

Stress and Vulnerability Due to the Care Task: An Observational Study on Older Caregivers

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Abstract: As worldwide population ages, an increase of inhabitants who suffer neurodegenerative diseases can be observed. Considering that the task of caregiving is generally carried out by a family member, he becomes an easy target for diseases, especially for being subjected to a stressing process.

This study intends to analyze whether the older caregivers' health suffers affections if compared with the health conditions of those who do not take care of family members. The present investigation defends the fact that the person who develops the activity of caregiving has high probabilities of developing diseases.

An observational, analytical, cross sectional study was made. One hundred and twenty four (124) older adults divided in two groups were cross-examined: 62 interviewees were caregivers of chronic patients and 62 were not. The total amount of candidates was given two questionnaires: one analyzed socio-demographic data and the other one health disturbances.

The results showed that 48% of the sample experienced unfavorable changes in their health, and that the condition of being a caregiver somehow predicted the changes (OR 15.) As for the kind of disturbance, it can be said that 85% of the caregivers went through psychical disturbances; however, there were no significant differences found between the self-perception of the caregivers and non-caregivers health conditions.

The findings confirm the established hypothesis and coincide with other investigations: the caregiver suffers unfavorable health effects despite the fact that sometimes he is not aware of those negative consequences experienced. Therefore, family caregivers are referred to as "hidden patients." Health services should promote psycho-educational intervention programs and diagnose for proper pharmacological treatment of depression and anxiety usually with SSRIs according to co-morbid conditions of the patient.

Keywords: Caregivers, chronic disease, health disturbances, older adults, self perception of health, stress, vulnerability.

INTRODUCTION

The aging of worldwide population is part of an intrinsic process of the demographic transition. The above mentioned process reduces the group of youth and increases the group of elderly. During the last 60 years in Argentina the population pyramid has suffered considerable changes in its structure. While in 1950 it had a solid base due to the high grade of fecundity, in 1985 its triangular structure began to fade due to the increase of the older proportion, and by 2020 it is expected to have an inverted population pyramid, similar to the one of developed countries. At present, in Argentina, the percentage of adults over 65 is 10.2%. Buenos Aires city has the highest percentage of this age group (17%) being the oldest population of the country [1].

As the older population increases, a growth in the indexes of prevalence of diseases can be observed. The reasons are both: human behavior and neurodegenerative

processes. Alzheimer's and Parkinson's diseases maintain a sustained growth. It is estimated that in Argentina, the Alzheimer's disease is diagnosed in 12,18% of the individuals of 65+ and in 40% of the individuals aged 85+, which means that about 500.000 adults in old age are affected [2, 3].

This situation leads to the fact that a great amount of adults present high probabilities of suffering disabilities during the old age and count on few young members of their social net to assist them [4]. Therefore, it is estimated that a large part of this age group will not only face the difficulties of aging, but there are also possibilities for them to become informal family caregivers of patients with chronic diseases [5].

The informal caregiver is the relative, friend or neighbor that belongs to the social support net of the chronic patient. The caregiver dedicates most of his time to provide assistance, is not monetarily compensated for what he does and is considered the principal responsible for the assistance by the rest of the family [6, 7].

During the last decades, the Scientific Community has been interested in investigating the impact that the assistance

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of chronic patients produces over the family caregiver [8]. Connected to this, numerous studies that have been developed pointed out that taking care of a disabled person is a stressful process which increases the risk of physical and mental problems and tends to reduce the caregivers' social life. The caregiver feels his most important relationship is the one developed between himself and the patient [9-11].

In this respect, one of the negative repercussions of the care of a chronic patient is "The Burden Feeling" of the caregiver [12] which, from the Transactional Stress Theory [13], is defined as an emotional expression of social and psychological stress generated by the caring situation. Stress is defined as a dynamic process in which an individual and its environment interact. When the level of demand implied in the assistance of a sick relative with dementia exceeds the internal and external resources of the caregiver, he will experience negative emotions and perceptions which are characteristic in his subjective state due to the feelings of grief, burden, oppression and uneasiness with his function of taking care [14, 15].

Lazarus and Folkman add that the effects on the psychophysical well-being of the caregiver will depend on the mechanisms of the cognitive appraisals he has. The key to understand the process is to be able to differentiate between negative events or stress sources and the appraisal and reaction of the caregivers who have to face this stressing situation [16, 17].

In the article "Is Caregiving Hazardous to One's Physical Health?" Vitaliano, Zhang and Scanlan [18] made a meta-analysis of 23 scientific studies where the physical health effects of the tasks over caregivers and non-caregivers were compared. The above mentioned authors stated that when facing the stressor the family caregiver will react according to his vulnerability and resources. Vulnerability is defined as those permanent characteristics of the individual, such as age, sex, race, family background and hereditary load.

They stated that the resources are changeable, they are affected by the interaction of the caregiver with the environment; its nature is multidimensional: it includes the physical, psychological and material characteristics of the individual. The conditions that make a person vulnerable are established in the early stages of his individual development, whereas the resources can be predictive and are also the consequences of the caregiver role.

The way in which a caregiver faces different caring issues depends on his resources and vulnerability, and both of them will determine whether the presence of psychological disturbances and the kind of health habits. The connection among these consequences will generate physiological answers facilitating the appearance of diseases and the increase of individual mortality.

The aim of the present study is to analyze the negative health effects an older adult in the role of family caregiver of a chronic patient might suffer in comparison with those adults who do not lead this role.

MATERIALS AND METHOD

Design

An observational analytic cross sectional study has been made.

Sample

One hundred and forty five (145) people were invited, of which: nine (9) did not meet the requirements of the inclusion criteria, four (4) refused to participate and eight (8) did not finish the interview. The elderly were divided in two groups: sixty two (62) caregivers of chronic sick relatives (Group 1) and sixty two (62) non-caregivers (Group 2).

The technique of the sample used was non probabilistic of intentional type. The subjects were interviewed individually between April and August, 2013.

Inclusion criterion: retirees over sixty years old, caregivers and non-caregivers of chronic sick relatives.

Exclusion criterion: old age people with motor and/or severe sensory deficit that impede the evaluation and those individuals who had serious psychiatric disturbances.

Procedure

Instruments

- *Questionnaire of socio-demographic data.* This instrument was made *ad hoc* and had 22 questions. The information requested for both groups was the following: age, gender, nationality, marital status, education and previous occupation.
- *Questionnaire of Health disturbances.* This questionnaire was made *ad hoc* with the purpose of evaluating health disturbances in older adults. Considering the investigation made by Mateo Rodriguez *et al.* [19] in which he described the symptoms of the caregivers, 12 questions were asked. The purpose was to detect the presence of physical (asthenia, migraine, sleep disturbances, low back pain, skin problems, and gastrointestinal disturbances) and psychical problems (tiredness feelings, sadness, anxiety, depression, irritability and guilt) as well as the time when the disease appeared and developed. A question about the self-perception of the older adult's health was also made. It was evaluated through a Likert scale of 5 categories (very good-good-fair-bad-very bad.)

Data Collection

To obtain the permission to interview seniors, we contacted authorities of day centers and workshops dependent on the Government of Ciudad Autónoma de Buenos Aires, as well as institutions of public and private health such as the hospitals "Dr. César Milstein" and "Dr. Abel Zubizarreta" and the Institute of Neurosciences Buenos Aires, "INEBA."

For this purpose, relevant authorities received a summary of the research project, the evaluation protocol and the informed consent. Through the informed consent, seniors gave their approval to participate voluntarily and were granted anonymity for their responses.

After the pilot study was finished, the assessment protocol selected was administered to older adults through an individual interview that lasted approximately 40 minutes.

Statistical Analyses

Based on the recruitment of 124 older adults a confidence interval of 95% was expected divided in the following proportions: 33% (25-42), 50% (41-59). Percentages, means and standard deviation for the description of the studied variables were calculated.

For the bivariate analysis the comparisons were made using the Chi-square test on the categorical variables and the simple logistical regression for the ordinal variables. The continuous variables were categorized and were analyzed with logistical regression as it is shown as follows (see Table 1).

A multi-varied model of logistical regression was used to examine the association between changes in health and specified predictors (age, sex, marital status, nationality, educational level, previous occupational level and the caregiver’s role.) With that purpose, the variables with significance next to .02 were included.

For the bivariate and multivariate analysis the variables were categorized in individuals aged 72+, female, married, argentine, primary, secondary, tertiary and university education, as well as the previous occupational level: low, medium and high according to ESOMAR [20] and the

caregiver’s role.

RESULTS

All the individuals interviewed were self-sufficient and the group was composed in the following way:

- Gender: men, 31% - women, 69%
- Age: between 66 and 80 years old, with an average of 73 years (sd=6,6)
- Nationality: most of them were argentine, 88%
- Marital status, married (or living with a couple):
 - Caregivers, 87%
 - Non-caregivers, 50%
- Educational level:
 - Caregivers (primary studies) 63%
 - Non-caregivers (secondary and tertiary studies) 82%
- Occupational level:
 - Caregivers: crafts, 35% - housewives, 32%
 - Non-caregivers: (employees, teachers, independent professionals) 71%

In Table 1, the results of the bivariate and multivariate analysis are presented using logistical regression for the evaluation between the change in the older adults’ health,

Table 1. Bivariate and multivariate analysis to calculate the change association over the health and demographic predictors. n=124.

	Changes Over the Health				OR	IC95%	P Value	OR	IC 95%	P Value
	No. n= 64		Yes n=60							
	n	%	n	%						
Age										
> 72	35	54.70	29	45.30	0.77	(0.38 -1.58)	0.48			
Sex										
female	47	73.40	38	63.30	0.63	(0.29 -1.35)	0.23	0.98	(0.35 -2.77)	0.97
Marital status										
married	39	60.90	44	73.30	1.76	(0.81 -3.81)	0.14	0.47	(0.15 -1.43)	0.18
Nationality										
Argentine	57	89.10	52	86.90	0.79	(0.26 -2.37)	0.68			
Education										
elementary school	20	31.20	30	50.00	1		NA	1		NA
high school	25	39.00	21	35.00	0.56	(0.24 -1.26)	0.16	1.51	(0.52 -4.42)	0.44
higher education	19	29.70	9	15.00	0.31	(0.12 -0.84)	0.02	1.14	(0.30 -4.34)	0.84
Previous occupation level										
Low	19	26.70	34	56.70	1			1		NA
Medium	35	54.70	18	30.00	0.29	(0.12 -0.63)	0.002	0.78	(0.27 -2.20)	0.63
High	10	15.60	8	13.30	0.45	(0.15 -1.32)	0.15	1.55	(0.36 -6.71)	0.55
Caregiver	16	25.00	46	76.70	9.85	(3.75 -25.9)	0.000	15.7	(4.55 -53.85)	0

socio-demographic predictors and the caregiver's role. It was observed that as regards the prevalence and predictors of changes on the health conditions, 60 older adults (48%) reported unfavorable variations and the main reason was the fact of being a caregiver (Group I: n=46, 77% and Group II, n=15, 25% -OR 9.85, IC95% 3.75-25.9-, $p < 0.001$.)

Other predictors such as educational level and the previous occupational level were statistically significant in the bivariate analysis but not in the multi-varied model. Therefore, it was observed from the multi-varied model that the role of caregivers predicts changes over the health (OR 15), being the only one in the interviewed sample.

In connection to the type of health disturbance, the principal changes reported by the 60 people who got sick had psychical origins in 75% of the cases. Of the total percentage of interviewees, 85% were caregivers (n=39) and 43% (n=6) non-caregivers (OR 7.10, IC 95% 1.88-28.9, $p = 0.004$.)

Finally, related to the variable of health self-perception more than the half of both groups described their health as "good" without finding statistically significant differences between health perception of older adults who are caregivers and those who are not ($p=0.11$.)

DISCUSSION

In relation to the socio-demographic profile of the caregivers of chronic patients, the findings obtained in the present study are similar to those of other empirical researches: most of the caregivers belong to the female gender, have low educative levels and do not have any labor occupation [21-24]. However, although historically single or widow daughters firstly tended to have this role, in the latest years most of the female caregivers are married and they are aged 45-65 years old, being in most cases patients' spouses [25-27]. They are called "the Hing Generation" because they are middle aged women that besides providing assistance to the patient, they must carry out several assistance tasks with their children, husbands and in some cases grandchildren. This situation is consolidated in a source of conflicts that affect the family dynamic negatively [28-31].

As regards the age of older adults who are caregivers, it can be stated that in comparison with the young ones, they present a minor physical resistance to these tasks but they are more experienced [32, 33]. With respect to the marital status, spouses who are caregivers are said to feel more fragile, stressed and isolated; however, their husband's care is considered a marital duty.

When the importance of socio-demographic characteristics and the performance of the caregiver's role as predictors of change over the health were analyzed, the conclusion obtained was that the caregiver can predict the changes. This finding affirms the hypothesis supported in the study herein and agrees with different empirical surveys when defending the fact that caregiving a chronic family patient produces unfavorable repercussions over the psycho-physic health of the caregiver. Due to this reason, family caregivers are called "second victims" or "hidden patients" [34, 35]. It is important to point out that from the perspective of Systemic Psychology, it is considered that the development of a

chronic disease does not only affect the patient but it also involves the whole family system [36].

What is more, from an epidemiological point of view, the family caregivers of chronic patients are referred to as the "exposed group" [37] due to the fact that the progressive increase of the patient's deterioration is associated with health risks the caregiver might experience [38-41]. The risks are understood as the probability of developing different disturbances that are grouped and described as "Caregivers Syndrome." The mentioned syndrome connects physical (asthenia, migraine, sleep disturbances, low back pain, skin diseases, gastro-intestinal disturbances) and psychological disturbances (feelings of tiredness, sadness, anxiety, depression, irritability and guilt) [19].

It was found that the principal unfavorable change experienced by the caregivers who became sick had psychical origins. Depression, anxiety and psychological stress were the most frequent disturbances. These results agree with other researches [42, 43] which studied the depression in a caregiver population. Schulz, O'Brien, Bookwala and Fleissner [42], analyzed the morbidity in caregivers of chronic patients, a depression average of 22% was obtained, doubling the average obtained in a non-caregivers' population [43]. Other study [44] found that 73% of the caregivers with previous background of depression had a recurrence while they performed care tasks; as only 30% of the adults who were non-caregivers with a depression background suffered from a recurrent pathology.

The disease an individual suffers can have even further negative consequences because of two main reasons: on the one side, the disease can evolve to other pathologies; on the other, the rehabilitation process may be subject to interruptions and during those periods functional, mental and social deteriorations gain territory [45-48]. Likewise, depression raises death risks, not only because of the suicidal increase but also due to the alteration of the immune system and the increase of the psycho-physiological disorders [49-51]. Regarding the stress, other comparative researches signal out that stressed caregivers present a higher death rate (63%) than non-caregivers, a descent of the immune system and present new diseases and/or aggravation of existent pathologies [52, 53].

Finally, the delicate situation of the caregivers worsens because of the invisibility of the suffering. The results obtained enabled scientists to confirm that despite the caregivers get sick more frequently than non-caregivers, both groups consider their health condition is good. Consequently, caregivers who are sick become under-diagnosed since they do not usually attend medical consultations, postponing them until the death of the family member they assist. Generally, a caregiver considers his own disease is not important if compared with the tragic situation of the person he takes care of. It is possible that while the caregiver is developing his role he does not have enough time to go to the doctor or does not receive the adequate assistance [54, 55].

TREATMENT

It is important to comment that the family caregiver of a chronic patient plays an essential role in the treatment. He

shortens the gaps of social services and avoids or delays the institutionalization of older adults [56]. In this sense, the study "Learning to Become a Family Caregiver" [57] emphasizes the importance of having a proactive psycho-educative program with active participation of family caregivers of chronic patients. The above mentioned study makes reference to the necessity of the caregiver's assistance from the moment of the patient is diagnosed. It is considered a key point for the caregiver's adaptation to the new challenges he will have to face.

The literature about this topic considers as indissoluble the binomial patient-caregiver [58] since the existent relationship between them determines the level of stress, the feeling of burden (whether increasing or softening) [21, 59, 60], the recovery of the patient and his adherence to the treatment. For this reason, the family caregiver participates in two treatments: the one of the patient and his own [61].

Non-Pharmacological Treatment

Claramonika Uribe [62], points out that in the field of neuropsychological rehabilitation, family caregivers, at the beginning, had the sole function of informing professionals the changes experienced by the patient. As time went by, different researches [63-67], began to underline the significant role that family caregivers have as the central column in the rehabilitation process called non-pharmacological treatment.

From the given information, health team members can establish, together with other evaluation tools, the basis line for the subsequent training study. The caregiver's attitude, motivation and grade of collaboration are key elements concerning the consolidation and generalization of the skills worked during the training sessions. When the family caregiver feels that he is a member of the work team, his commitment is larger and this permits the continuity and improvement of the treatment.

In this way, not only does the patient benefit but also the family caregiver. This will have positive repercussions on the patient and will strengthen the established objectives for the treatment. The caregivers benefit from the work experience, since they can better understand what is affecting the patient. As a consequence, his feelings of guilt, defenseless and anger diminish when he becomes part and gets involved in the patient's recovery.

Muñoz Céspedes and Tirapu Ustarroz [68] adduce that the caregivers are in an excellent position to favor the absorption of knowledge of the patient generated during the recovery sessions. They can: 1) continue learning/teaching different strategies worked in the training sessions in places different than the doctor's office, 2) encourage the patient to put into practice the different strategies learnt until they can be followed automatically, 3) facilitate the application of these strategies in different situations, 4) learn/teach other relatives and acquaintances to follow the established rules in the rehabilitation sessions, 5) give verbal and/or visual help when there is an error or forgetfulness in the application of strategies and 6) reinforce the tasks when the patient has fulfilled the aims stated.

Interventions for the Family Caregivers

To accompany and soften the stress and burden feelings of the family caregivers with chronic diseases, in recent years different strategies of participation have been designed, such as psycho-educative workshops, help groups and psycho-therapeutic groups [69].

Psycho-Educative Workshops or Informative Groups

The principal aim of these groups is to give medical information and/or refer to the basic infirmity cares that the patients require. These groups generally have a limited duration. In each meeting the topic to be treated is ruled and developed by a professional of the rehabilitation team, by means of a clear exposition, in which all the given information must be understood by all the participants. The professional in charge of the group develops and explains how to handle different situations and take good care of the patient. The central point of this activity is to help the family caregivers to look after the patient [57].

Help Groups

In most groups the 'leader' is a health professional, but in the case of help groups, it is an experienced caregiver the one in charge. This singularity promotes the spontaneous circulation of information about the disease among peers. The negative aspect of the lack of a professional is that the information is sometimes interpreted wrongly and there is no opportunity to clarify it, or give further explanations. Therefore, as Conde Sala [70] points out, the self-help groups among relatives are useful if they are created as complementary therapies or after professional participation.

Psycho-Therapeutic Groups

In this work area the main objective is to reduce the levels of anxiety and depression the family caregiver might experience [71]. Muñoz Céspedes and Tirapu Ustarroz [68] state that the essential purpose of a therapeutic group program for relatives is to give them a higher sense of ability and to increase their self-esteem as they learn the necessary participation strategies to cope with physical, neuropsychological and behavioral alterations sequels the patient experiences.

For that reason, the therapeutic approaches must be flexible enough so as to understand and collaborate in the search of answers before a wide variety of difficulties, generally linked to: a) the serious neurological damage, b) the behavioral changes in the personality of the affected patient, c) the type of physical and cognitive disorders that will determine the grade of disability and its evolution, d) assistance with legal and financial aspects.

The session dynamic generally has the characteristic of favoring the emotional expression of the caregivers. Frequently it starts with testimonies of the difficulties or important events connected with the patient and after that, caregivers are free to favor the emotional connection with their own mood and the emotions that this situation produces.

Pharmacological Treatment

In addition to psychotherapy and the support groups previously mentioned, sometimes the use of antidepressants

may be helpful. Elderly patients are more susceptible to suffer adverse reactions to drugs, so the suggestion is to take special care with the prescription of psychotropic medications. Drugs with anticholinergic are proved to have multiple adverse effects (confusion, memory impairment, dry mouth, hallucinations, blurred vision, constipation, urinary retention, etc.) [80, 81], because of this, Beer *et al.* (1991) developed certain criterion to be taken into account when prescribing medicine. In general, they discourage the use of amitriptyline, clozaoine, thioridazine, chlorpromazine, nortriptyline, olanzapine and paroxetine.

For older patients the selective serotonin reuptake inhibitor antidepressants (SSRIs) are the first choice. Sertraline has been widely studied for this age group and its use is safe. In patients who experience adverse effects (diarrhea and hyponatremia) and suffer from insomnia, agitation or restlessness, the mirtanzapina is recommended [72]. Escitalopram has been gaining ground in recent years for its high effectiveness and low side effects [73, 74]. Citalopram can be used but with caution because of the prolonged QT syndrome [75, 76], although it is as effective as escitalopram to control symptoms [77].

Venlafaxine and duloxetine are second-line drugs, reserved in case of failure to treatment with SSRIs. The length of treatment in a first episode of depression varies from 6 months to 1 year [83].

Another health problem expressed by most caregivers is the anxiety disorder. Current recommendations suggest the use of SSRIs as first choice. In some cases, the use of clonazepam or lorazepam can relieve symptoms before the drugs start to make effect (usually after two weeks.)

For tensional headaches the patients are usually treated with acetaminophen or ibuprofen. In cases of an acute event, local measures are also suggested to relieve tension, such as kinesiology, massage or yoga. Chronic headache should not be treated with Non-Steroidal Anti-inflammatory drugs (NSAID). Preventive treatment with amitriptyline, propranolol or flunarizine is the best option. Mirtanzapine and venlafaxine can be used as second choices [78].

Chronic pain (low back pain, for example) should be treated with a combination of acetaminophen plus tramadol or codeine, avoiding the chronic use of conventional NSAIDs, because these drugs can lead to gastrointestinal bleeding and affect renal function or blood pressure. The use of COX-2 NSAIDs is effective and safe [79].

The treatment of psychopathological disorders, a proper control and adjustment of the doses of medication and closely monitoring therapies to check for the existence of side effects in patients may paradoxically improve the quality of life of caregivers by reducing their feeling of burden.

Limitations: the results provide empirical evidence that demonstrate the existence of impacts on the caregiver's health. The caregivers studied in this investigation were in charge of patients with chronic diseases and located in Ciudad Autónoma de Buenos Aires. The present research was carried out with empirically validated instruments previously used in other investigations by professionals trained to collect data. For that reason, no loss of information

was registered. Nevertheless, two limitations can be mentioned: the non-probabilistic sample strategy used and the reduced size of the sample analyzed.

Finally, to enhance the importance of replicating the study in an older population, it is recommended to make further longitudinal studies that enable the analysis of the caregivers' health and well-being. Future investigations must be developed since the moment the patient is diagnosed with assistance of health professionals. The possibility of validating a telephone version is being considered so as to be able to perform a massive study in the population of elder citizens.

CONFLICT OF INTEREST

Authors declare to have no conflict of interest.

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