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### TELEPHONE GROUP EDUCATION: A STRATEGY FOR CAREGIVERS OF VETERANS WITH DEMENTIA

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Background: This study was designed to evaluate the impact of a Telehealth Education Program (TEP) on veterans with moderate to severe dementia and their spouse caregivers. The TEP is a program of education, coping skills, problem solving and support presented to caregivers of veterans with dementia by teleconference in ten weekly, one-hour sessions. The TEP was based on a stress and coping model aimed to enhance the knowledge, skills and feelings of support of the caregivers who participated. Methods: This study employed a randomized controlled design of 2 interventions, 3 times of measurement, 2 sites and 4 leaders. Veterans with moderate to severe dementia and their spouses were recruited and randomly assigned to TEP or usual care (UC). They were assessed at baseline, three and twelve months after baseline. Psychosocial outcome data and health care cost and utilization data were collected to examine three hypotheses: 1) whether TEP veterans would experience significant reduction in behavior problems, agitation and symptoms of depression; 2) whether TEP caregivers would experience a significant increase in dementia management skills; 3) whether TEP veterans would experience significant more days in the community, fewer hospital admissions, and nursing home admissions.. Outcome variables were analyzed using mixed effects regression models. Healthcare cost and utilization data were abstracted from VISTA databases within the VA. Results: There were 158 caregiverveteran dyads, 83 in TEP and 75 in UC. There were no significant baseline differences in demographic variables across groups. Results show that TEP caregivers perceived significant changes in some outcome variables as compared to UC caregivers. Healthcare cost data showed a significant (p=0.039) cost savings of \$2768 at six months for TEP as compared to UC, but were not significant at one year. Inpatient, outpatient and nursing home costs were assessed but only TEP nursing home costs reached significance(p=0.009) with a savings of \$1057 at six months. Conclusions: TEP resulted in short term cost savings and perceived improvements in some psychosocial variables for TEP caregivers.

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## ATTITUDES TO SUBJECTIVE MEMORY IMPAIRMENT AND HELP SEEKING IN PRIMARY CARE

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Background: There is a growing interest in the early detection of dementia and pre-clinical stages of the disease. Subjective memory impairment (SMI) is a recognised pre clinical stage and is often used in the formal assessment of mild cognitive impairment (MCI). However little is known about how and why people will present to primary care services with this symptoms. Methods: A cross sectional study was carried out of 126 people aged 65+, drawn from registration lists of two primary care centres in London. Structured questionnaires were administered ascertaining memory complaints and other common disorders/symptoms, their subjective importance, previous help-seeking behaviour and perceived relative salience. Participants were blind to the specific focus on SMI. In-depth qualitative interviews were carried out in 10 participants with SMI. Results: SMI was present to any degree in 66% and to a significant degree in 31%. When present, memory symptoms were rated as the second most concerning relative to other symptoms/disorders. However only 3% of participants with SMI had mentioned this to their GP. Qualitative analysis highlighted several barriers to help-seeking including embarrassment, fear of a dementia diagnosis, nihilism about therapeutic opportunities, and perceptions of the GP role. Conclusions: Memory complaints are common in older people and perceived as concerning, but rarely reported to primary care services. Further research is required to clarify facilitators / barriers to help-seeking.

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## SCENARIO SPECIFICITY OF MENTAL CAPACITY FOR TREATMENT DECISION IN VERY MILD DEMENTIA

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Background: Complicated treatment regimes for chronic medical disorders are challenging to the cognitive capacity of older persons. It would be important to examine the mental capacity to consent for treatment in older persons with different cognitive capacities. This study examines the scenarios specificity in affecting decisional making capacity for treatment in Chinese older persons. Methods: Fifty-six Chinese community-dwelling older adults (aged from 65 to 87) were recruited. Mental capacity for treatment of dementia and Diabetes mellitus was assessed using hypothetical case scenarios by the Chinese version of the MacArthur Competence Assessment Tool - Treatment (MacCAT-T). Cognitive function was assessed by the Clinical Dementia Rating (CDR), Mini-mental state examination (MMSE), Alzheimer's Disease Assessment Scale - Cognitive subscale (ADAS-Cog) and verbal fluency (CVFT). Results: 33 subjects were not demented (CDR 0), 23 were suffering from very mild dementia (CDR 0.5). According to global MacCAT-T ratings, 79% of CDR 0 subjects were considered capable and 50% of CDR 0.5 subjects were incapable of making consent for treatment of dementia (p= 0.026). As for DM treatment, 88% of CDR 0 subjects were capable and 68% of CDR 0.5 subjects were capable (p= 0.074). For subjects rated as mentally capable for consenting to only one scenario (DM or dementia, but not both), a higher proportion of subjects were able to consent for treatment of DM than dementia (70% versus 30%), the proportion is similar in CDR 0 and CDR 0.5 subjects (p=0.88). Conclusions: The findings suggested careful evaluation of treatment decision making capacity is required for older persons with early signs of cognitive impairment. While cognitive function is an essential determinant for mental capacity, it should also be acknowledged that assessment of mental capacity should be situation specific.

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THE IMPACT OF AN EDUCATION AND RISK EVALUATION PROTOCOL ON PERCEIVED BENEFITS AND RISKS OF GENETIC SUSCEPTIBILITY TESTING FOR ALZHEIMER'S DISEASE

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**Background:** Perceived benefits and risks of genetic testing are wellestablished determinants of people's decisions to seek genetic testing. However, few studies have assessed how appraisal of these risks and benefits changes after undergoing genetic counseling and disclosure of test results. Methods: First degree relatives of Alzheimer's disease (AD) patients were enrolled in the Risk Evaluation and Education for Alzheimer's Disease (REVEAL) Study, an NIH-funded, multi-center randomized clinical trial providing APOE genotype-based risk assessments. Study participants read a list of commonly cited reasons for pursuing or declining genetic testing for AD risk such as, "the need to make arrangements for my long-term care," and "the test results might upset my loved ones." Participants ranked the importance of each item to them using a 5 point scale (1 = not at all important to 5 = extremely)important). Mean perceived benefits was derived by averaging responses to 12 reasons for pursuing testing, and mean perceived risks was derived by averaging responses to 10 reasons for declining testing. Scores were assessed for 273 participants prior to an education and genetic counseling session (pre-ed) and again 12 months after a risk disclosure session. 1-sample t tests were performed on the changes in scores. Analyses were also run on subscales and individual items. **Results:** Mean perceived benefits remained high 12 months after risk disclosure although significantly lower than at pre-ed (3.17 vs 3.34, p<.01). Analysis of individual items showed the sharpest drop on, "to seek information on preventive measures" (3.74 vs 4.26, p<.01). Mean perceived risks remained low at 12 months and the change from pre-ed was not statistically significant (1.90 vs 1.84, p=.09). However, a 3-item "fear of discrimination" subscale did have a significant increase at 12 months (2.08 vs 1.91, p<.01). No effects were detected for gender, self-identified race, age, education, genotype or randomization status. Conclusions: Education, genetic counseling and genetic testing can change beliefs about the pros and cons of genetic susceptibility testing for AD. Beliefs about risk reduction and genetic discrimination appear particularly likely to change following this process. Further research needs to be conducted to explain why these changes occurred.

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# DO NOT ASK, DO NOT TELL: INFREQUENT HELP-SEEKING FOR BEHAVIORAL DISTURBANCES IN COGNITIVELY IMPAIRED LATINO ELDERLY DESPITE HIGH NEED

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Background: Behavioral symptoms are common in Latino eldelry with dementia and associated with incresed care recipient disability, elevated caregiver depression, and risk of institutionalization. This study presents quantitative findings on patterns of help-seeking for behavioral disturbances in a community sample of cognitively impaired Latino elderly. Methods: Cognitively impaired Latino eldelry were identified through a community-based cohort study of Latino elderly (Sacramento Area Latino Study on Aging or SALSA). Neuropsychiatric symptoms were measured with the Neuropsychiatric Inventory of NPI. Episodes of outpatient health service use were measured using a structured questionnaire. For each episode of health service use, help-seeking for neuropsychiatric symptoms was probed. Medication prescriptions were also inventoried. Results: The data analysis involves examining patterns of help-seeking were identified in a group of Latino elderly with "high need" (i.e. high level of neuropsychiatric symptoms and high associated caregiver distress) based on a survey instrument. This analysis led to the identification of three distinct groups: absent helpseeking (no reported recent help-seeking and no psychiatric medications), past help-seeking only (no reported recent help-seeking and psychiatric medications), and active help-seeking (recent help-seeking with or without psychiatric medication). Overall, less than 20% of the sample fell into the active help-seeking group. Conclusions: Based on prior qualitative work with caregivers of Latino elderly with dementia and their primary care providers, possible reasons for the low frequency of help-seeking despite high levels of need are presented. Conceptual implications of these findings for current models of help-seeking are also highlighted.

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### ETHICAL CHALLENGES FOR DEMENTIA RESEARCH IN DEVELOPING COUNTRIES

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Background: The Maracaibo Aging Study (MAS) is a populationbased, longitudinal study of aging in the urban community of Maracaibo, Venezuela. The MAS has reported prevalence figures for dementia, risk factors, and associated conditions. Here, we report on the ethical concerns that have arisen since the beginning of the study. Methods: A focus group with the goal of recognizing ethical dilemmas was identified from among the multidisciplinary team of the MAS. Results: The following ethical dilemmas and implications of dementia research in developing countries were identified: 1) Dementia is a condition that is not usually perceived as a disease and may be medicalized as a result of the research. 2) Benefits that participants are entitled to receive from the study team are based on scarcity, rather than on their actual needs. 3) Serious imbalances in power between researchers and participants generate motivations among participants that are often not related to their contribution to science and knowledge. 4) Programs for protection of human subjects are deficient, because the research institutions and governmental science programs in developing countries have limited experience and capacity for conducting ethical and scientific review and follow up. 5) It is critical to distinguish between procedural and ethical challenges that reflect substantive differences in ethical standards between developed and developing countries. 6) Community leaders may play a role in gaining permission to approach potential research participants, and other interests than the well being of the community may determine their willingness to participate. 7) Local socio-economic conditions, cultural differences, and family structure affect competency issues related not only to informed consent but also is in regard to advance directives that specify how a participant shall be treated when they are no longer competent to make their own decisions. Conclusions: Every phase of a dementia study in developing countries raise significant ethical challenges. Dementia researchers must be trained to make judgments that are sensitive to the cultural demands of the research setting, and that respect the international ethical standards of collaborative research. Capacity building in ethics should be part of every collaborative research project studying dementia in developing countries.

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#### CULTURAL RELEVANCE IN TREATING DEMENTIA

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Background: The mystery of Dementia is gradually unfolding. The expectation is that in the near future, dementia will be cured. As we advance to this expectation, it is very significant that in all ramifications, the treatment of dementia should be holistic in nature. One area, that need be focused on in order to successfully treat the symptoms of dementia is understanding of culture and individual's perceptions as it relate to their psychosocial wellbeing. Though individuals with the diagnosis of dementia may share similar symptoms and with similar expecations, the treatment of these individuals will vary greatly on the level of understanding and the interpretation of the culture and background information available in the hands of the professionals caring for these individuals. Methods: The relevance of culture to understanding and treating individuals with dementia cannot be overemphasized. Treating people with dementia requires specialized trainings; one of such training is cultural compentence and sensitivity. Results: Understanding of the culture of dementia individuals in their care curriculum is significant in the elimination of behaviors of dementia. For instance,