

# The Experience of Elderly Immigrants of Mexican Origin with Life Limiting Illness: A Critical Ethnography

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# Problem

- Nursing and the United States (U.S.) health care delivery system face a growing number of Hispanics in need of health care, and specifically immigrants of Mexican origin (Gonzalez-Barrera & Lopez, 2013; U.S. Census Bureau, 2011; U.S. Census Bureau, 2010, March 24).
- Hispanics have recorded the highest uninsured rate of any ethnic group in the U.S., with 34.8% of foreign-born Mexicans living without health insurance (CDC, 2012)
- There is an overall disparity of health services for immigrant elders (Lowman, Hunter, & Reddy, 2008; Lum & Vanderaa, 2010).
- Confusion about terminology (Gonzalez-Barrera & Lopez, 2013; Humes et al., 2011; Massey & Pren, 2012; Passel & Taylor, 2010; Talamantes & Sanchez-Reilly, 2010; Taylor et al., 2012; Vargas & Bishop, 2015).
- Studies have not addressed contextual factors or the nursing practice implications.



# What's happening in Texas?

- Hispanics or Latinos of any race = 37.6% of the Texas population (U.S. Census Bureau, 2011)
- Of Texans aged 65 and older, 20.4% are Hispanic or Latino (Hoque, Pecotte, & Verdugo, 2012)



# Purpose and Research Question

- Purpose: to describe and explain the health care experiences of elderly immigrants of Mexican origin who face life-limiting illness in the United States.
- Research question: What are the perceptions of elderly immigrants of Mexican origin with life-limiting illness about their experiences with the health care system in the United States?



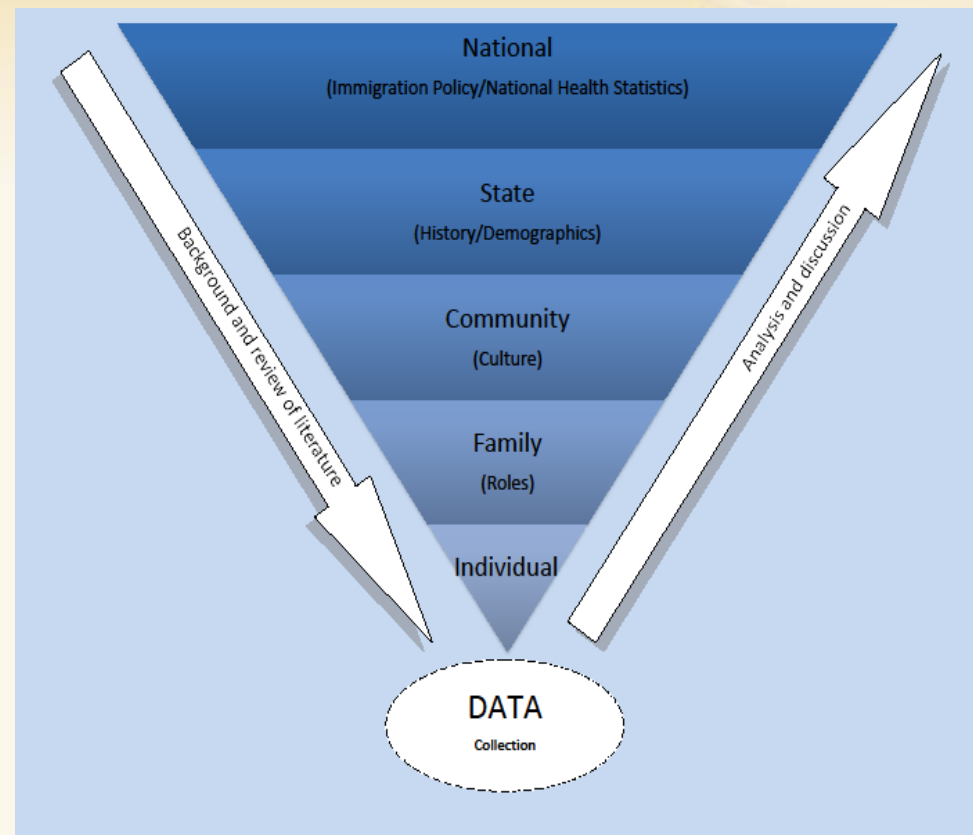
# Literature Review Conclusions

- Overall disparity in culturally-informed and accessible care for the growing demographic of immigrants
- Need to understand contextual factors and experiences of elderly immigrants of Mexican origin
- Need to include both first and second generation immigrants
- Need for nursing recommendations




# Philosophical/Theoretical Framework

- Research design – critical ethnography
- Philosophical underpinning - Habermas' critical social theory
- Organizing framework - Bronfenbrenner's Ecological Model
- Methodological approach – Carspecken's model for critical qualitative research



# University of Texas Medical Branch, Galveston, Texas, USA Institutional Review Board Approval

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Institutional Review Board  
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31-Aug-2015

**MEMORANDUM**

**TO:** Sandra McNeely, MSN, RN, CNE/Yolanda Davila, PhD, RN  
Grad School Biomedical Science

**FROM:**   
Janak Patel, MD  
Institutional Review Board, Chairman

**RE:** Contingent Study Approval

**IRB #:** IRB # 13-0427

**TITLE:** The Experience of Elderly Immigrants of Mexican Origin with Life-Limiting Illness: A  
Critical Ethnography

Your research study requiring the use of human participants received review by the UTMB Institutional Review Board (IRB) under an expedited review process on **28-Aug-2015**.

The IRB found your research project to be approvable, contingent upon your satisfactory response to the following stipulations:

**OTHER CHANGES:**

1. Please be reminded that the on-line training for the protection of research participants is an institutional requirement and needs to be renewed every two years. Yolanda Davila's on-line training for the protection of research participants has expired. They will need to log on at [www.clliprogram.org](http://www.clliprogram.org) to renew their certification.
2. Please be reminded that anyone participating in research at the University must meet the annual Conflict of Interest requirements. The COI Office does not have a record of COI training/disclosure for Sandra McNeely. Please have the individual listed complete their COI training/disclosure as required. Upon completion, the COI office will review the disclosure forms submitted at which time the COI Office will email a memorandum to you confirming all COI requirements have been met. Please upload the COI signed memorandum when responding to this stipulation. For collaborators not employed by UTMB, or for all other COI related issues/questions, please contact Angela Ellis at (409) 747-8795 or Helen MacKay at (409) 266-9426.

Please do not revise the originally reviewed study documents to include changes other than those

## UTMB IRB Protocol #13-0427



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# Inclusion Criteria

**Elderly** – 65 years and older (Centers for Medicare and Medicaid Services, 2012; World Health Organization, 2013)

**First generation** – foreign born in a country other than the U.S. to parents neither of whom was U.S. citizen (Pew Research Center, 2013)

**Second generation** – born in the U.S. to at least one first generation immigrant parent (Pew Research Center, 2013)

**Mexican** – self-identification of Mexican origin or descent, not necessarily place of birth or nationality (Ennis, Ríos-Vargas, & Albert, 2011)

**Life-limiting illness** – heart disease, cancer, stroke, chronic respiratory disease, and/or diabetes (CDC, 2013)

**Cognitive ability to participate** in an interview, and **self-report to be English-speaking** with evident ability to converse with the researcher (Braes, Milisen, & Foreman, 2012; Milisen, Braes, Fick, & Foreman, 2006)





# Setting and Recruitment

- Recruitment Efforts throughout Southeast and Central Texas
- Community Centers
- Churches
- Clinics
- Home Health Agencies
- Professional and Personal Connections
- Presentations to Groups
- Snowballing


**Your help is needed!**

Are you:


1. Age sixty-five or older?
2. Of Mexican origin?
3. Born or at least have one one parent born in a country other than the United States?
4. Someone who has heart disease, cancer, stroke, lung disease or diabetes?

You may be eligible to be in a research study to help healthcare providers learn about your experience with health care in the United States. There will be 1-2 interviews in English with the researcher, lasting up to 60 minutes.

You will receive a small bag of healthy snacks, a copy of a senior resource guide, and a \$25 gift card for your time.



Please contact Sandra McNeely  
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# Sample

Variable	N	Years	Mean
Age in Years	13	65-86	74
Gender			
Female	7		
Male	6		
Highest Grade Completed			
4 <sup>th</sup> – 6 <sup>th</sup> grade	6		
8 <sup>th</sup> grade	1		
High School	3*		
Junior College	2		
Bachelor Degree	1**		
Immigration			
1 <sup>st</sup>	5		
2 <sup>nd</sup>	8***		
Time in U.S. (1 <sup>st</sup> generation)		38-58	50.4
Insurance			
Medicare Plan	12		
Non-insured	1		
Location of Residence			
Texas Coastal Community	6		
Central Texas City	7		

Diagnosis	N (%)
Heart Disease	4 (30.7%)
Stroke	3 (23%)
Cancer	1 (7%)
Lung Disease	4 (30%)
Diabetes	8 (61.5%)*



# Data Collection



- An investigator-designed demographic data form and semi-structured interview guide
- Participants interviewed in private homes, or private clinic rooms
- Received \$25 gift card, bag of healthy snacks, and Senior Resource Guide specific to their regional area



# Reconstructive Analysis

- Applied Carspecken's Coding Techniques (1996, 2012)
- Raw Coding – data transcription by investigator
- Low-Level Coding, primary objective, repeated use of phrases, very close to the primary record with little abstraction
- High-level Coding, select analytic emphasis with higher abstraction
- Organization of codes into Sub-Categories and Categories
- Selection of Categories for Emphasis and Final Write-up
- PEER DEBRIEFER USED THROUGHOUT THE ENTIRE PROCESS



# Provisions for Validity

- Using multiple ways of recording the data to triangulate the data
- Peer-debriefing to check for biases or leading
- Use of member checks
- Use of an audit trail
- Use of non-leading interview techniques



# Findings

- Large Category: *REACTING* to the Diagnosis  
sub-categories: feelings and family experiences
- Large Category: *RESPONDING* to the Illness  
sub-categories: self-management, self-advocacy, and community interaction
- Large Category: *RELATING* to the Health Care Providers  
sub-categories: experiences with physicians and nurses



# REACTING to the Diagnosis: Feelings

- Investigator: I heard you say that when you were diagnosed it hit you kind of hard.
- Participant: Uh-huh, and really, and I got sick, and I remember cause I take three weeks from work, and it really hit me. But it, it's that I thought that I was gonna take insulin, and I, and I don't like, no, uh-huh.  
P8, L211-214



# *REACTING* to the Diagnosis: Family Experiences

- I cried and cried and cried. Because, ah, it runs in the family. My grandfather, my father, my oldest sister, and one more, and me, all got diabetes. And that makes me think, but it's something that you, you, you got it in you blood, you know, and, and uh, like a heritage... Yeah, genetics, and uh, we don't like it. It's not easy to live to see what the diabetes do to you. P4, L76-90





# *RESPONDING* to the Illness: Self- Management

- Yes, and I asked, I asked the doctor, I said, can I take them all together? I said, I don't want take one at 11, the other one at 1, and then the other one at 2, and I said no, do, no and I said is that all right that I take them all together all the time? He said that's all right. So that's what I do. P8, L303-312



# *RESPONDING* to the Illness: Self-Advocacy

- P11 was successfully transferred to a different floor in the hospital where he felt more supported: “But other than that, I mean, just the whole way, the way the nurse seemed to, on that floor, treated the patients, was totally different than the way they did upstairs.” P11, L438-457



# *RESPONDING* to the Illness: Community Interaction

- We need to have some kind of education at the clinics, because once the people leave the clinic, they're not gonna, they're not gonna get on the bus, to go to a class or something like that, you need to have it while they're here. And, you, you need to also educate their family, not just the patients...Because the first support they have should be at home, you know. P11, L553-574



# *RELATING* to Health Care Providers

- And they (nurses) put in an IV. And they put it back, the IV. And my hand was swelling. And I call the nurse, and told her come. Finally one coming. I said, please, I need the nurse. My nurse pass on me and don't come. And I know the nurse, it was not my nurse. I said, "Please give me something." This is awful. It hurt...The sheets too, when I was there, the sheets smelled bad, like rot meat. The sheets. And I tell her, these sheets stink. She said, "Oh no." I want to change the sheets. "We'll change the sheets all today." And then when I did (change own sheets), I turned it (the smell) over. P2, L 228-253



# Discussion: Habermas

- The understanding of speech acts and truth claims is especially important for nursing, because communication with patients is critical to high quality care, patient safety, and patient satisfaction (Vasconcellos-Silva, Rivera, & Siebeneichler, 2007).
- Healthcare organizations are linguistic communities (Vasconcellos-Silva et al. 2007)
- The situations in which health care professionals and patients agree to coordinate action plans would occur after an ideal speech act, one in which deep listening and shared understanding and meaning has been reached.



# Discussion: Ecological Model

- Individual: The individual self-management of medication practices that occurred is important to recognize as genuine instead of non-compliance or non-adherence (Pylypa, 2001).
- Family: Participants framed family as how they contracted diabetes, since it runs in their families. This is an area that may warrant additional inquiry to explore more in-depth how individuals consider their families as forbearers and contributors to their disease burden. There may be ways that preventive measures can be applied considering family as a unit or system.



# Discussion: Ecological Model

- **Community:** Alemán (2000) recommends that agencies need to develop programs and outreach efforts that encourage utilization of services, as elders' are traditionally reluctant to use community-based services.
- **Policy:** Literature notes a new “Latino underclass”  
(Massey & Pren, 2012).



# Discussion: Cultural Norms

- Simpatía
- Personalismo
- Respeto
- Familismo
- Fatalismo
- U.S. Healthcare System = time and task oriented (Carteret, 2011).





# Study Limitations

- Small sample size
- English-speaking only – participants
- Transcription - translation of concepts by culturally bound words may affect understanding and interpretation of meaning  
(Smith et al., 2008; van Nes et al., 2010).
- Difference in community and investigator definition of 1<sup>st</sup> and 2<sup>nd</sup> generation
- Difference in community and investigator definitions of “doctor” and “nurse”



# Recommendations for Nursing

- The next generation of older adults will likely be 20% Hispanic, the largest minority population aged 65 years and older (Villa et al., 2012).
- Health inequities and risks of the Mexican-origin, accumulated over a lifetime, are likely to persist into the elder years (Villa et al., 2012; Weigel et al., 2013).
- Nurses must be culturally prepared to care for the population, along with strong clinical competency that understands the unique needs of Mexican-origin elders.



# Recommendations for Nursing

- Increased nursing intervention immediately following the diagnosis.
- Nurses are well-positioned to inform, influence, and support health policy, and we have moral duty to advocate for patients and populations (Hall-Long, 2010; McCracken, 2010).



# Recommendations for Research

- Spanish-speaking only immigrants;
- Immigrants who do not use community services, in terms of their own perceptions and experiences;
- Immigrants of other ethnicities and nationalities;
- Family input, especially how experience with family members who have the disease shape the individual and family reaction to diagnoses, and response to the illness.



# Increase Hispanic Participation in Research

- Study materials in Spanish, Spanish-speaking clinicians in the trial (Ford et al., 2013; Trevino et al., 2013)
- Clearly explain that immigration status will not be documented and will not prevent participation, fair compensation, recruit participants in community contexts (Ford et al., 2013)
- Spanish-speaking research sites (Aponte-Rivera et al., 2014)
- Social networking (Martinez, 2014)



# Conclusion



# A Very Special Thanks

- The Marie and Albert Aulds Scholarship
- Mr. Harry Moore Scholarship
- John P. McGovern Award
- **Alpha Delta Chapter of Sigma Theta Tau International**
- Hattie Mae Jackson Scholarship
- Arthur V. Simmang Academic Scholarships Award
- NLN Foundation for Nursing Education
- Salute to Nursing Scholars' Award
- Edgar and Grace Gnitzinger Scholarship Fund for Geriatric Nursing
- David and Janet Niesel Scholarship
- Florence Thelma Hall Distinguished Professorship in Nursing Award
- Promise of Nursing for Houston/Galveston Regional Faculty Fellowship
- Lois E. Nickerson, RN Endowed Scholarship



# Dedication

This study is dedicated to the participants, who generously shared their stories with me.

They are, of course, unnamed due to research confidentiality guidelines, but I am ever so grateful to them for allowing me into their lives, families, homes, and communities.





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