



Perspectives of Hispanic Caregivers of Patients Living with Dementia: A Qualitative Study

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Results

Theme	Focused Code	Description
Health literacy and knowledge about dementia care	Family history and experiences with dementia	Some caregivers noted experiencing dementia in other family members and comparing PLWD's symptoms to them. For example, caregivers reported being familiar with swallowing problems in PLWD from experience with other family members with dementia
	Continuum of health literacy and advocacy on behalf of the patient	Caregivers in our sample had varying levels of health literacy and knowledge regarding the health care system, medications, the dying process, dementia, geriatrics, and symptom management. Caregivers spoke of using the internet, email, and the patient portal to access medical information. Some caregivers noted they were discerning by being selective with online resources or questioning the treatment plan.
Caregiver stress and burnout	Sacrifices	Caregivers reported sacrificing personal and work time to care for PLWD, in what is considered emotional work. Caregivers felt that they are not supported emotionally, lose their patience, and may feel that attempts to help PLWD are futile.
	Loneliness	Caregiver feeling alone in disclosing the death of a relative to PLWD
	Frustration with managing food.	Caregivers reported feeling frustrated about PLWD's repeated questions and complaints about food.
	Lack of social support Effects of the pandemic	Caregiver lacking connections to people with similar experiences Caregivers reported feeling frustrated because of the lack of senior day care support and felt that these PLWD were socially isolated and depressed due to the COVID-19 pandemic.
Mixed experiences interacting with the medical system and physicians	Family responsibility	Hispanic caregivers worry about the safety of PLWD and sacrifice time and money to care for them, even with imminent death, due to the idea of family duty in the Hispanic community.
	Connection to community resources	A caregiver's ability to connect to resources was determined by limited awareness, lack of connections to others, and location.
	Positive interactions with clinicians Caregiver needs	Caregivers reported some positive experiences with the medical system regarding physician behavior and accessibility. One caregiver noted that their physician regularly gave them hugs, which made them feel loved. Caregivers in our sample noted that they want increased dissemination and accessibility of resources, networking opportunities, and knowledge about fall prevention. Caregivers also reported wanting immediate access to advice from a doctor
Strategies to manage symptoms of dementia	Negative experiences with clinicians/health system	Hispanic caregivers experience pushback, dismissal of concerns, brevity of interaction, limited suggestions, dissatisfaction, care discontinuity, and false hope by physicians, especially when a language barrier is present. In addition, caregivers think appointments are hard to come by initially, are too long, and do not cater to immigrants.
	Communication with PLWD	Caregivers in our sample noted they would comfort PLWD who worry over their forgetfulness or repeat questions. They expressed understanding of PLWD's incontinence to reduce embarrassment. Caregivers avoided answering questions to force PLWD to think and encourage PLWD to not give up. They felt that PLWD often acted similar to children and used similar techniques to manage their behavior, such as enforcing "time outs."
	Avoiding altercations	Caregivers avoided altercations or mood fluctuations in PLWD to prevent aggression or hypertension.
	Creating activities for PLWD	Caregivers engaged PLWD in physical and mental activities, including exercise, conversation, and games. Caregiver initiating games of dominoes or bingo with PLWD
	Managing nutrition and food Daily activities of caregiving	Caregivers implemented health snacks, hid unhealthy foods, rewarded healthy eating with sweets, and found substitutes to combat appetite changes in PLWD. Caregivers prepared, controlled and supervised food intake, assisted PLWD with hygiene and toileting, and created and enforced house rules.
Cultural and gender expectations about caregiving	Cultural and gender influences	Caregivers in our sample reported that Hispanic PLWD valued communal over individual ownership, enjoyed unhealthy foods from their home country, preferentially followed commands from male figure, struggled with losing autonomy, and communicated frequently with friends and family. In one case, a Hispanic male PLWD tended to withdraw participation from therapy sessions, reject assistive technology (hearing aid) and withheld information from healthcare teams.
	Family responsibilities	We found variation in the level of support for caregivers from family members, where some caregivers share responsibilities and others resent absent family members.
	Feeling pride in caregiving	Some caregivers prided themselves in their ability to care for PLWD single-handedly. One caregiver noted feeling pride in being able to care for PLWD without help or nurses by being efficient
Managing medications	Complexity of medication management	Caregivers manage, time, measure, and reconcile multiple medications for PLWD. Caregivers adjust medications to manage side effects or infectious disease. Caregivers may trick PLWD into taking medications, especially when PLWDs are suspicious about medication management, and confirm consumption of some medications by checking vital signs.

Objectives

- 1: Identify knowledge, attitudes, and beliefs about dementia care among Hispanic caregivers of Persons Living with Dementia (PLWD).
- 2: Identify preferences for care delivery and education among diverse Hispanic caregivers of PLWD.
- 3: Identify strategies to reduce burnout among Hispanic caregivers of PLWD.

Background

- Hispanic PLWD are more likely than white PLWD to experience inappropriate use of feeding tubes and antipsychotics
- There is limited research on the perceptions and interactions Hispanic caregivers of PLWD have with physicians and other medical personnel.
- Hispanic caregivers for PLWD experience high degrees of burnout and distress.

Methods

- Qualitative study design informed by Constructivist Grounded Theory (CTG) methodology
- Recruitment: flyers in Cedars-Sinai and UCLA clinics, snowball sampling, flyers distributed to community organizations and senior day care centers
- Phone-based semi-structured interviews (n=8)
- Inclusion criteria for study participants: Adults (>=18 years) who self-identified as Hispanic and caregivers for PLWD
- The interviews were transcribed and checked for accuracy
- Two coders used line-by-line coding using gerunds to create codes (e.g., *caregiver feeling frustrated with physician*)
- Initial codes were grouped into focused codes
- Focused codes were grouped into larger themes

Conclusion

- Physicians should not assume that Hispanic caregivers of PLWD have strong family support, as caregivers may experience various levels of family support from their family. Clinicians should ensure that caregivers are supported and have access to resources
- Access to resources and medical information varies along the health literacy and trust continuum among Hispanic caregivers of PLWD
- PLWD have high levels of multi-morbidity and caregivers are interacting with multiple physicians, which can be challenging
- PLWD and/or their caregivers from Latin American countries may have experiences of trauma and PTSD. Clinicians should connect patients and caregivers with linguistically tailored mental health support
- Stigma/shame around certain dementia/Alzheimer's Disease can make it harder for Hispanic caregivers of PLWD to get support

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