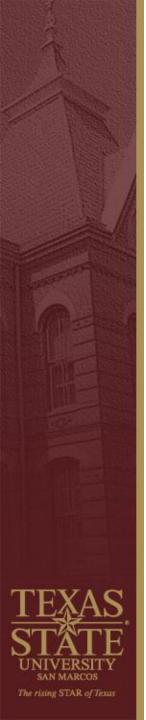
CAREGIVING THROUGH THE EYES OF HISPANIC CAREGIVERS

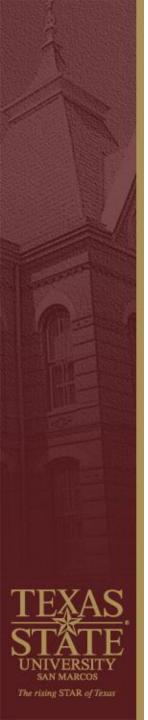
Lyda C. Arevalo-Flechas PhD, RN
JAHF Claire M. Fagin Fellow
St. David's School of Nursing



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CAREGIVING

***BURDEN**

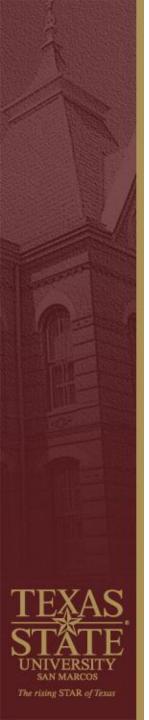
CARGA

Physical load



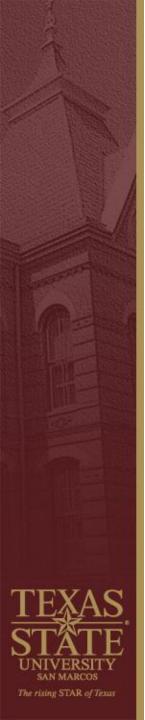
Culture and Language

- Caregiver burden does not precisely translate into a relevant and accurate concept among Latino/Hispanic caregivers.
- Many Latino/Hispanic caregivers do not perceive their work as a caregiver in this way, but rather describe it as challenging, satisfying, or as an honorable duty (Arévalo-Flechas, 2008



Screen for Caregiver Burden

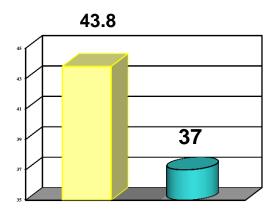
- Subjective and Objective Burden
- Spanish SCB, which has been translated from English to Spanish, may not fully capture Latino/Hispanic caregivers' perception of their role.

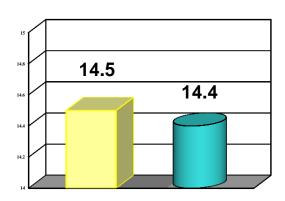


PILOT STUDY N=8

Comparison of Subjective
Caregiver Burden Between
SCB-English Version and SCBSpanish Version

Comparison of *Objective*Caregiver Burden Between SCBEnglish Version and SCBSpanish Version





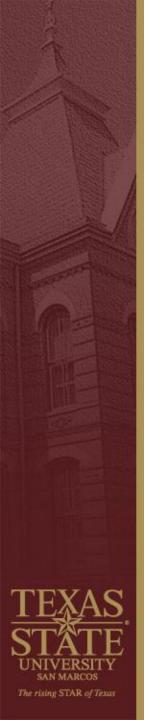






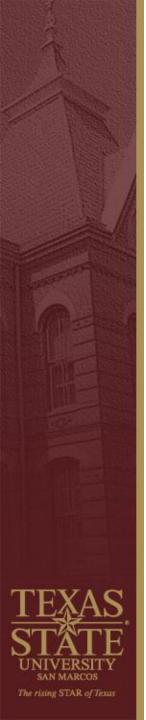
Purpose

To compare subjective and objective scores from the Screen for Caregiver Burden (SCB) administered to a bilingual Latino/Hispanic population caring for a relative living with AD, and to examine if any differences exist between scores when the instrument is administered in English and Spanish



Sample

- 40 Latino/Hispanic, bilingual caregivers of relatives living with Alzheimer's Disease.
- Participants resided in south Texas, had provided care for their relative for at least one year prior to admission to the study
- ❖ 18 years of age or older.

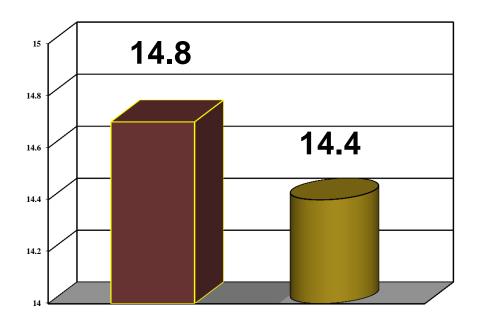


4 Groups

- 1) English interview- English SCB- Spanish Interview- Spanish SCB.
- 2) English interview- Spanish SCB- Spanish interview- Spanish SCB.
- 3) Spanish interview- Spanish SCB- English interview- English SCB.
- 4) Spanish interview- English SCB- English interview- Spanish SCB.

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OBJECTIVE BURDEN

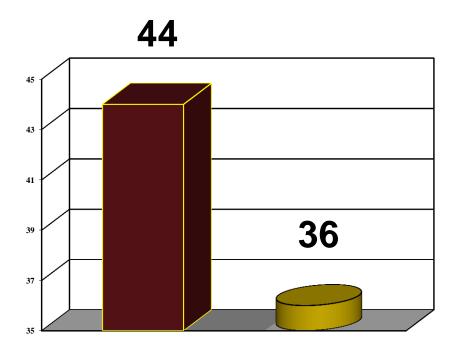






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SUBJECTIVE BURDEN



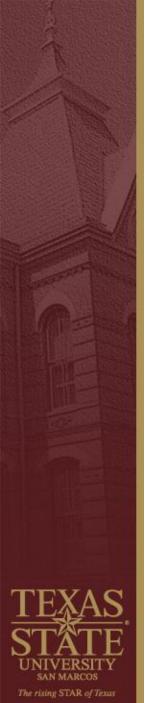






Bilingual Caregivers

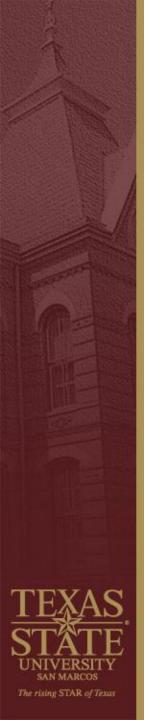
Unbearable **Overwhelming Frustrating Depressing Powerlessness Holding back** Difficult Hard **Challenging** A load you carry with love A heavy cross Something you wish you did not have to do



Monolingual Caregivers

RESPONSIBILIDAD **DIFICULTAD DESESPERACIÓN OBLIGACIÓN** DEBER SACRIFICE **UNA CRUZ PESADA** TAREA PESADA QUE SE **HACE CON AMOR**

(RESPONSIBILITY) (DIFFICULTY) (DESPAIR) (OBLIGATION) (DUTY) (SACRIFICE) (A HEAVY CROSS) (HEAVY JOB DONE WITH LOVE)



Meaning of Carga

Objeto pesado

Peso

Bulto

Encargado

Al pendiente

Algo que se lleva

Algo que se tira

Lo que se lleva a cuestas

Molestia permanente
Lo que llevan los
camiones o los animales
Difícil y que esclaviza

(heavy object)

(weight)

(sack)

(in charge of)

(attentive, paying attention

(something you carry)

(something you dispose of)

(what you carry on your

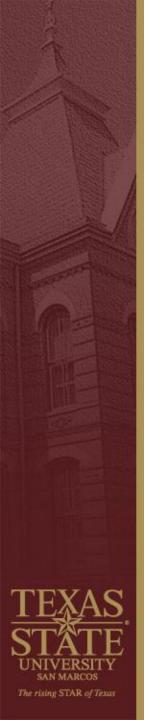
back)

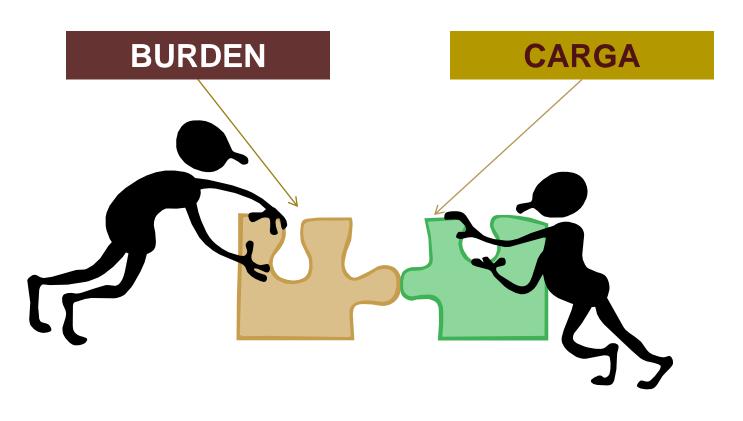
(permanent bother)

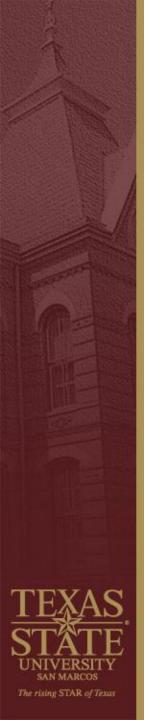
(what is carried by trucks

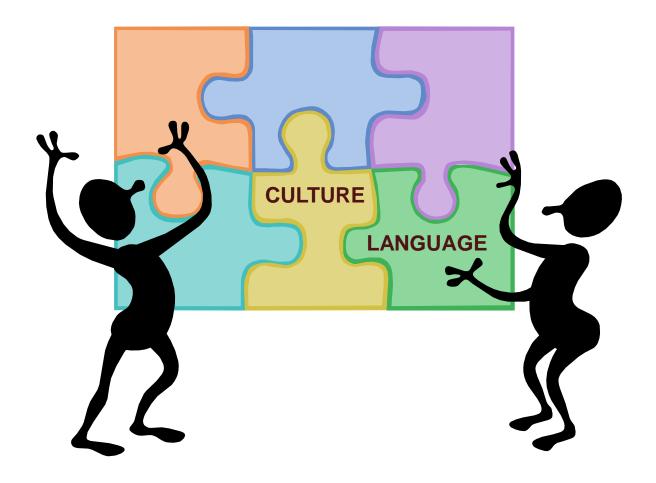
or animals)

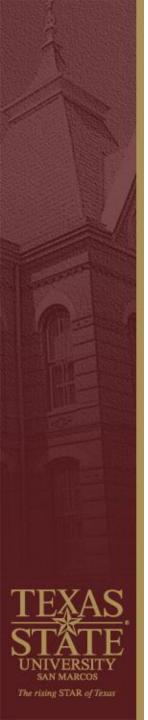
(difficult and enslaving)

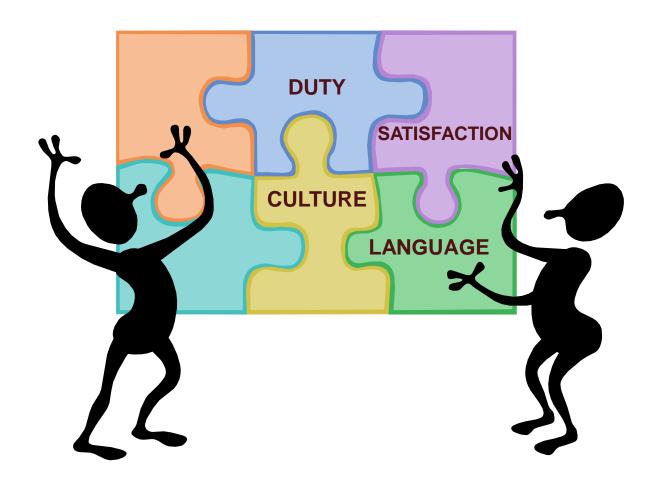


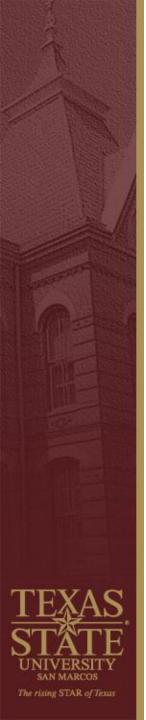












The manner in which these caregivers describe their caregiving experience is congruent with Hispanic values of familismo, personalismo, marianismo, collectivism, and respect.







Instruments that capture caregiver satisfaction and caregiver duty fulfillment as described by Latino/Hispanic caregivers remain to be developed.

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CULTURALLY INFORMED CONCEPTUAL ORIENTATION OF CAREGIVING

ANTECEDENTS

Regardless of racial or ethnic background, caregivers face these day-to-day situations that are antecedents to coping and perception

CONSEQUENCES

The resulting outcome is the perception that the caregiver has of the overall caregiving experience.

Realities of Caregiving



Coping



Perception of Caregiving

Caregiver Expenditure:

Degree to which one offers time, as well as physical, financial, environmental, and personal resources on behalf of another.

Caregiver Coping Response

Degree to which caregiver mobilizes resources (personal, physical, financial, social, and environmental) to increase one's ability to manage stressful events.

Caregiver Duty Fulfillment

Degree to which a person feels honored to be a dutiful caregiver and responsible for another.

Caregiver Satisfaction

Degree to which caregiver perceives balance between the changes made to care for another and sense of duty or responsibility.

Caregiver Burden

Degree to which one perceives the inability to deal with the stress when responsibility for another is assumed.

Examples:

Amount of money spent. Amount of time spent. Amount of travel time. Amount of hours slept. Amount of time to self.

Examples:

Lazarus Coping Scale Geriatric Hopelessness Scale Perceived Social Support Scale Social Functioning Scale

Scales that reflect the Latino/Hispanic values and collectivist perception of caregiving.

To be developed.

Examples:

Carer's Assessment of Satisfaction Index Positive Aspects of Caregiving Pending Cross-cultural validation

Examples:

Screen for Caregiver Burden Revised Memory and Behavior Problem Checklist Pending cross-cultural validation

CULTURE AND LANGUAGE

(Arévalo-Flechas 2008)