



LET US NOT FORGET THOSE WHO CAN NO LONGER REMEMBER US: THE FACES OF ALZHEIMER

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INTRODUCTION

During the last few decades, Alzheimer's cases in Puerto Rico have been rising dramatically. According to the Health Department of Puerto Rico, for the year 2015 the confirmed numbers Alzheimer's patients rose to about 34,500, although conservative estimates adding undiagnosed cases was about 70,000. Alzheimer's is considered to be the fourth cause of death in Puerto Rico.

Those who suffer from Alzheimer's need family care 24 hours a day, 7 days a week, just to maintain basic life function. The care of the Alzheimer's patient requires efforts and changes in life priorities for caregivers, but they must learn to balance the patient care with their own needs and the needs of other family members. All family members should be educated on the conditions and progression of the disease, and must exercise preventative healthy lifestyle choices to protect themselves and the Alzheimer's patient. Many studies have shown that most families reach a point when the home care of the patient is unbearable, so it is recommended that families of Alzheimer's patients consider early in the disease the financial options needed to place the patient in a live-in full time care institution specializing in those patients.

According to the World Health Organization (OMS), chronic diseases are defined as having long duration and of slow progression. Following this definition, the Health Department of Puerto Rico defines Alzheimer's as a chronic condition, neurologically progressive, which affects mental processes such as memory, attention deficiency, executive functions, as well as speech, among other behavioral changes. According to the Alzheimer's Association, caring for a loved one can be a satisfying experience, while demanding great responsibility and time sacrifices. This Association suggests that the care givers should endeavor to watch out for themselves, seek assistance from other family members and community resources.

In the light of the above issues this mixed study was made.

OBJECTIVES / HYPOTHESIS

The following objectives have been identified for this study:

- Learn the best techniques and strategies for caring for an Alzheimer's patient.
- Identify the best ways for a care giver to stay healthy, physically, mentally and emotionally.

The hypothesis to prove are as follows:

- The best care is given by someone who has been well educated about the disease, its progression and its needs.
- The care giver can maintain their own healthy lifestyle while caring for their Alzheimer's patient.

METHODOLOGY

For the quantitative analysis, a questionnaire was used from a sample population of 12 caregivers. It consisted of ten questions available through the "Survey Monkey" program, and its contents were kept confidential to avoid tainting the results. Five of the ten questions are presented:

Quality of Life of Caregivers of People with Alzheimer's

1. Are you more stressed since you take care of that person?
 - always
 - almost always
 - sometimes
 - almost never
 - never
2. Do you feel that important decisions about your life revolve around the person you care for?
 - always
 - almost always
 - sometimes
 - almost never
 - never
3. Do you feel alone in the process of care giving responsibilities?
 - always
 - almost always
 - sometimes
 - almost never
 - Never
4. Do you want to end your caregiver responsibility?
 - always
 - almost always
 - sometimes
 - almost never
 - never
5. Are you satisfied with your work in caring for that person?
 - always
 - almost always
 - sometimes
 - almost never
 - never

For the qualitative portion of this study an interview approach was used on a sample population of 5 caregivers, using questions intended to identify the most difficult tasks and techniques utilized to achieve the best results.

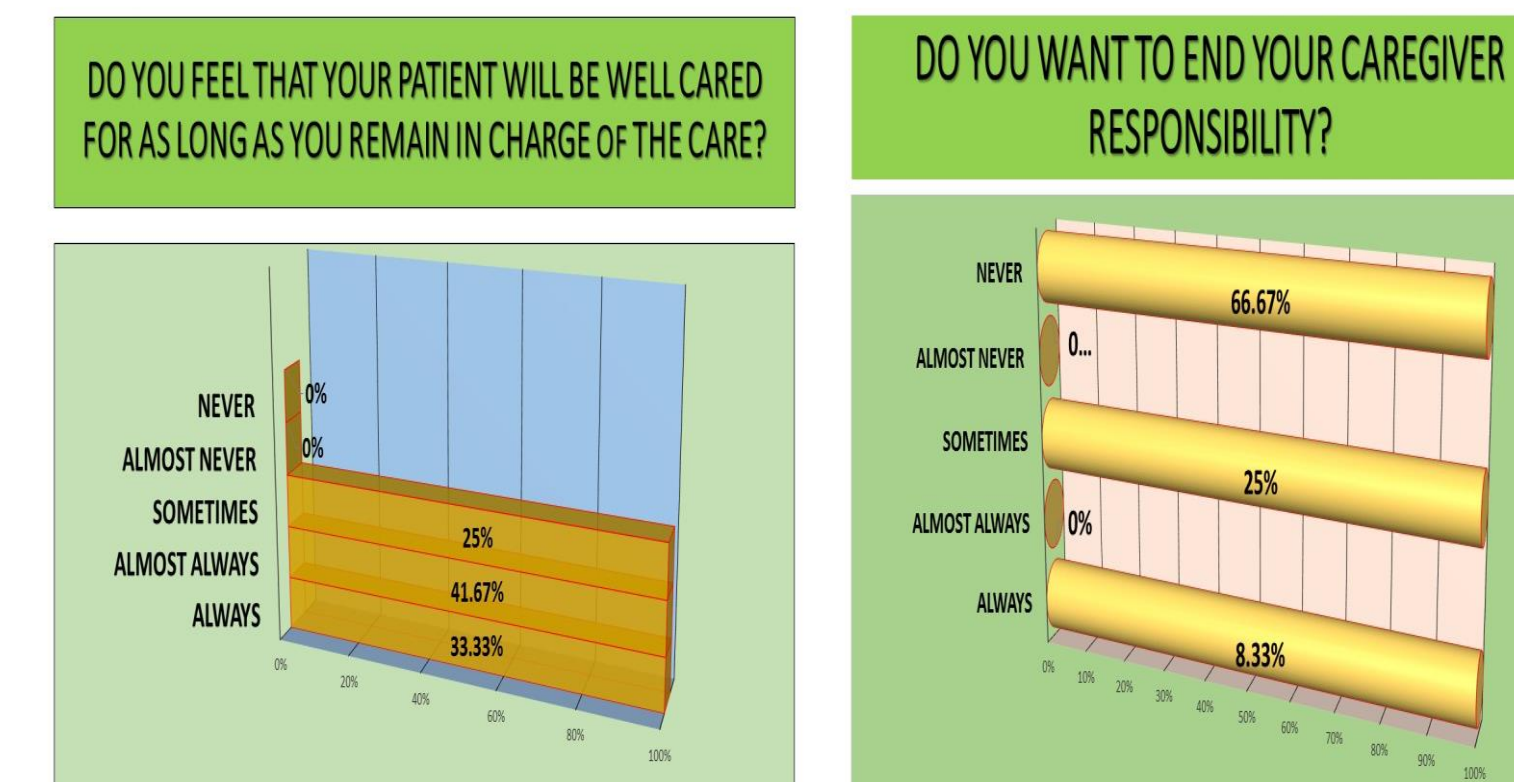
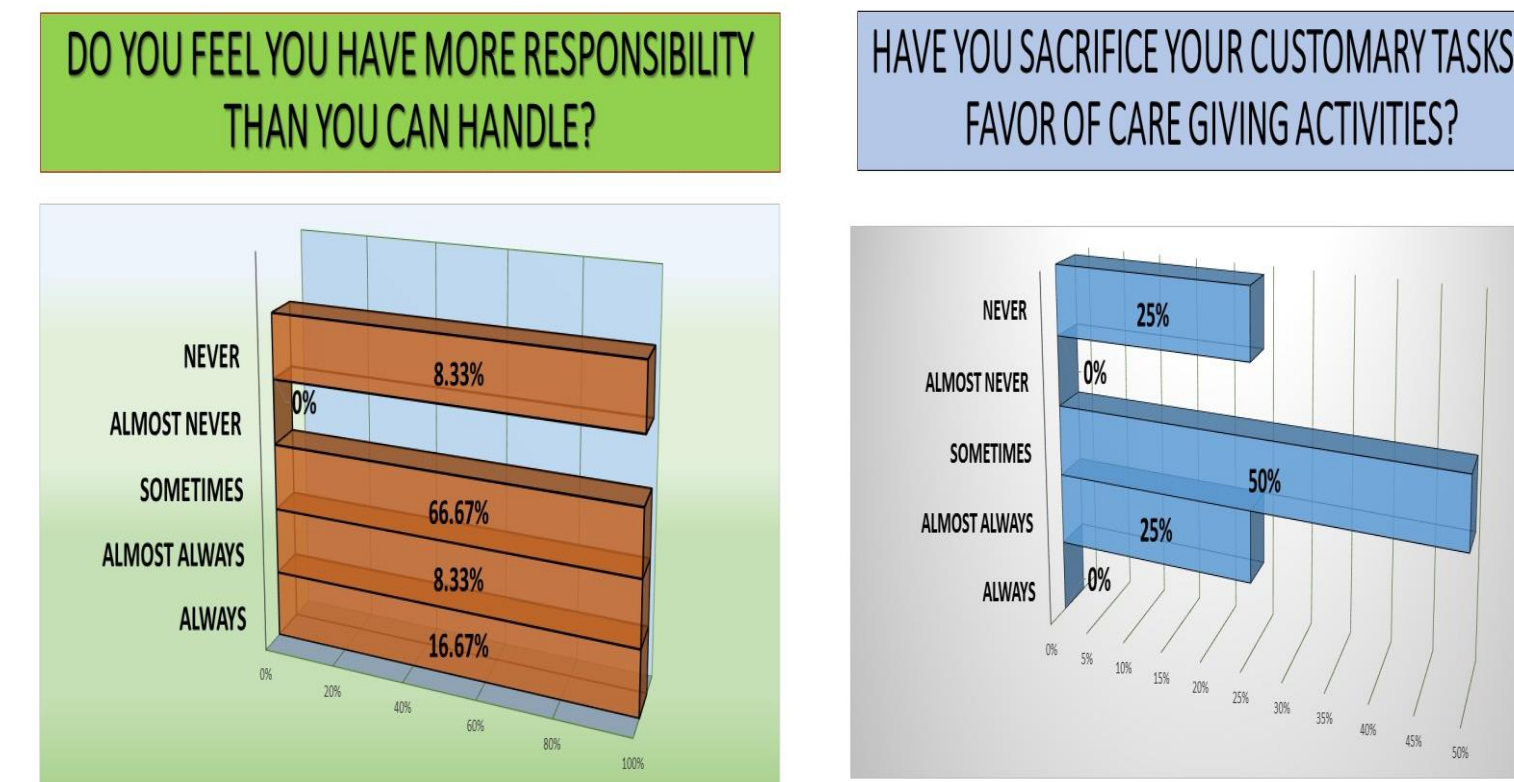
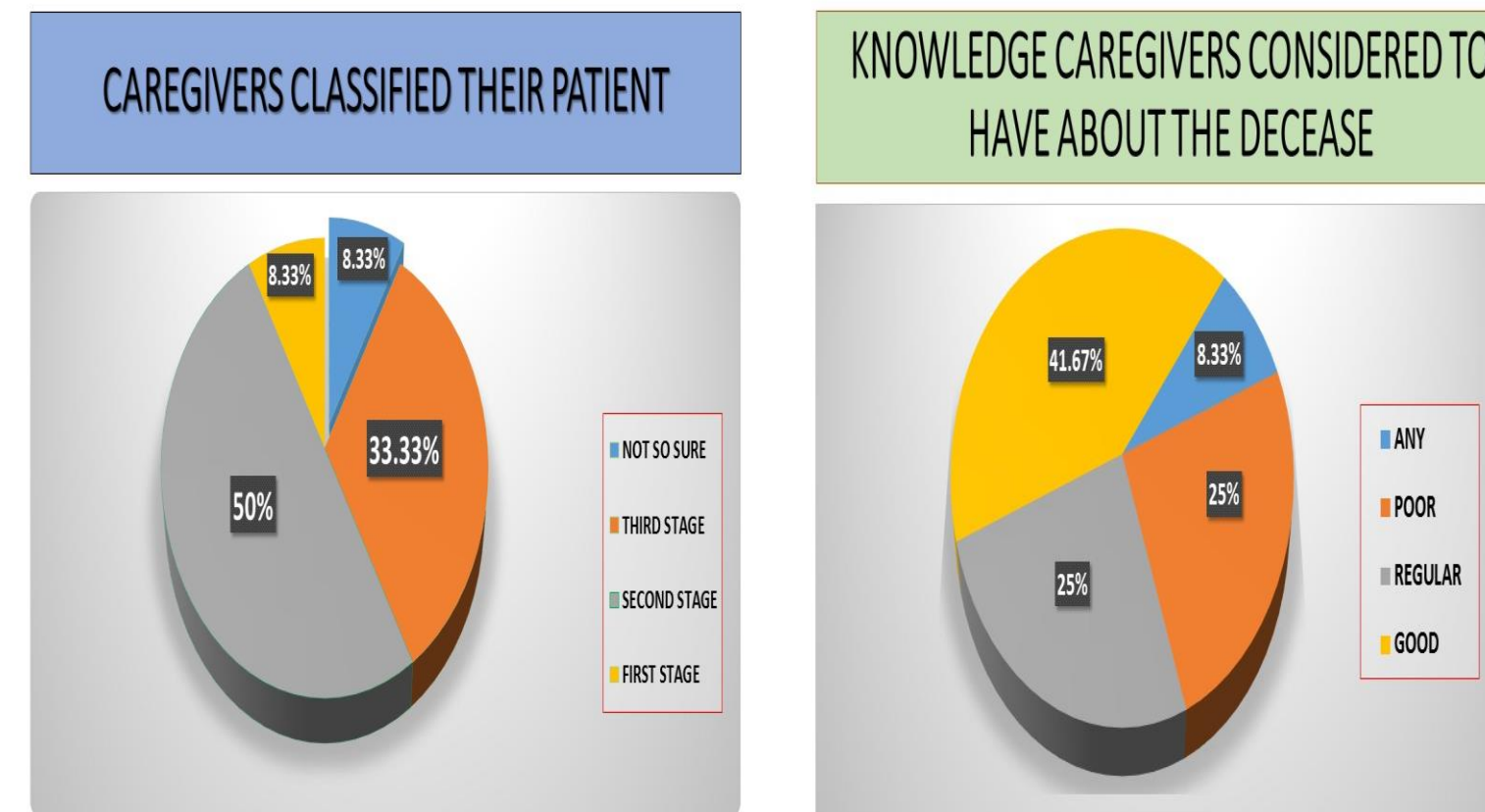
Field data was also compiled by observations of the fallows activities:

- "Camina por tu Heroe", which took place in September 2016 in San Juan P.R.
- A meeting of the Support Group of Caregivers in Manati, P.R., during November 2015.



RESULTS

The results of the questionnaire were as follows:



RESULTS

Other results of the questionnaire are:

- Six caregivers (50%) sometimes consider themselves to be more stressed than before starting caring for their patients.
- Five caregivers (41.67%) sometime feel many of their most important life decisions are prioritized around the care giving responsibilities.
- Four caregivers (33.33%) almost always feel alone in their care giving responsibilities and other four caregivers (33.33%) sometimes feel the same way.
- Six caregivers (50%) sometimes feel satisfied with their care giving efforts.

Among the questions asked are:

1. What have been the most difficult tasks to deal with the patient? The following responses are listed in order of decreasing frequency:
 - To get the patient to bathe
 - Manage patient feeding
 - To get the patient to follow instructions
 - To get patient to cooperate in taking medications
 - Manage the patient's moods
2. Which strategies are best for good care?
 - "When the patient refuses to bathe, I say that the doctor is coming to visit, then the patient goes ahead and showers".
 - "In the meal, I offer the dessert last".
 - "I am flexible, avoiding confrontation".
 - "I play happy music to improve the patient's mood or disposition".
 - "Patience, music and a peaceful environment help me achieve the best care. Everything is easier when I am relaxed, if I take care of my needs first, then there is no rush while taking care of the patient, for the patient can take every ounce of patience I have".

There was space in the questionnaire left for the caregiver to add whatever they considered important in their responsibilities, following are some of the responses:

- "The responsibility is so much that I have difficulty sleeping, worrying about what I need to do the following day".
- "I consider it an honor and a privilege to care for my mother in her condition. She continues to be my teacher and inspiration of tenacity and perseverance".
- "The family does not always recognize the condition and needs of the patient".

Field observations include the following:

- Availability of educational resources regarding the disease.
- Interest of the care givers and family members in seeking educational resources.
- Opportunities for sharing feelings and experiences of caregivers with other caregivers in similar situations.
- Participation of the different health agencies and organizations.

DISCUSSION

The objectives of the study have been met:

- The techniques and strategies for providing better care have been developed by the care givers thru a process of trial and error.
- Care givers have shared findings amongst each other, and have been applied according to the individual needs.
- The tasks needed to maintain the health of the care giver include keeping good organization, seek community support, meet with support groups and seek assistance as needed.

The hypothesis that the Alzheimer's caregivers are most effective when they are well educated on the disease and its evolution is proved. A direct proportional relationship was established between the level of education and the quality of the Alzheimer's patient's care. The greater the knowledge, the better the care, the lower the knowledge the lower the confidence of the care giver and the quality of care as well.

The hypothesis that the care giver can maintain a healthy lifestyle while simultaneously caring for the Alzheimer's patient remains unproven.

The research produced the following findings:

- Care for an Alzheimer's patient is a multidisciplinary and familiar effort.
- The whole family must participate in the care efforts.
- If the family is unable to directly care for the patient, then financial arrangements must be made for professional patient care, because a single family member caregiver will suffer burn out due to the exhaustive responsibilities of the care effort.

This hypothesis was not able to be proven, more research is needed.

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