

Relationship of Stigma to Caregivers Burden in Alzheimer's disease Patients

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Gomez-Gomez Celina¹, Riquelme-Heras Hector^{1*}, Aranda-Garza Ileana¹, Gutierrez-Herrera Raul¹, Mendez-Espinosa Eduardo¹, Martinez-Lazcano Felix¹, and Gutierrez-Sanchez Pablo¹

¹Family Medicine Department, Universidad Autonoma de Nuevo Leon, Mexico

Abstract

Objective: To correlate the stigma to caregiver burden of family member with Alzheimer's disease.

Methods: Correlational and descriptive study, interviews for convenience sample to 60 primary caregivers. Validated Alzheimer's Stigma scale (FS-AD) and Zarit scale that measures burden were applied. Spearman correlation between the Zarit score and the different types of stigma.

Results: The most stigmatizing aspects are the emotions that the caregiver feels about the Alzheimer's patient: fear, sadness, pity, compassion, shame, etc.

The most remarkable finding is the impact of family stigma on caregiver burden, $r: 0.68$ Cronbach alpha 0.85 , $p < 0.001$. Public stigma affects the caregiver's burden to a lesser degree than the family, $r: 0.69$ Cronbach alpha 0.87 , $p < 0.001$. Structural stigma is not affected.

Conclusions: Family stigma is more related to caregiver burden than the public stigma. Structural stigma is not affected. The effects of stigma are harmful to caregiver's burden.

Key words: Stigma, Alzheimer's disease, caregiver, burden, Primary care

Introduction

Alzheimer's disease (AD) represents between 60 to 70% of dementias and in the United States of America is estimated that 13% of people over 65 years of age suffer from this disease [1].

Dementia is a chronic disease with declining memory, thinking capacity and social behavior; progressive and irreversible that affects activities of daily life and quality of life [2].

The Alzheimer International Association estimates that 44 million people live with dementia around the world and that these figures will increase to 66 million by 2030 and 115 million by 2050 [3].

In the United States of America, 5 million people suffer it and 100,000 die annually. It is the fourth cause of mortality among adults [4]. In Mexico, more than 850,000 people are affected by the disease and 2,030 patients die annually from it [4]. These data do not match reality.

A major challenge in dementia diseases is the diagnosis. Recently, biomarkers have facilitated an early diagnosis. Even so, the disease is under-diagnosed [5].

Greeks gave the origin to the term "stigma" referring to bodily signs that exposed something unusual and bad about the moral status of its bearer. In sociology, stigma is a condition, attribute, trait or behavior that causes its bearer to be seen as "culturally unacceptable" or inferior.

"Although it is generally assumed that people with AD and their family caregivers are victims of stigmatization, the stigma of the family in the area of AD has received surprisingly limited attention [6]."

Three types of stigma affect the burden of the caregiver of patients with dementia:

*Corresponding Author: Hector Riquelme-Hera, MD, PhD. Family Medicine Department, Universidad Autonoma de Nuevo Leon, Mexico, Tel: 528180204829 Email: riquelme@doctor.com

family, public and structural stigma. Family stigma represents stigmatizing beliefs reported by caregivers of a family member with dementia; public stigma represents what others do or think about the sick family member, how caregivers think they are perceived by others, and structural stigma refers to both the effects of stigma on social structures, policies and legal regulations and the provision of mental health services [7,8].

Some quantitative studies on stigma and AD found that stigma in the family cause's caregivers to avoid looking for services that can potentially reduce the burden in the caregiver, and that the stigma is strongly related to the characteristics of the disease and negative stereotypes attributed to age [9-11].

Another study explores the subjective experiences of stigma in the family; authors found the stigma similar to that of mental illness, shame, and reflects a process in which cognitive or causal attributions or stereotypes (such as aesthetics) lead to emotional reactions (such as shame, fear and pity) and consequences of behavior or discrimination (as concealment and distancing) [12].

Many factors influence the perceived burden of caring for a family member with AD. These factors include the caregiver's characteristics such as kinship, gender, psychological resources and coping strategies; characteristics of people with dementia as cognitive status, behavioral problems and characteristics of the context of care such as length of care, social support and quality of family relationships [13].

The concept of caregiver burden is seen as a construct that comprises both subjective and objective components that have multiple repercussions [14]. Caregiver's burden is a multidimensional response that includes physical, emotional, social, and financial consequences for family members caring for a loved one with dementia [15].

The perception of caregivers living with "stigmatic beliefs" is probably associated with an increased burden of care [12]. Caregivers who live daily with stigmatic beliefs because a patient with AD represents a greater burden in the care, and who mostly is a close relative, parent or spouse. Even so, research in the area of stigma and AD is scarce, especially in the area of the family.

Objectives

To correlate the different types of stigma to the burden of the caregiver of a family member with Alzheimer's disease.

To identify the most frequent type of stigma and to obtain the degree of burden in the caregiver.

Methods

Correlational and descriptive study, sample of 60 primary caregivers of an Alzheimer Association, In Monterrey, Mexico. The study was conducted in the span of 6 months of 2015. Patients were selected by nonrandomized simple sampling.

Operational definition

Primary caregiver refers to the person who provides emotional or instrumental care to a loved one, without receiving any remuneration.

Inclusion criteria:

- Being over 18 years.

- Being the primary caregiver of a family member with Alzheimer.

- Acceptance to participate.

Exclusion criteria:

- Primary caregivers of relatives with dementia other than Alzheimer.

- Primary caregivers without blood ties.

- Formal caregivers of patients with Alzheimer.

Elimination criteria:

- Incomplete interviews.

Information collection Instruments

A questionnaire was applied, divided into sections that include socio-demographic data such as gender, age, marital status, schooling, occupation, place of residence, religion, medical insurance, economic income, type of housing, other illnesses suffered, hospitalizations of both caregiver and person with dementia; in the case of the caregiver also if he/she receives some kind of help for the care and the characteristics of the same, among others. Also are described the characteristics of the disease, diagnosis time and stage of dementia.

The validated scale FS-AD (Family Stigma in Alzheimer's disease Scale) was applied [6]. This scale values stigma as a process in which causal or cognitive attributions (stereotypes) such as aesthetics (has a very unpleasant odor, looks dirty, looks neglected, unkempt appearance) and dangerousness (if is dangerous to oneself, or dangerous for others) lead to emotional reactions (prejudices) such as compassion, guilt, repulsion, shame, etc., and consequences of behavior (discrimination) such as concealment of the diagnosis and distance from the person with the disease, among others. The scale has 62 items, rated on a Likert scale ranging from 1 to 5. The stigma was assessed in three areas: family, public and structural. Each question was answered with: 1 = never 2 = almost never 3 = sometimes 4 = most of the time 5 = always, and frequencies and percentages of the positive responses were made (category 3, 4 and 5 and in the responses of structural stigma, 1 and 2).

The burden scale of the caregiver was applied (Zarit, Orr and Zarit, 1985) [16,17], instrument that explores the negative effects on the caregiver in different areas of his/her life: physical and mental health, social activities and economic resources; each issue is evaluated using a Likert-type scale with 5 possible answers ranging from never to almost always with values from 1 to 5 respectively. The total score is the sum of all the questions and the range is between 22 and 110. The cut points proposed by the authors of the adaptation and validation are: no burden: 22-46, mild burden: 47-55 and intense burden: 56-110.

Data Analysis

The analysis of the data was made in the Statistical Package for Social Sciences (SPSS) version 20 for Windows. Frequencies and percentages were obtained. Spearman correlation was made between the Zarit score, which assesses the burden and the different types of stigma. Chi [2] was used for categorical variables with a p value of <0.05.

Ethical Aspects

The protocol was approved by the Ethics and Research Committees of the Hospital Iversitario with the code MF14-005. Informed consent was requested and the confidentiality of the information was guaranteed.

Results

Caregiver Profile: The majority are women, married, average age of 53 years, with university studies, housewives, Catholics, with medical insurance and with income above the minimum.

They have less than 5 years of caring for their relative, usually their mothers, 7 days a week, 24 hours a day.

A third part is supported by 2 people, usually siblings. Half of the caregivers do not suffer from any disease and those who suffer from it are hypertension and diabetes.

Elderly Profile: Most of them are women, average age of 78 years, more than half are widows, with elementary studies, housewives, with medical insurance, Catholics; a third without economic income. The 58% live in their home and 42% in the caregiver's. In 63.3% is the mother of the caregiver the person who has dementia, in 15% the spouse and in 13.3% the father. The 20% have diabetes, 15% have hypertension and 8.3% have another cardiovascular problem. Only 13% have been hospitalized once in the last year.

Medical Characteristics of the Elderly

Patients with dementia presented the following medical characteristics in relation to their health state. Diagnostic time: 1 to 5 years, 61.6%; less than a year, 21.7%; 6 to 10 years, 15%; 11 years or more, 1.7%.

Severity of the disease: moderate 45%, mild 31%, and severe 18.3%, serious 5.0%.

They also presented other problems associated with dementia in behavior disorders: Isolation: 31.6%, apathy 28.5%, aggressiveness 16.7%, wandering 8.3%, motor disability 26.7%, speech problems 10% and none 43.1%.

Stigma

The most notable finding is the impact of family stigma on caregiver burden, $r: 0.68$ Cronbach alpha 0.85 , $p < 0.001$. Public stigma affects the caregiver's burden to a lesser degree than the family, $r: 0.69$ Cronbach alpha 0.87 , $p < 0.001$. The structural stigma is not affected.

The results are the following: Table 1 shows the frequencies and percentages of the most frequent responses that represented some type of stigma. Outstanding in the family stigma related to emotional attributions are: concern 91.7%, sadness 85%, uneasiness 56.7%, fear 53.3%, compassion 45%, pain 41.7%, among others. In relation to aesthetics, 26.7% have a very unpleasant odor, 23.3% have a non-aesthetic appearance and 20% look neglected. In dangerousness, 23.3% is dangerous to oneself and 15% represents danger to others. The 13.3% conceal the diagnosis from friends; 33.3% of the caregiver's report distancing with the person with Alzheimer's disease and 38.3% limited interaction with the person with dementia.

Table 1: Family Stigma.

Family Stigma	f	%	M	DE
Esthetics:				
1. Has a disgusting odor	16	26.7	1.78	.865
2. Looks not esthetics	14	23.3	1.72	.865
3. Looks neglected	12	20.0	1.58	.829
Dangerousness:				
1. Is dangerous to himself/herself	14	23.3	1.60	.942
2. Is dangerous to others	9	15.0	1.43	.767
Emotional Attributions:				
1. Shame	10	16.7	1.55	.769
2. Embarrassment	12	20.0	1.65	.820
3. Disgust	18	30.0	1.88	.885
4. Fear	32	53.3	2.47	1.228
5. Disgrace	21	35.0	2.07	1.313
6. Uneasiness	34	56.7	2.67	1.284
7. Dread	10	16.7	1.52	1.033
8. Sadness	51	85.0	3.22	1.106
9. Concern	55	91.7	3.87	1.065
10. Pity	25	41.7	2.18	1.269
11. Sorrow	17	28.3	1.83	1.224
12. Compassion	27	45.0	2.27	1.351
Concealment of the Diagnosis:				
1. Conceal the diagnosis from friends	8	13.3	1.47	.999
Distancing:				
1. Distance yourself from the person with AD	20	33.3	1.95	.964
2. Limit social interactions with the person with AD	23	38.3	2.15	1.147

n= 60

The most significant stigma was family. The average of caregivers of the patients with dementia was 35.6%.

Public stigma prevails as in the family stigma related to emotional attributions in equal percentages. The same happens when it comes to aesthetics. With regard to the severity of the disease, 88.3% of people with Alzheimer's disease do not understand simple instructions or remember recent events, 71.7% do not recognize family members, 46.7% have language problems, 35% disturb people around them, 35% suffer from urinary incontinence and 20% fecal. In behavior reactions, 58.3% limit family relationships with the person with dementia, 56.7% ignore the person with Alzheimer, 55% limit social contact with the person with Alzheimer, 55% stay away from the person with Alzheimer, 51.7% avoid the person with Alzheimer and 46.7% want to keep the person with Alzheimer's disease away from public places. (Table 2)

In Table 3 of the structural stigma, it is observed that more than half of the interviewees expressed a positive opinion of the resources available in the community for people with Alzheimer's disease and highlight some negative data about the expressed needs, such as: 36.7% competent doctors for the diagnosis and treatment of AD, 48.3% professionals (nurses, social workers) that can handle the treatment, and 48.3% adequate services in the community for the caregivers, among others.

Table 4 shows that only the number of days a week the family member cares for his/her relative with dementia has a statistical correlation with the family stigma, $p = 0.002$.

Other variables have no statistical significance with family stigma; no relationship was observed between burden and gender, nor with the time of diagnosis of the disease, etc. Spearman's linear correlation is established in the diagrams.

In relation to caregiver's burden, it was found that it was mild

Table 2: Public Stigma.

Public Stigma	f	%	M	DE
Severity of the Disease:				
1. Does not understand simple instructions	53	88.3	3.03	.863
2. Does not remember recent events	50	83.3	3.28	1.091
3. Does not recognize his/her family members	43	71.7	2.85	1.287
4. Has speech problems	28	46.7	2.27	1.260
5. Disturb the persons around him/her	21	35.0	1.75	1.052
6. Suffers from urinary incontinence	21	35.0	2.15	1.412
7. Suffers from fecal incontinence	12	20.0	1.68	1.172
Esthetics:				
1. Has a disgusting odor	16	26.7	1.83	.867
2. Looks neglected	12	20.0	1.58	.809
3. Looks unkempt	11	18.3	1.60	.785
4. Looks not aesthetic	14	23.3	1.70	.869
Dangerousness:				
1. Dangerous to himself/herself	14	23.3	1.60	.960
2. Dangerous to others	9	15.0	1.40	.741
Emotional Attributions:				
1. Shame	10	16.7	1.55	.769
2. Embarrassment	12	20.0	1.63	.802
3. Disgust	18	30.0	1.83	.867
4. Fear	32	53.3	2.42	1.29
5. Disgrace	21	35.0	2.05	1.358
6. Uneasiness	34	56.7	2.63	1.314
7. Dread	10	16.7	1.48	1.000
8. Sadness	51	85.0	3.22	1.106
9. Concern	55	91.7	3.76	1.159
10. Pity	25	41.7	2.10	1.203
11. Sorrow	17	28.3	1.78	1.136
12. Compassion	27	45.0	2.23	1.307
Behavioral Reactions:				
1. Limit social contact of the person with AD	33	55.0	2.33	1.100
2. Limit family ties of the person with AD	35	58.3	2.40	1.012
3. Avoid the person with AD	31	51.7	2.32	1.017
4. Want to keep the person with AD away from public places	28	46.7	2.30	1.078
5. Keep away from the person with AD	33	55.0	2.45	1.126
6. Ignore the person with AD	34	56.7	2.48	1.172

n= 60

Table 3: Structural Stigma.

Structural Stigma	f	%	M	DE
To what extent do you think that there are:				
1. Adequate community services for persons with AD	29	48.3	2.70	1.225
2. Available sources of knowledge for persons with AD	23	38.3	3.28	1.091
3. Available community services for persons with AD	37	61.7	2.52	1.172
4. Competent physicians for the diagnosis of AD	22	36.7	3.08	1.094
5. Competent physicians for the treatment of AD	22	36.7	3.08	1.094
6. Professionals who help caregivers of persons with AD	29	48.3	2.97	1.207
7. Professionals (physicians, nurses, and social workers) who can manage the treatment of persons with AD	29	48.3	2.83	1.092
8. Adequate community services for caregivers of persons with A	39	65.0	2.37	1.057

n= 60

Table 4: Statistical Correlation with Family Stigma.

Variables	p Value
1. Caregiver's care time	0.846
2. Caregiver's schooling	0.461
3. Caregiver's gender	0.638
4. Caregiver's occupation	0.296
5. Caregiver's religion	0.105
6. Caregiver's monthly income	0.874
7. Caregiver's care days of the week	0.002
8. Caregiver's relationship	0.854
9. Patient's diseases	0.462
10. Alzheimer's diagnosis time	0.763
11. Disease's severity	0.575

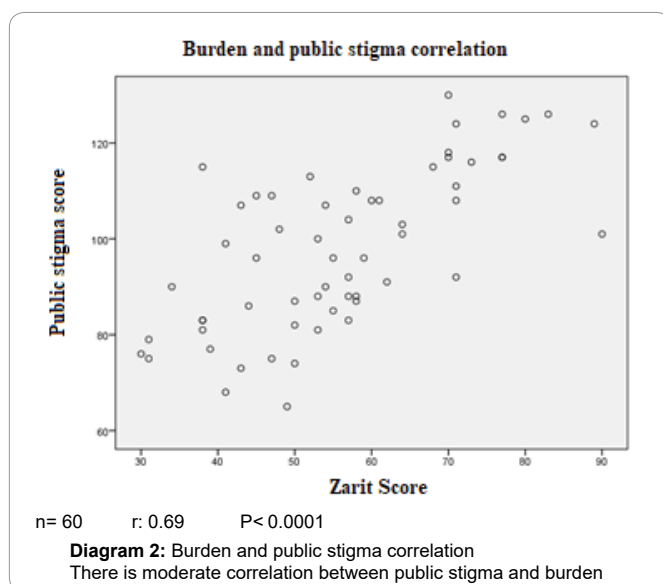
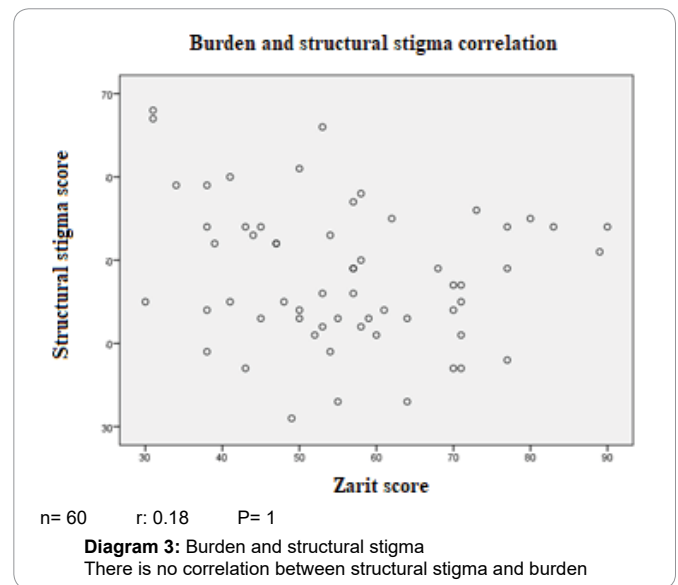
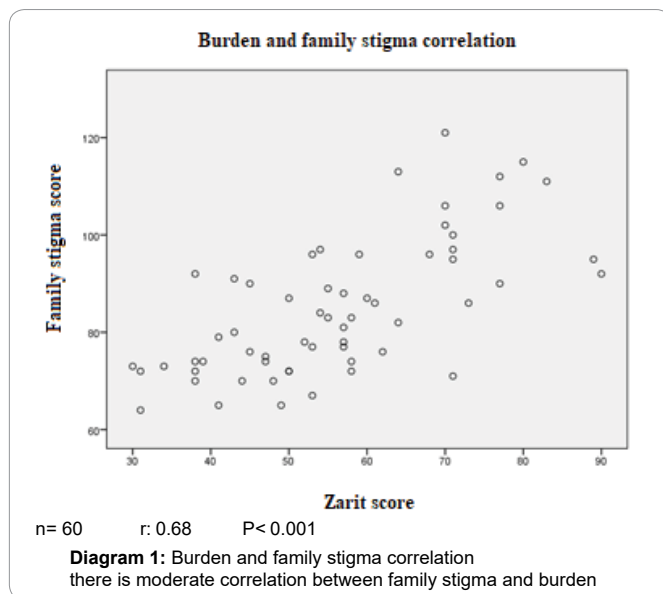
n= 60

Table 5: Zarit Scale Results.

Caregivers Burden	f	%
Mild to moderate	9	15.0
Moderate to severe	31	51.7
Intense	20	33.3
Total	60	100.0

to moderate, 15%, moderate to severe, 51.7% and intense, 33.3%. Table 5 shows the relationship of the different stigmas with the burden of the caregiver.

Finally, diagrams 1 and 2 show a moderate correlation between family and public stigma with caregiver burden ($r: 0.68 p < 0.001$ and $r: 0.69 p < 0.001$, respectively). In diagram 3 is observed that there is no correlation with structural stigma and burden ($r: 0.18 p = 1.0$).



Discussion

About relation to aesthetics, in family stigma, it is striking that the person suffering from Alzheimer does not have an unpleasant odor, does not look dirty or careless, does not look unkempt or disgusting; what speaks about the good care provided by the family caregiver and of what people perceive that in some way they interact with the person with dementia. It represents stigma in a quarter of the cases.

A very important aspect is related to the danger, in which both the family and the public stigma the person is perceived as not dangerous to himself/herself or others, contrary to what is observed in mental illness. The difference could be due to the divergent characteristics of the diseases. Mental illness in general, and schizophrenia in particular, is associated with high perceptions of dangerousness, which can lead to further stigmatization [18,19] In contrast, AD is associated with low perceptions of dangerousness [20]; and in less than a quarter

of the cases it was considered dangerous for him/her and for others.

In emotional attributions, both in the family and in the public stigma predominated the desire to be useful, support and help. Positive emotions, like sympathy, were elevated both in the family and in the dimensions of the public. Contrary to what was reported by Werner, Mittelman, Goldstein and Heinik [21], in which shame was elevated both in the family and in the dimensions of the public stigma. Shame accounted for 16.7% of the cases.

Other important emotions are the concern caregivers have for all aspects of the disease and for the loved one affected in 91.7% and the sadness, which is experienced in this situation in 85%. It was found that emotional reactions, superior to cognitive attributions, suggest that in family caregivers, family stigma is more associated with feelings or prejudices than with cognitive inferences or stereotypes except for the high level found by the elements of cognitive attribution in public stigma associated with the physical and cognitive functioning of the person with dementia of how caregivers believe they are perceived by others.

This is consistent with other studies that show that the severity of dementia is directly related to stigmatic beliefs [22]; Werner & Davison [23]. These authors found that persons with Alzheimer cause more positive than negative reactions in both people and caregivers. A little more than half of the caregivers are afraid to face the disease in the care of their loved one, perhaps because of what they are facing and what awaits them with the progression of the disease and the lack of family and social support. In less than half of the cases, compassion, grief and disgrace appeared. In the third part there was disgust, embarrassment and dread to take care of the family member. Two thirds of the population presented other types of alterations.

It is observed that there is no problem in the area of concealment of diagnosis by the spouse, children, parents, friends, neighbors or health professionals. Little more than one-tenth conceals the diagnosis from friends.

More than a third of the caregivers report a limited distance and social interaction with the person suffering from Alzheimer's

disease, perhaps due to a lack of knowledge about the disease and the reactions of others to the behavior problems of their loved one.

In the public stigma, emotional attributions are the same as those of family stigma. It highlights the severity of the illness in which the majority does not understand simple instructions, does not remember recent events, does not recognize family members, speaks nonsense, disturbs people around him/her and suffers urinary incontinence and/or fecal, among others; characteristics of Alzheimer's that are presented according to the progression and severity of the disease.

In public stigma, limited family relationships with the person with Alzheimer's disease in more than half of the cases, ignoring the person with Alzheimer's disease, limiting family relationships, keeping the person with Alzheimer's disease away, avoiding the person, and not taking him/her to public places. Not with the same severity as found by Liu et al [11]. These findings reported a reduction in the visits and interactions of others with the affected person and a gradual decrease in the social life of the network and support system for both the caregiver and for the affected person. They found that caregivers attribute their frustration for not being recognized by the person with Alzheimer. In the study, seven out of ten do not recognize family members.

In the structural dimension of stigma, caregivers recognize that there are some adequate services in the community that can be useful to them and that there are some professionals (doctors, nurses and social workers) that can manage the treatment of people with Alzheimer.

Caregivers recognize that there is a lack of available sources of knowledge for people with Alzheimer's disease, competent physicians to diagnose the disease and for its treatment [9]. The perception of a decrease in available resources was not associated with an increase in caregiver burden ($r: 0.18_{yp} = 1$).

In a study from Argentina, a scale of attitudes toward dementia, people with disabilities, aging and negative stereotypes towards old age were carried out; and it was found that "greater education and previous contact with patients with dementia were associated with more positive attitudes [24]".

A study made in Israel by P. Werner reported an average of 21.7 caretakers with Stigma related to patients with AD [9]. In the present study, the average of some type of stigma was 35.6%.

The score of the Zarit scale was 56.1 which corresponds a moderate to severe burden. The highest score corresponded to the fact that the family member depends on the caregiver, the fear for the future that awaits their loved one and the stress that comes with taking care of them, as well as taking care of other responsibilities. The burden of care of a relative with dementia is well documented in the literature. So the number of personal, family and social victims associated with the care of a person with Alzheimer is aggravated by the stigma associated with the disease.

No statistical significance was observed between burden and gender, time of care, hours for the day caring or with the time of diagnosis of the disease as expected, perhaps due to the size of the sample.

The most notable finding of this study is the impact of family stigma on caregiver burden (correlation with Zarit of $r: 0.68$ and $p < 0.001$). These findings suggest the caregiver's perception of

being stigmatized by his/her association with the sick family member, increases the negative experiences of care beyond the effects of factors traditionally studied, such as the behavioral problems associated with the disease and the number of years who participate in the provision of care.

Results show that public stigma affects the caregiver's burden to a lesser degree than family stigma; correlation with Zarit of $r: 0.69$ with $p < 0.0001$). It is not affected in the structural stigma; correlation with Zarit of $r: 0.18$ and $p < 1$, because this is associated mainly with the availability of services. This type of stigma refers to the effects of stigma on social structures, policies and legal regulations, as well as the provision of mental health services.

Findings reflect that despite the negative physical and psychological outcomes associated with caring for a person with dementia, family caregivers want to continue to support and assist their loved ones as demonstrated by Eters and colleagues [13].

Results have social and political implications. Health care providers and social service providers should be aware of the impact of the stigma of caregivers of people with dementia, so that they can provide more effective support.

Educating the general public about the causes of Alzheimer and the behavioral manifestations of the disease can reduce stigma reactions. A better understanding of the causes and effects of stigma can lead to interventions that reduce its impact [21].

Limitations of the Study

Convenience sampling limits the generalization of the results since the participants may not be representative of all caregivers.

The importance of stigma in caregiver burden should be examined in other socioeconomic levels and also in institutionalized demented patients.

Conclusions

Stigma has been frequently associated with chronic diseases, especially dementia in various studies in different countries

The general objective of correlating the stigma with the burden of the caregiver of a relative with AD was achieved.

It was identified that the most frequent stigma related to burden is family stigma followed by public stigma. Structural stigma is not related to caregiver burden.

The caregiver of a relative with AD has a moderate to severe burden due to stigma.

The effectiveness of evidence based clinical interventions may be significantly increased if we evaluate and address caregiver stigma.

Conflicts of Interest

Authors agree with the content and results of the manuscript and declare that we do not have conflict of interest of any kind since no type of financing was received

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