	1	7 (21.9%)	1
Self-care	5 (15.6%)	1	7 (21.9%)	2	7 (21.9%)	1
Caring for others	4 (12.5%)	0	2 (6.3%)	0	4 (25.0%)	0
Daytime activities	4 (12.5%)	3	5 (15.6%)	5	5 (15.6%)	5
Memory	8 (25.0%)	1	7 (21.9%)	2	6 (18.8%)	2
Eyesight/hearing	15 (50.0%)	6	12 (37.5%)	7	13 (40.6%)	5
Mobility/falls	11 (34.4%)	3	9 (28.1%)	3	12 (37.5%)	3
Continence	4 (12.5%)	1	2 (6.3%)	0	6 (18.8%)	1
Physical Health	28 (90.6%)	3	25 (78.1%)	3	30 (93.8%)	4
Drugs	3 (9.4%)	0	2 (6.3%)	1	4 (25.0%)	0
Psychotic symptoms	2 (6.3%)	0	5 (15.6%)	1	6 (18.8%)	1
Psychological distress	9 (28.1%)	5	6 (18.8%)	5	8 (25.0%)	5
Information	6 (18.8%)	3	1 (3.1%)	0	2 (6.3%)	1
Safety (deliberate self-harm)	2 (6.3%)	1	3 (9.4%)	2	4 (25.0%)	3
Safety (accidental self-harm)	4 (12.5%)	1	3 (9.4%)	1	6 (18.8%)	1
Abuse/neglect	2 (6.3%)	1	1 (3.1%)	1	3 (9.4%)	2
Behavior	0 (0.0%)	0	4 (25.0%)	0	3 (9.4%)	1
Alcohol	0 (0.0%)	0	0 (0.0%)	0	0 (0.0%)	0
Company	6 (18.8%)	3	14 (43.8%)	3	6 (18.8%)	3
Intimate relationships	6 (18.8%)	1	1 (3.1%)	0	5 (15.6%)	0
Money	2 (6.3%)	1	4 (25.0%)	2	4 (25.0%)	1
Benefits	3 (9.4%)	1	3 (9.4%)	0	2 (6.3%)	0
Caregiver's need for information	9 (28.1%)	7	9 (28.1%)	6	14 (43.8%)	10
Caregiver's psychological distress	6 (18.8%)	2	6 (18.8%)	1	9 (28.1%)	3

CANE item. Agreement on any needs was excellent for almost all items, good for participant's report of physical health needs and caregiver's report of needs arising from drug dependency and fair for caregiver's report of need for information. Agreement on unmet needs was fair to good for most items. Intra-class correlations for total needs were 0.99 (0.99-1.00) for participants and 0.99 (0.97-0.99) for caregivers. For total unmet needs the ICCs were slightly lower, 0.76 (0.58-0.87) and 0.87 (0.77-0.93), respectively.

2. Concurrent validity

Caregivers' reports of total needs correlated more strongly with the WHODAS II (r = 0.55) than did those of the participant (r = 0.42) or the interviewer (r = 0.40). For unmet needs the correlation coefficients were 0.44 (caregiver), 0.42 (participant) and 0.45 (interviewer). Total needs were higher for dementia cases then non-cases according to caregivers (mean difference 5.3, 2.3-8.3) and interviewers (3.3, 1.3-5.3), the difference being smaller and not statistically significant for participant reports (2.1, -1.5-5.2). Total needs for AGECAT depression cases were higher than for non-cases according to participants, the difference being smaller and not statistically significant for caregiver and interviewer's ratings.

3. Feasibility

The CANE was feasible and practical. However some adaptations were necessary to suit the local health system, and these together with the need to explain carefully the concept of need to uneducated participants meant that the duration of the assessment was around 40 minutes. More practically orientated domains such as "looking after home", "food", "self-care", and "benefits" were better understood, and more easily rated. Domains such as "psychological distress", "behavior" and "intimate relationships" were too abstract for some participants. Many participants lived in precarious accommodation, with overcrowding and poor sanitation. A need for accommodation was constantly present according to interviewers, although sometimes not rated by the participant.

Discussion

Previous studies from developed countries have shown the CANE to have robust psychometric properties[6,8,15]. An adult version of the CAN has been validated in Brazil[5]. However, the present study is the first to assess the feasibility, reliability and validity of the CANE in a disadvantaged elderly population with limited access to health and social care. The CANE had good internal scale consistency, good to excellent inter-rater reliability at item and scale level, high levels of agreement between participant, caregiver and interviewer ratings, and good convergent validity. Although feasible, in comparison with studies in high income countries[6,8,15], it took longer to administer the CANE in Brazil, probably because of the difficulty of conveying the concept of need in non-technical terms to participants with little formal education.

Tentatively, given the small sample size, our findings suggest some directions for future research and practice. While physical health care needs were generally considered to have been met, there seemed to be an unmet need for audiological and ophthalmological services. Needs arising from psychological distress were common and unmet, despite recent health service contact. Social needs for company and for daily activities were strikingly unmet. Finally caregivers needed more information about the older persons' health conditions and treatment. Unmet needs could be considerably reduced if such support was provided for caregivers.

Studies of needs, met and unmet, within a larger community-based sample can inform health care planning and provision. In Brazil, policymakers are implementing a new model of care, the Family Health Program,[15] which is being rapidly rolled-out. Family Health teams provide basic healthcare for all residents in small catchment areas and refer more complex cases to specialized services. The CANE could be a useful tool for the new community health workers on the Family Health Program.

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Disclosures

Writting group member	Employment	Research grant[1]	Other research grant or medical continuous education[2]	Speakear's honoraria	Ownership interest	Consultant/ Advisory board	Other[3]
Renata Mello de Magalhães Sousa	King's College London	Wellcome Trust	---	---	---	---	---
Márcia Scazufca	USP	CNPq Wellcome Trust	---	---	---	---	---
Paulo Rossi Menezes	USP	CNPq Wellcome Trust	---	---	---	---	---
André Luiz Crepaldi	USP	---	---	---	---	---	---
Martin James Prince	King's College London	Wellcome Trust	---	---	---	---	---

** Modest*
*** Significant*
**** Significant. Amounts given to the author's institution or to a colleague for research in which the author has participation, not directly to the author.*
Note: USP = Universidade de São Paulo; CNPq = Conselho Nacional de Desenvolvimento Cientifico e Tecnológico.
For more information, see Instructions for authors.

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APPENDIX

1. Acomodação

O Sr/Sra acha que a sua casa é adequada para as suas necessidades?

(Se está adequada é porque o Sr/Sra recebe ajuda?)

1.1 O sujeito tem um lugar para morar?

Notas	Significado	Exemplo
0	Sem necessidades	Sujeito tem um lar adequado (mesmo internado atualmente), mora com a família. Não precisa de ajuda para acomodação.
1	Necessidades satisfeitas	Sujeito precisa e recebe ajuda com acomodação, por exemplo, vive em lar abrigado, albergue ou moradia assistida, mora com a família por causa da doença.
2	Necessidades não satisfeitas	Sujeito é morador de rua, com acomodações precárias ou não apresenta instalações básicas como água ou eletricidade. Mora em cortiços, barracos ou cômodo impróprio, por exemplo, dorme num colchão na cozinha ou divide lugar de dormir com mais de cinco pessoas.
9	Não se sabe	

Se nota for 0 ou 9, ir para próxima seção.

1.2 Quanta ajuda o sujeito recebe de amigos e parentes, com relação à acomodação?

Notas	Significado	Exemplo
0	Nenhuma	
1	Pouca ajuda	Ocasionalmente recebe alguma ajuda para melhorar a acomodação, como alguns móveis, objetos, decoração ou despesas de aluguel, condomínio, água e luz.
2	Ajuda moderada	Ajuda substancial para melhorar acomodações, como manutenção da moradia ou despesas de aluguel e condomínio, mesmo que receba todo o dinheiro.
3	Muita ajuda	Vive com parente porque suas acomodações próprias são insatisfatórias ou não tem acomodação própria
9	Não se sabe	

1.3 Quanta ajuda o sujeito *recebe* dos serviços locais, com relação à acomodação?

1.4 Quanta ajuda o sujeito *precisa* dos serviços locais, com relação à acomodação?

Notas	Significado	Exemplo
0	Nenhuma ajuda	
1	Pouca ajuda	Pequena ajuda para móveis, objetos ou decoração, material de construção ou endereço para procurar acomodação (imóvel, pensão).
2	Ajuda moderada	Melhorias importantes, encaminhado à secretaria de assistência social (por ex. albergue, casa de convivência).
3	Muita ajuda	Sendo realocada, vivendo em moradia assistida, albergue
9	Não se sabe	

1.5 O sujeito recebe o tipo certo de ajuda com relação à acomodação?

(0 = não; 1 = sim; 9 = não se sabe).

1.6 No geral, o sujeito está satisfeito com a quantidade de ajuda que recebe para sua acomodação?

(0 = não está satisfeito; 1 = satisfeito; 9 = não se sabe)