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Delivering a psycho-educational intervention to Hispanic hospice informal caregivers

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Patient and family beliefs, values, customs, languages, and immigration status all have a strong influence on decision-making at the end of life and on the hospice experience.¹ Previous research suggests Latinos, characterized as a collectivistic culture, assume that their family members know their wishes without being told and thus advance directives are not necessary.² Subsequent research on attitudes and beliefs about end-of-life care among Latinos illustrate an emphasis on spirituality as a primary means of coping and a high value on the holistic well being of both patient and family.³ Previous research demonstrates that several barriers contribute to less-frequent use of hospice among the Hispanic population: cultural perceptions of autonomy, language challenges, providers' lack of cultural understanding, immigration status, and lack of hospice outreach.¹

Informal caregivers, namely family, friends or others who assume an unpaid caregiving role, play a key role in the hospice, but this role is found to often affect caregivers' own well being. As caregivers deal with complex and stressful challenges, psycho-educational or cognitive-behavioral interventions may be appropriate to assist with coping and problem solving. There is currently a lack of systematic evidence related to the efficacy of psycho-educational interventions, and little attention has been paid to the role of culture, ethnicity or race on the feasibility and effectiveness of psycho-educational interventions for hospice caregivers.

In this letter we highlight the analysis of socio-cultural factors that may arise when delivering a psycho-educational intervention for Hispanic hospice caregivers as they identify and work to address their most pressing issues and challenges during the caregiving experience. Specifically, we focus on three cases of Hispanic caregivers who received a

problem-solving intervention (PSI) as part of a larger clinical trial. PSI is a brief, structured, cognitive-behavioral intervention that teaches people problem-solving coping skills.

We enrolled caregivers from two participating hospice agencies. Three intervention visits were scheduled to go over the definition of caregivers' problems and realistic goals, implementing and evaluating a solution. Caregiver A was a Hispanic 63-year-old male caring for his wife diagnosed with cancer. He identified his own anxiety as his most pressing issue. Caregiver B was a 28-year-old female caring for her mother diagnosed with cancer. She identified her own depression resulting from her mother's terminal illness as her most significant problem. Caregiver C was a 56-year-old female caring for her mother with a primary diagnosis of chronic obstructive pulmonary disease. She identified her mother's mental confusion and the difficulty in communicating with her as the most challenging problems.

As these participants discussed their own experiences and attitudes, they often referred to challenges identified by Betancourt et al. as socio-cultural barriers that contribute to health disparities.⁴ *Structural barriers* include lack of interpreter services, complex intake and referral processes, and difficulty in obtaining healthcare.⁴ As one of the eligibility criteria was the ability to speak English, the need for interpreter services was not identified. Subjects, however, did address complex processes that may become burdensome. Caregivers A and C commented on the large number of people coming in and out of one's home and how this can be both helpful and also stressful. Caregiver B discussed how she was agonizing over her mother's pain and in spite of the complex and multiple services offered by hospice, she was still emotionally consumed by her mother's pain. Clinical barriers, characterized as differences between healthcare provider and patient and family, including differences in health beliefs and practices, involve provider-patient/family communication.⁴ Caregiver A referred to having been raised in a religious setting where guilt was an integral part of his life and, while hospice staff would recommend addressing and potentially eliminating these feelings, he had learned to accept feelings of guilt as part of his identity. Caregiver B emphasized that her own depression was something she did not feel she could discuss with healthcare providers: 'People don't want to hear what I'm saying'. Finally, Caregiver C commented on the attitude of the hospice providers: 'When people come in all the time, and they have a good attitude, it has an effect on you'.

In order to ensure that psycho-educational interventions in the hospice are culturally sensitive, we believe that an ongoing analysis of interactions and assessments focusing specifically on socio-cultural factors (as highlighted in this example with the Hispanic population) needs to become a routine and ongoing part of an intervention fidelity protocol.

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