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Making sense of behavioral disturbances in persons with dementia: Latino family caregiver attributions of Neuropsychiatric Inventory domains

Ladson Hinton, MD[*],
Department of Psychiatry & Alzheimer's' Disease Center, University of California, Davis

Darin Chambers, M.D., and
University of California, San Francisco

Alexandra Velásquez, B.S.
University of California, San Francisco

Abstract

The purpose of this study was to describe the nature and frequency of Latino family caregiver attributions for dementia-related neuropsychiatric symptoms. This is a cross-sectional study conducted in the Sacramento, California area. Participants were 30 Latino family caregivers of community-dwelling Latino elderly meeting research criteria for dementia who were selected from an ongoing cohort study of older Latinos (Sacramento Area Latino Study on Aging). Open-ended probes were used to elicit caregiver attribution for each symptom domain of the Neuropsychiatric Inventory (NPI). Across the 30 caregivers, 121 explanations for neuropsychiatric domains were present. Content analysis of these explanations revealed seven different attribution categories (i.e. Alzheimer's disease, interpersonal problems, other medical conditions, personality, mental, aging, and genetics). Overall, Alzheimer's disease was the most frequent attribution category but accounted for less than 30% of the total attributions. In conclusion, this study found that Latino caregivers were more likely to attribute neuropsychiatric symptoms to causes other than Alzheimer's disease or a related dementia.

Keywords

caregiving; Latinos; attributions; neuropsychiatric symptoms; Alzheimer's disease

INTRODUCTION

Identifying and overcoming barriers to care for dementia among minority populations is an important priority as our older population becomes more ethnically diverse[1]. This is particularly true for older Latinos, who may experience earlier onset of Alzheimer's disease[2] and who are historically underserved by our healthcare system. Understanding factors that may impede timely recognition and treatment of non-cognitive symptoms associated with dementia in Latino families is important for several reasons. Recent studies have found that neuropsychiatric symptoms, such as depression, agitation, and irritability may be more common among community-dwelling Latino elderly with dementia compared with white non-Hispanics[3, 4, 5, 6]. Neuropsychiatric symptoms contribute to disability in Latino elderly with

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[*] Corresponding author: 2230 Stockton Blvd, Sacramento, CA 95817, 916-734-3485, ladson.hinton@ucdmc.ucdavis.edu.

dementia[7], are associated with increased caregiver depression[5], and increase risk of nursing home placement[8]. While dementia neuropsychiatric symptoms and their associated caregiver distress are responsive to non-pharmacological and pharmacological interventions, Latinos report significant unmet need for professional help, particularly counseling and education[9].

Family recognition and interpretation of illness symptoms may contribute to under-recognition and under-treatment of dementia[1, 10] as well as other chronic illnesses[11]. Attributing symptoms, for example, to causes other than dementia may delay or hinder their recognition and treatment. Studies in the anthropological and gerontological literature suggest that minority elderly may be more likely to view dementia in ways that differ from the biomedical model[12]. In prior work we have found, for example, that minority elderly and those with less formal education are more likely to attribute dementia to causes that fall outside the biomedical model, such as normal aging[13].

One gap in our understanding of the attribution process as it relates to dementia is how caregivers recognize and interpret dementia-related neuropsychiatric symptoms, such as depression, anxiety, agitation and psychosis. The goal of this study was to address this gap in the literature by describing the nature and frequency of Latino caregiver attributions of neuropsychiatric symptom domains contained in the Neuropsychiatric Inventory, one of the most widely used assessment tools in the field of Alzheimer’s disease research.

METHODS

Subjects

Subjects in this study were Latino elderly meeting research criteria for dementia in the Sacramento Area Latino Study on Aging, (SALSA) a prospective epidemiological longitudinal cohort study of nearly 1800 Latino elderly and their family caregivers in the Sacramento area. The purpose of SALSA is to gain knowledge regarding the prevalence and incidence of dementia in addition to examining risk factors for dementia, cognitive and functional decline among Latinos age 60 and above in the larger Sacramento area[14]. An ancillary study of family caregiving to cognitively impaired SALSA participants was conducted during the first two waves of SALSA data collection, from 1998–2000. To be eligible for this sub-study, participants needed to be non-institutionalized and to have an identified family caregiver who was available and willing to be interviewed. Caregivers were identified as a family member either a spouse, adult child, sibling, in-law, or friend who provided the most day-to-day care to the person with dementia.

We attempted to recruit all SALSA participants with dementia during the first two waves of data collection, from 1998–2000. During this time frame, SALSA identified 82 persons with dementia were identified, 29 of whom were either not eligible or not available for this ancillary caregiving because they were either institutionalized, deceased, moved out of the area, or did not have an identified caregiver. Of the remaining 53, we were able to successfully recruit 38, or 72%. For the current analyses, we have further restricted the sample to the 30 SALSA participants meeting research criteria for dementia who also had one or more behavioral symptoms on the Neuropsychiatric inventory, a standard caregiver report instrument used to measure neuropsychiatric symptoms in older adults with dementia. The general methods, including the use of the Neuropsychiatric Inventory and prevalence of symptoms in this sample, are described elsewhere[5].

Methods

Caregivers were interviewed in their home either in English or Spanish by a bilingual interviewer. Neuropsychiatric disturbances were measured by the neuropsychiatric symptom inventory (NPI)[15], a semi-structured interview that includes modules to assess the presence, frequency, and severity of 10 neuropsychiatric symptoms: depression, anxiety, apathy, inappropriate elation, aggression, irritability, disinhibition, hallucinations, delusions, and aberrant motor activity. For each neuropsychiatric symptom that was present, the caregiver was asked: "What do you think is the cause of this symptom?" Thus, individual caregivers could report on attribution for each neuropsychiatric symptom that was present. Responses (usually one or two sentences) were recorded verbatim in either Spanish or English. A Spanish language version of the NPI and probes were developed through a translation/back-translation method[5].

Analysis

Analysis was done in several steps using standard approaches to content analysis of qualitative data[16]. Initially, qualitative responses from the survey were copied into an excel spreadsheet. Next, the PI and two research assistants independently reviewed the qualitative responses and generated a list of attribution categories. Through a process of comparison and consensus among the three raters, a list of categories was developed along with definitions. A code book was developed with definitions of each category and corresponding examples. Next, three bilingual raters independently rated the symptoms using the code book and responses were compared. Raters were instructed to code each attribution response under the single category that was most emphasized in the response - - if it was felt that two categories were equally emphasized, then the rater could code two attribution categories. The inter-rater agreement was 88.5%. The remaining 11.5% of the cases were resolved by the two raters and the PI. Finally, the frequency of each type of attribution was tabulated.

RESULTS

Sociodemographic and clinical characteristics

The mean age of caregivers was 60 (s.d. 13) with a range of 22–80 and care recipients was 74 (s.d. 8) with a range of 60–97. The majority of caregivers was women (70%) and spouses (60%). Of the care recipients, 53% were women. An equal number of caregivers were born in the US versus outside the US (usually Mexico). The mean number of behavioral symptoms was 4 (s.d. 2.3) with 10% of caregivers reporting only one neuropsychiatric symptom in the past month, 60% 2–4, and 30% >4. Nineteen of the 30 interviews (63%) were conducted in Spanish.

Description of attributions

In this section, we describe each of the attribution categories in more detail with examples. Overall, the 30 subjects reported 121 neuropsychiatric symptoms, each with an associated explanation. Coding of the explanations resulted in the identification of 8 categories plus an "other" category with more difficult to categorize explanations due to vagueness. Of the 121 explanations, 10 were judged to be compound, containing two attribution categories rather than one. Thus, the total number of individual attributions was 131. The following data are from those categories with an overall frequency of 5% or higher. Less frequent categories (genetics, aging) were combined into an "other" category.

Alzheimer's disease or a related dementia—The common thread in the explanations that fall into this category is that the behavior is attributed to an underlying brain disease or pathology related to the biomedical model of dementia. Included in this category are professional diagnostic labels, such as Alzheimer's disease or strokes, as well as the more general term dementia. In addition, terms that are commonly used by physicians and families to refer to Alzheimer's disease or a related degenerative dementia, such as memory loss illness, memory problems, or memory disorder, were included in this category.

Medical conditions—Behavioral problems were attributed to medical conditions other than dementia, such as other diseases, medications, or medical treatments and procedures. For example, several participants attributed the behavioral changes to control of diabetes, a medical condition that is common among older Latinos. Also included in this category are mentions of nonspecific illness terms such as enfermedad (illness), medications, and medical treatments or procedures.

Interpersonal—Behavioral changes were often viewed as a product of interpersonal loss and distress. Thus, caregivers cited the importance of family conflicts, lack of social support or contact, and loss of family members (due to illness, death, divorce, migration) as causes of behavioral changes. Also included are attributions of lack of communication with family, the family not helping out or visiting the patient.

Mental—For many caregivers, behavioral symptoms were attributed to emotional distress or disorder. These attributions included the use of less stigmatizing folk labels such as nervios, as well as references to mental illness or craziness. Among Latinos, nerves or “nervios” is a particularly common folk illness that frequently used to label psychological distress or suffering.[17]

Personality—In contrast to emotional factors, which signify a more transient state, a number of caregivers attributed behaviors to more long-standing traits or personality of the person.

Other—Several other attribution categories were identified but occurred in fewer than 5% of the caregivers and are not included in Table 1. Falling into this group were caregivers who attributed neuropsychiatric symptoms to the process of aging itself. For example, one caregiver told us *Su edad, ya no puede valerse por si mismo (his age, he can no longer have value for himself).* In addition, two family caregivers cited genetics as a possible explanation for neuropsychiatric symptoms. Finally, there were explanations that did not fit neatly into the above categories and are subsumed into the category of “other.” As an example, one caregiver told us: *She gets like that when she wants her cigars.* Another caregiver cited inactivity as a cause of behavioral symptoms.

Attribution frequency: The frequency with which caregivers cited each of the above categories to explain neuropsychiatric symptoms is reported in Table 2. The second column refers to the frequency of attributions based on the total number of attributions (i.e. 131). While Alzheimer’s disease was the most frequent attribution category, it accounted for less than 30% of the total attributions. Since one caregiver might have cited a particular attribution multiple times (i.e. as an explanation for multiple co-morbid neuropsychiatric symptoms), we also report how often attribution categories are reported by caregivers as an explanation for one or more neuropsychiatric symptom domains (Table 2, column 3). Viewed in this way, Alzheimer’s disease or a related dementia remains the most common attribution category followed closely by interpersonal attributions. Finally, Table 3 presents the frequency of Alzheimer’s disease or a related dementia versus other attribution categories for individual NPI symptoms domains. With the exception of aberrant motor behaviors, non-ADC attributions were more common than ADC attributions. Interestingly, the most prevalent symptom, depression, was the least likely to be attributed to Alzheimer disease or a related dementia (only 11% of the time) whereas irritability was attributed to Alzheimer’s disease or a related dementia nearly 50% of the time.

DISCUSSION

This study has two main findings. First, in this community sample of Latino family caregivers of elderly meeting criteria for dementia, it was more common to attribute neuropsychiatric symptoms to causes other than Alzheimer’s disease and a related dementia, such as other physical health problems, interpersonal problems, and personality. Alzheimer's disease and a related dementia was the single most frequent attribution but only accounted for less than 30% of the total attributions elicited. Second, the most common neuropsychiatric symptom in this sample, depression, was also the least likely to be attributed to Alzheimer's disease and related dementias. Nearly 90% of caregivers attributed depression to something other than Alzheimer's disease and related dementia.

To our knowledge, this is the first study to examine attributions of behavioral symptoms in families of elderly with dementia, either minority or non-minority, in the United States. Our results are consistent with one prior study that examined attribution of caregivers for problem behaviors, including both cognitive and non-cognitive symptoms.[18] Based in England (ethnic breakdown not reported), this study found that problematic, non-cognitive symptoms were often attributed to causes other than dementia. The fact that two separate studies conducted in different countries have similar findings suggests the relevance for other populations as well.

Attribution of behavioral symptoms may be influenced by a number of factors. The illness behavior model offers one framework for understanding the process of symptom recognition and labeling[11, 19]. According to this model, the interpretation of symptoms may be influenced by the characteristics of the person, characteristics of the family member, the nature of their relationship, and interactions with others in their formal and informal network. While a comprehensive review of all of these factors is beyond the scope of this manuscript, Latino caregivers characteristics that might influence the attribution process include prior personal experiences of persons with Alzheimer's disease, years of formal education, health literacy, acculturation level, language limitation, insurance status. There is considerable variability in how caregivers understand dementia itself [13] and this may play an important role in how they view neuropsychiatric symptoms. Characteristics of the person with dementia relevant to the caregiver's symptom attribution might include severity of the neuropsychiatric symptoms, dementia stage (early vs. moderate or late stage), and the presence of co-morbid medical or psychiatric illnesses.

Encounters with primary care providers may be important opportunities for the clinical recognition and family psychoeducation about dementia-related behavioral problems that have become particularly difficult or burdensome. However, dementia neuropsychiatric symptoms and behavioral problems may go unrecognized or under-treated in primary care settings due to clinicians' lack of knowledge as well as time, reimbursement, and other constraints inherent to many primary care settings.[7] In prior qualitative work, we have shown that the cause or nature of non-cognitive symptoms, such as aggression or irritability is often ambiguous when viewed from the perspectives of both primary care physicians and families [9]. While in some cases the neuropsychiatric symptoms represent a dramatic departure from how the person was prior to the development of dementia, in other cases neuropsychiatric symptoms may be understood as an outgrowth of pre-existing personality. Ultimately, the "cause" of neuropsychiatric symptoms is often multi-factorial, reflecting the interaction of underlying brain pathology with psychological, interpersonal, and environmental factors.

It is important to mention the strengths and limitations of this study. One strength of this study is that it is based on a sample drawn from a community-based study and is therefore more representative of the general population in the target area (Sacramento Area) compared with clinic-based or convenience samples. Because of the modest sample size - - 30 dementia caregivers - - the data on frequency of the attribution categories should be viewed with caution. In addition, a larger sample or more in-depth exploration of caregiver attributions might have yielded additional attribution categories.

The implications of these findings for clinical care and help-seeking deserve further attention and study. It is possible that caregivers who attribute problematic symptoms to causes other than Alzheimer's disease may be more likely to feel that the person with dementia has full control of their symptoms, a view that may increase interpersonal tension and behavioral disturbances through blame and criticism. It is also possible that attributing behavioral symptoms to causes other than dementia may delay or prevent families from seeking formal care, leading to unnecessary caregiver burden and strain. Improved primary-care based psychoeducation of caregivers about difficult behavioral problems and more proactive screening has the potential to improve the quality of life for both the patient and family, as it may help them better understand and manage these behaviors and also motivate them to access appropriate community services, such as support groups.

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Table 1

Attribution categories with examples

Alzheimer's disease or a related dementia
I think it's the dementia & nothing else
Es resultado del stroke. No hacía eso antes. (It's a result of the stroke. She didn't do this before)
Es la enfermedad de la memoria (It's a memory illness)
Medical conditions
Por su medicinas (because of his medications)
It's the diabetes
Es su enfermedad; seizures (it's his illness; seizures)
Interpersonal:
Loneliness (soledad)
Le hace falta convivir con personas de su edad (They miss being with people their own age)
Es por los hijos. No todos viven aqui, se preocupa por los hijos en Mexico(/It's because of the kids. Not all of them live here, she worries about the kids in Mexico)
Yo le echo la culpa a un hijo que nos salio un poco mal. Ella se preocupa mucho por él. (I place the blame on our son who came out a little troubled. She worries so much about him).
Mental
Psychosis
Los nervios
Personality
Es caprichudo y enojon como siempre (He is stubborn and argumentative like always)
No sabe controlarse y se enoja de todo. Siempre ha sido asi. (He doesn't know how to control himself and he gets mad at everything)

Table 2

Percentage of frequency and subjects neuropsychiatric symptom attributions

Perceived Cause	**Overall frequency (n=131)**	**Number of caregivers citing as cause of one or more symptoms (n=30)**
Alzheimer’s, n (%)	40 (31%)	12 (40.0%)
Medical, n (%)	22 (17%)	9 (30.0%)
Interpersonal, n (%)	21 (16%)	11 (36.6%)
Personality, n (%)	18 (14%)	6 (20.0%)
Mental, n (%)	12 (9%)	8 (26.6%)
Aging, n (%)	3 (2%)	3 (10%)
Genetics, n (%)	2 (2%)	2 (7%)
Other, n (%)	19 (14%)	13 (43.3%)

Table 3

Attribution of Neuropsychiatric Inventory (NPI) domains to Alzheimer's disease and related conditions (ADC) versus other causes (N varies by individual symptom)

NPI Domain	ADC, n (%)	Non-ADC, n (%)
Depression, n=27	3 (11.1)	24 (88.9)
Anxiety, n=14	2 (14.3)	12 (85.7)
Elation, n=9	2 (22.2)	7 (77.8)
Apathy, n=12	5 (41.7)	7 (58.3)
Disinhibition, n=13	5 (38.5)	8 (61.5)
Irritability, n=17	8 (47.1)	9 (52.9)
Aberrant motor, n=6	4 (66.7)	2 (33.3)
Delusions, n=9	3 (33.3)	6 (66.7)
Hallucinations, n=11	3 (27.3)	8 (72.7)
Aggression, n=13	5 (38.5)	8 (61.5)