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Dementia Knowledge Among Hispanic Family Caregivers

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Abstract

The Health Projects Center (HPC) was established in 1980 as a non-profit corporation serving Monterey, Santa Cruz, and San Benito Counties. HPC offers programs to health and social service professionals, older adults, and family caregivers. At HPC many caregivers experience health problems associated with caregiving distress. To address this concern, "*Dementia Knowledge Among Hispanic Caregivers*" was implemented, to determine the effectiveness of the Caregiver Support Group at HPC. This group consisted of caregivers of Mexican descent, whose primary language is Spanish, who are caring for a loved one who suffers from dementia or a cognitive disorder. In order to assess caregivers' knowledge of dementia and stress, a questionnaire was used. The expected outcome was for all participants to recognize the symptoms of dementia and to recognize when they are under stress. The questions were read aloud for the participants to ensure there were no language barriers. The findings were that 66.67% recognize symptoms of Alzheimer's and even though, 83.33% recognized when they were under stress, only 50% practiced self-care. There are three recommendations for the agency, including implementing a session in the support group that focuses more on enhancing the caregiver's knowledge on different stages of dementia. Additionally, it is recommended to have two groups, one for experienced caregivers and the other for new caregivers. Finally, all caregivers could use more support on how to actually practice self-care.

Keywords: Hispanic, caregivers, dementia, distress, awareness

I. Agency and community served

The Health Projects Center (HPC) is a private non-profit 501(c) community-based health organization serving Monterey, Santa Cruz, and San Benito Counties. The HPC offers health and social programs serving health and social service professionals, older adults and family caregivers. The agency addresses the health and human needs of individual, families, and communities of California's Central Coast by developing and implementing high-quality programs and strategies. The Health Projects Center implements multiple programs such as the Multipurpose Senior Services (MSSP) and the Caregiver Resource Center Program (CRC). The Del Mar Caregiver Resource Center is affiliated with the California Health Care Services statewide Caregiver Resource Center network, serving people who caring for a family member or friend over 18 years old, with brain impairment resulting from conditions such as cerebrovascular/stroke, traumatic brain injuries or tumors, Alzheimer's disease, multiple sclerosis, Parkinson's disease, mild cognitive impairment, other mild cognitive impairment, and other conditions that may cause memory loss or confusion (The Health Projects Center, n.d.).

Del Mar CRC is 75% state funded along with funding from grants and donations. The goals of Del Mar CRC are to improve quality of life for in-home caregivers and their families caring for a loved one with a neurocognitive disorder, improve access to and quality of health services for the medically underserved, improve outreach, community relationships, and marketing efforts, and improve existing systems and operational workflow. CRC supports family caregivers with care planning and support services including support groups, education, respite care, legal consultation, counseling, and referrals. Services are free of cost or require a modest co-pay (The Health Projects Center, n.d.).

II. The problem

One sentence statement of the problem

Hispanic caregivers encounter health problems associated with caregiving distress.

Problem definition and description

A caregiver is an informal person caring for an adult friend or family member at home with no pay. Mainly women, take the responsibility of a caregiver when a loved one has a cognitive disorder caused by dementia. Dementia is a chronic or persistent disorder of the mental processes caused by brain disease or injury and marked by memory disorders, personality changes, and impaired reasoning (Health Projects Center, n.d.). A person who suffers from dementia will need more long-term care from the caregiver, thus putting caregivers at risk of developing high levels of stress, leading to chronic conditions such depression, cardiovascular problems, high blood pressure and other physiological conditions (Schulz & Sherwood, 2008).

Contributing Factors

The first contributing factor is the lack of knowledge about dementia among Hispanic caregivers. Caregiver's lack of understanding of "care recipient's behavior problems, cognitive impairment, and functional disabilities" (Schulz & Sherwood, 2008, p. 25), can lead to stressful situations when they cannot comprehend what is happening with their loved one and how to manage their behavior affecting how caregivers interact with care receivers.

The second contributing factor is cultural barriers. The limited information available in Spanish lacks cultural context. Hispanic caregivers find it hard to relate to the translated information because the advice sounds foreign and inappropriate. Another cultural barrier is machismo; in the Hispanic culture, it is expected for the closest female family member to take

care of an elder (Cucciare et al., 2010). Because of this expectation, Hispanic caregivers hardly seek help within the family system.

The third contributing factor is the language barrier. Hispanic family caregivers who cannot communicate in their native language have difficulties understanding information provided. While Tunner et al. (2015) argued that Latino dementia caregivers reported that when they asked for help they did not get the adequate help needed from the doctors or nurses, Yeo and Gallagher-Thompson (2006) observed that the “inability to speak English had been empirically associated with less care seeking and reduced access to services” (p. 334). Caregivers’ lack of English language skills becomes a barrier when they are trying to have access to quality information or resources needed for themselves and their loved one.

Problem consequences

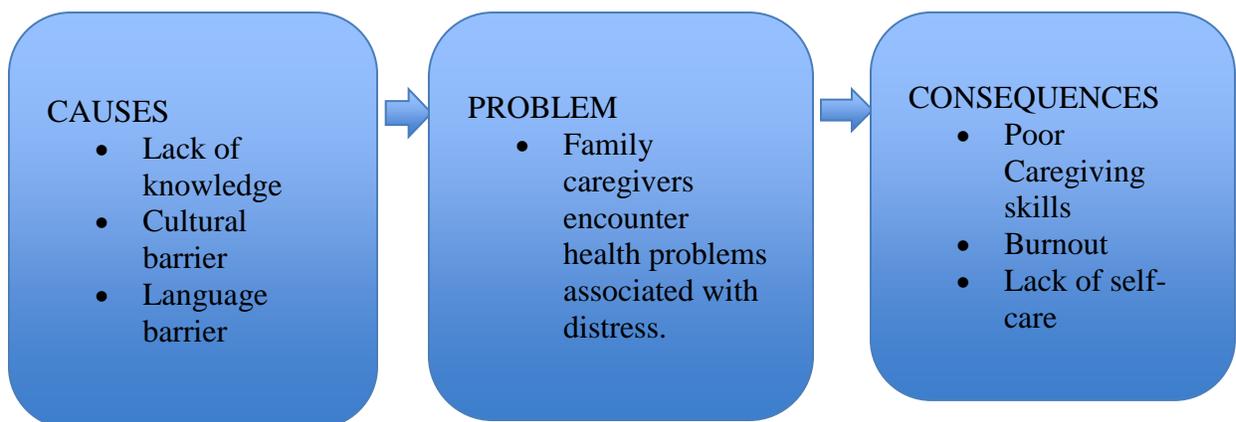
Poor caregiving skills are one of the consequences that caregivers face when they cannot recognize the symptoms of dementia. According to Cucciare et al. (2010), Hispanic caregivers are more likely to provide care for a disabled person for more than one decade. When caregiver’s health gets compromised, their ability to provide quality care for their loved one diminishes. As a result, poor caregiving skills can lead to unintentional injuries and self-medication (American Psychological Association, 2018). Inevitably, strained caregivers are vulnerable to suffer from physical, mental, and emotional hardship (Health Projects Center, n.d).

Burnout is another consequence that caregivers face during the caregiving process. Caregivers face stressful situations when trying to cope with the demanding job and trying to balance their personal life. Consequently, they are more likely to suffer from chronic stress, leading to health problems, such as “depression and anxiety, pain of any kind, sleep problems, autoimmune diseases, digestive problems, skin conditions, such as eczema, heart disease, weight

problems, reproductive issues, thinking and memory problems” (Helpguide.org, 2018). When caring for a person with dementia, caregivers will suffer emotional and physical distress compared to other caregivers caring for a non-dementia related illness (Schulz & Sherwood, 2008).

The third consequence is the lack of self-care among Hispanic caregivers. According to Claudia Mendez, (Personal Communication, September 17, 2018) from her experience managing the Multipurpose Senior Services Program, she has observed that Hispanic caregivers sometimes do not know how to ask for help, thus creating barriers to community services or services within their family network. Even, when family members offer their support, they hesitate to accept it because of their cultural and personal values. Friedemann and Buckwalter (2014) noticed that in previous research, it was challenging to assess burden on “Mexican caregivers of both genders who had strong family commitment and could not admit to negative feelings since acknowledgment of burden was culturally unacceptable” (p. 316). Consequently, caregivers will reject any help even when they acknowledged their burden.

Problem model



III. Capstone project description and justification

Project title

Dementia Knowledge Among Hispanic Family Caregivers.

Project, Purpose, and Justification

The original capstone project consisted of three workshops in a series. The project was an educational intervention, and the purpose was to increase awareness about dementia and to reduce the stigma associated with this disease. Due to unexpected circumstances, the original capstone project was canceled one day before it was about to be implemented, and a second project replaced it (see Appendix A). The second project was a pilot project that consisted of evaluating the caregiver support group about dementia knowledge gained from the support group. The caregivers from the support group were women of Mexican descent. The caregiver support group consisted of a one-hour support group and one-hour educational session. This group meets every second Monday of each month from 5:30 pm to 7:30 pm.

The purpose was to find out how effective the support group was for the caregivers, and to address gaps if any. The implementation method consisted of gathering data through the distribution of a questionnaire. The goal of the project was for all participants to verbally agree to answer the questionnaire and to see the impact of the support group on the caregivers through data collection.

The project was a pilot and evaluated six Hispanic family caregivers of dementia patients. All of the caregivers provide informal care for a family member that suffers from a cognitive disorder. There is not enough research about Hispanic support groups' evaluations, and for this reason, the project aims to find out the effects of the caregiver support group among its participants. Llanque and Enriquez, (2016) argued that "Evidence-based interventions are needed

to facilitate and improve caregiving and health maintenance among the growing number of Hispanic/Latino caregivers and Hispanic/Latino older adults” (p. 31). Llanque and Enriquez, (2016) emphasized that “these interventions must build on the cultural strengths that Hispanic/Latino dementia caregivers possess” (p. 31). The goal of the project is for the support group to be inclusive and to provide information that is culturally sensitive to its participants.

The capstone project was similar to the one from Chou and Laoi (2004) which consisted of evaluating caregivers who were caring for a family member who had dementia. Their study consisted of one-time observation of caregiver’s interaction during the support group as well as quantitative data. Their objective was to indicate “that support groups have been one of the good intervention strategies to address the problems of caregivers” (Chou & Laoi, 2004, p. 1). The project may have similar results since 100% of participants of the caregiver support group are a minority with lower education.

Project implementation

The persons involved in the implementation of the project were Carmen Hernandez Gomez, intern, Claudia Mendez, and Christina Andrade, mentors. The questions for the questionnaire was written based on the purpose of the caregiver support group, which is to “connect with other caregivers in similar situations, learn about and understand their loved one’s disease process, stay informed of community resources, share common concerns and received needed support” (Health Projects Center, n.d.). The questions were rephrased among these topics. There were five self-rated awareness questions about stress, knowledge about dementia, and practice behaviors like self-care. All the questions were written in Spanish since that was the primary language of all participants. The questions needed to be short, concise and to the point, and use a simple enough language to convey meaning. A Google form was used to create the

questionnaire. Once the questionnaire was finished, a copy was printed to hand out to the mentor for approval. Once approved, copies were made for participants. Personal data was not collected through the questionnaire. The questionnaire was planned to be implemented in 15 minutes at the end of the support group. The questionnaire was handed out to participants, and they were told to wait until the questions were read aloud. See Appendix B for detailed scope of work.

Obstacles and unexpected circumstances

Obstacles presented during the implementation of the project were having new mentors that had little knowledge about the implementation of the original project. In the beginning, it seemed that everything was already prepared, but mentors realized that a lot of things were still vague. Another unexpected circumstance was that Salud Para la Gente canceled the first workshop of the project one day before its implementation, and mentor did not know what was going to happen with the second workshop. In consequence, other project had to be thought of right away, which consisted of an evaluation of dementia to the Spanish caregiver support group that already exist within the agency.

IV. Project Results

Assessment of project outcomes

One of the ways to assess knowledge gained as a result of the support group was a short test asking participants about dementia knowledge. The participants answered the following statements: I can describe dementia; I can recognize symptoms of Alzheimer's; I know what to do when my loved one has a crisis; I practice self-care; I can recognize when I'm under stress; (see Appendix C). Participants agreed to complete the questionnaire and results were analyzed using Microsoft Excel.

Results

A total of six caregivers were present during the caregiver support program, with one caregiver attending for the first time. All of the caregivers were middle age of Mexican descent women whose primary language was Spanish. Results and examples presented in the following paragraphs include information from observations.

The first question was about dementia knowledge and asked participants to respond whether or not they could describe dementia.

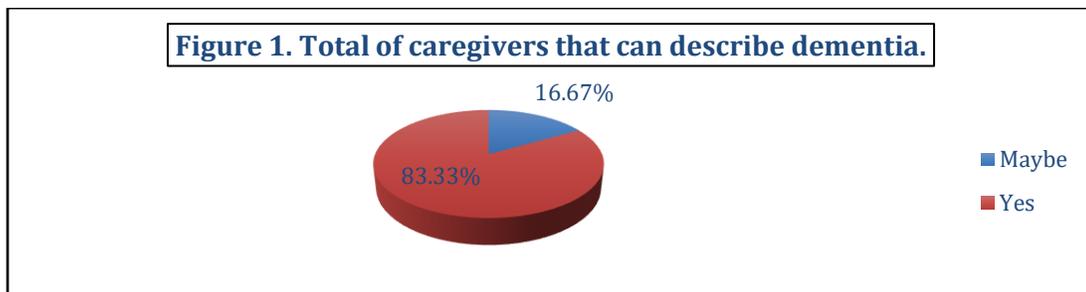


Figure 1. A total of five (83%) caregivers stated that they could describe dementia, only one (16%) responded “maybe.” The participant that responded maybe to the question was new to the support group.

The second question was asking participants if they could recognize symptoms of Alzheimer's.

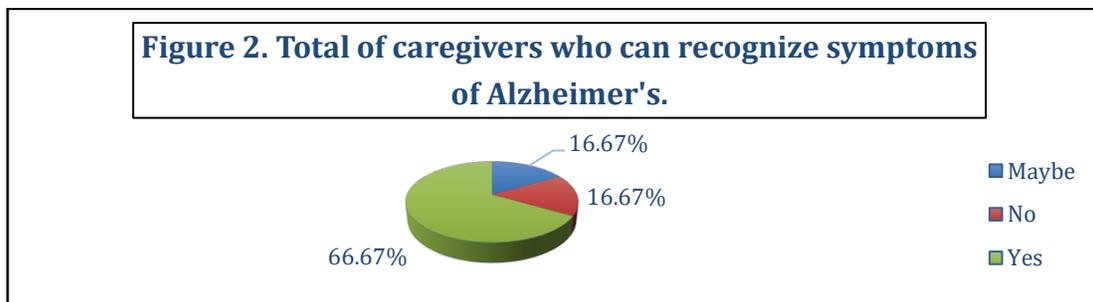


Figure 2. A total of four (66%) of the participants responded “yes,” and one (16%) responded “maybe,” and one (16%) responded “no.” This data contradicted the observational

data. When the participants were interacting trying to support the new participant, only three participants were able to recognize behaviors that were related to dementia. Some of the statements from the participants were “I do not understand her sometimes,” “I do not know why she is behaving that way,” “sometimes I feel that she is doing this to upset me.”

The third question was asking participants if they knew what to do in a crisis with their loved one.

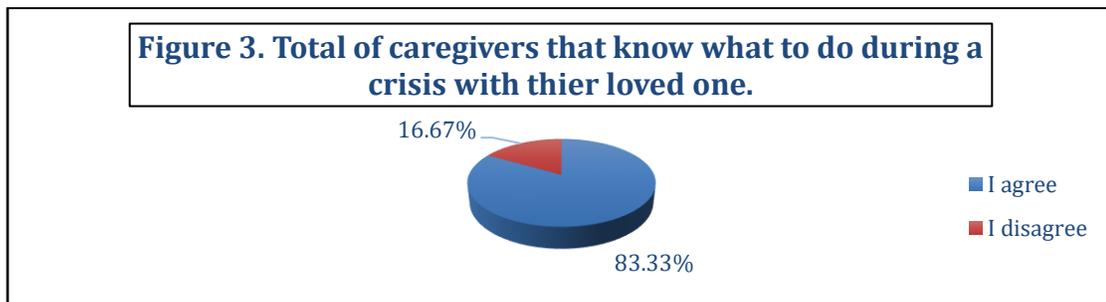


Figure 3. A total of five (83%) agree that they knew what to do in a crisis with their loved one, and one (16%) said “no.” The observational data contradicted the data from the questionnaire, since during the participant's interaction more than three participants felt overwhelmed by their loved one’s behavior, and reported feelings like walking away, quitting or not coming back to their loved one.

The fourth question asked participants how many times a week they practiced self-care.

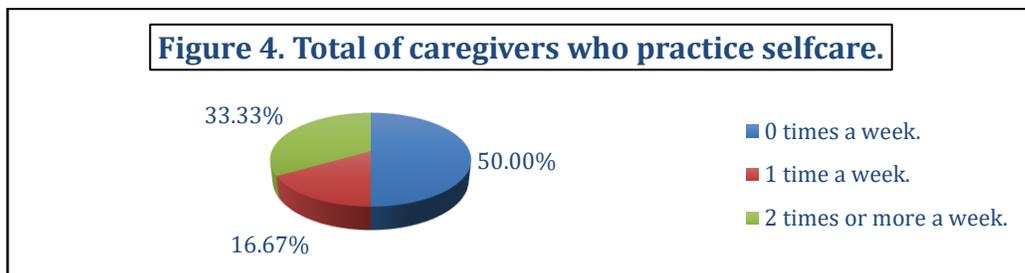


Figure 4. Two participants responded two times a week, one responded one time, and three responded zero times a week. This question had to be explained to the participants because

the majority asked what self-care meant. During the participant's interaction, comments like, “I am always too busy,” “I can never find time to relax,” “I'm already tired when I come home from work” were the main focus of the conversation. Only one participant was aware of the importance of self-care.

The last question was asking participants if they could recognize when they were under stress.

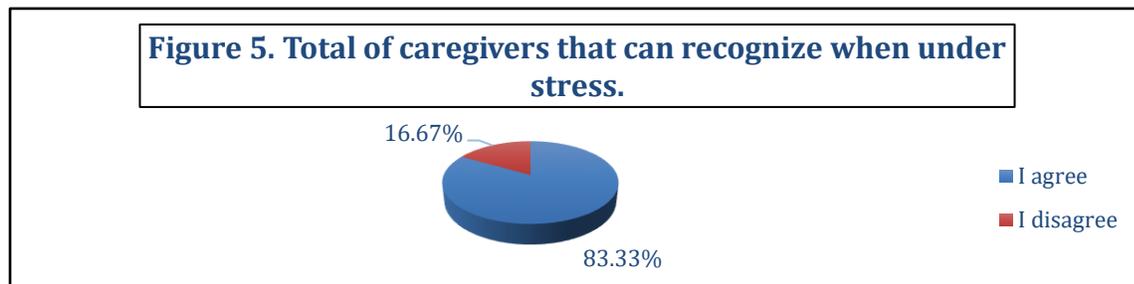


Figure 5. A total of five (83%) participants responded that they could recognize when they were under stress. Only one (16%) responded “disagree” to the question.

Participants got emotional when they were talking about how hard it was for them to take care of their loved one after a long day at work, and not having the support of their family members. Another caregiver said that she could not take it anymore and that she was about to quit. Another caregiver mentioned that she was having health problems and could not see a doctor because she did not have medical insurance.

Strengths/Successes

One of the strengths in the implementation of the project was that there was strong communication among the participants. As there were indications that the project was going to be canceled, mentors cooperated to approve the second project right away. Also, the facilitator of the support group was flexible by giving time at the end of the support group to implement the questionnaire. The participants agreed to answer the questionnaire without any previous notice. All of the points mentioned above contributed to the outcomes of the project.

Limitations/challenges

One of the limitations was time management. There was little time to prepare for the project since the group only meets once a month and that was the only opportunity to gather the data. Another challenge was that the participants did not know about the project in advance and did not know how the participants were going to react to the questionnaire.

V. Personal Reflection/final thoughts

Family caregivers faced an array of adversities as informal caregivers. They have to deal with their own needs, and also have to arrange the time to meet their loved one's care and medical needs. Sometimes caregivers are forced to quit their jobs to make sure that their loved ones are not alone at home, consequently, bringing financial hardship to the household. Hispanic family caregivers are more reluctant to seek or accept help from family members and from the resources that exist in their community. The project was an opportunity to look more closely at some of the specific needs of Hispanic family caregivers. For example, caregivers need to learn more about dementia and the importance of self-care. They also need to link their loved one's behavior to the disease. There are three recommendations for the agency, including implementing a session in the support group that focuses more on enhancing the caregiver's knowledge on different stages of dementia. Additionally, it is recommended to have two groups, one for experienced caregivers and the other for new caregivers. Finally, all caregivers could use more support on how to practice self-care.

One of the things learned from the implementation of the project was that the project gave insight on things that need to be addressed for the participants to be more effective caregivers. The agency will be able to implement educational sessions about how to alleviate the

burden of being an informal caregiver in a way that is culturally appropriate and sensitive for them.

Broader social significance

Family caregivers perform a challenging task every day, and one of the ways to address their caregiving needs is through support groups. Evaluations on support groups should be done at least once a year, especially when new members come into the group. Some caregivers react with concern when they hear how difficult it is for other caregivers handling their loved one's behavior. It would be ideal if they can learn how to manage challenging behavior from a professional perspective. Therefore, Hispanic family Caregivers will be more likely to know how to react to strange behaviors that are common for dementia patients.

The advice for a future capstone student is to always communicate with mentors and to establish a good relationship with them. Also, ask questions when things are not clear, especially when important things are at stake (e.g., graduation deadlines), and always follow your instincts. Another advice is to establish rapport with the clients, especially with the ones that will be part of your project and listen with the heart to comprehend better what they are going through every day with their loved ones.

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Appendix A

Activity Table 1.

Activities	Deliverables	Timeline	Estimated Completion of the project
Arranged a conference with capstone mentor and workshop facilitator	Gather information needed to prepare for the gathering data.	September 17, 2018	September 17, 2018
Revised PowerPoint	To make sure that is culturally appropriate	Sep. 15-Sept. 19, 2018	Sept. 28, 2018
Prepared tools, revised questions, went over the material.	Questionnaire and PowerPoint and handouts	Sept. 15 to Sept.17, 2018	Sept. 28, 2018
Mock-Run/ Review/ questions were added to ask during the class session.	PowerPoint	Sept. 17- Sept. 24	Sept. 24, 2018
Workshop # 1 Cancelled.	Project Cancelled	Oct. 4, 2018	

Appendix B

Activity Table 2.

Activities	Deliverables	Timeline	Estimated Completion of the project
Brainstormed for questions to have in the questionnaire.	Questionnaire.	Sept. 24 to Sept. 25, 2018	September 26, 2018
Typed the questionnaire in a google form.	Google form app.	Sep. 25, 2018	September 25, 2018
Went over the questionnaire with mentors, Claudia and Christina and it was approved.	Printed Questionnaire.	September 27	September 27
Made changes to one of the questions and printed copies.	Questionnaire copies.	October 1, 2018	October 1, 2018
Questionnaire was distributed to participant.	Spanish questionnaire.	October 1, 2018	October 1, 2018
Data gathered from questionnaire was enter into an Excel Spread Sheet.	Questionnaire and notes from observation.	October 02, to October 05, 2018	October 10, 2018
Data was translated from Spanish to English.	Questionnaire/ Excel Spread sheet.	October 7-10, 2018	October 11,2018
Data was analyzed using pivot tables.	Data and Excel Spread Sheet.	October 20-25	October 30, 2018

Appendix C

Cuestionario sobre el conocimiento de la demencia.

1. Puedo describir que es la demencia

Si

No

Tal vez

2. Puedo reconocer síntomas de Alzheimer.

Si

No

Tal vez

3. Se qué hacer cuando mi ser querido tiene una crisis.

Estoy de acuerdo

Estoy en desacuerdo

Estoy muy en desacuerdo

4. Me cuido a mí Mismo (a).

0 veces a la semana

1 vez a la semana

2 o más veces a la semana

5. Puedo reconocer cuando estoy estresado(a).

Estoy de acuerdo

Estoy en desacuerdo

Estoy muy en desacuerdo