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Depression in family caregivers of elderly people with dementia

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Abstract

The caregivers of elderly people with dementia suffer an affectation in the psychological and social order due to the low probability of total rehabilitation of the elderly and the progressive course of this pathology. In the municipality of Guisa, Granma Province there is a health problem regarding this problem since family caregivers of the elderly with dementia constantly go to the Psychology and Psychiatry consultations, in search of specialized help because they report feeling depressed. For this reason, this research was carried out with the objective of determining the main manifestations of depression in these caregivers. The results emanating from the triangulation of methods (scientific observation) and techniques (questionnaire, interviews and inventory Beck), employees at three stages of work where it was found that the main manifestations of depression of these caregivers are: p oss of interest or the ability to enjoy activities that were previously pleasurable, loss of emotional reactivity to pleasant environmental events and circumstances, sleep disturbances, marked loss of appetite, weight loss , irritability , muscular tension , feelings of sadness unmotivated that produces discomfort and sufferings, a nsiety, entities of handicap, blame, loss of self-confidence and feelings of inferiority , gloomy perspective of the future.

Keywords: : aging, dementia , family caregivers , depression.

Major classifications: Health Science

1. Introduction

The world is immersed in an important demographic transition, which for many social scientists becomes one of th e most significant worries in the international reality of this century. Population aging and in parallel, the growth of p revalence rates of diseases associated with age, such as dementias in the elderly, are part of the main topics of interes t of the scientific community (Bayarre, 2017).

It is estimated that, worldwide, the annual total number of people who reach this age is almost 58 million. According to recent data, between 2015 and 2050, the world's largest population will double and go from 900 million to 2000 million in 2050 (De Valle, Hernández, López, Zúñiga, & Martínez, 2014). Similarly, dementia behaves, studies show t hat approximately 15% of people over 60 suffer from it (LLibre, 2012), becoming the leading cause of disability in t he senescent, causing a progressive loss of autonomy.

These figures allow us to understand that aging is increasing rapidly from various economic and social patterns world wide, which will increase in the coming years and consequently these associated diseases.

Cuba is no exception, it exhibits an aging rate of 19.4%, the highest in Latin America (Bayarre, 2017). Although the increase in life expectancy is considered one of the achievements of contemporary medicine, systematically analyzes a re carried out that are based on the negative effects of the aging process, that is, the appearance of chronic diseases, physical, mental and mental dependence. social of the elderly and its influence on the family and the community.
In the country, the responsibility for the care in this long-term age group lies primarily with the family. It is a priorit y objective in the Cuban government strategy on aging, care and support for informal caregivers, because they start fr om the premise that knowledge, skills, values and experience are needed to provide care, so it is essential to provide these people education and training that allows them to do their job well (Benítez, 2016).

The importance of studying family caregivers of elderly people with dementia, comes from the need of their object, while there is an accelerated and systematic growth of the homes of older adults with dementia demanding special ca re given the characteristics of this pathology[1] .
In informal caregivers, their free time and leisure activities are often limited, their social life is affected by presenting difficulties in the family and work spheres, as well as physical and psychological health problems, which even affect everyone. the next of kin of the dependent elderly person become especially accused in the main caregiver.
In the conceivable care as an unexpected task imposed by the problems of the elderly and dependency levels ranging progressively achieved, and often so long, through stages, together with the other duties and responsibilities usually h ave, the caregivers becomes n in a group on social and health disadvantage with affectations in their welfare, appeari ng mental disorders such as depression that require prompt attention by qualified personnel due to the characteristics of this disorder.

In the depressed person, self-awareness is lacerated, there is no adequate rethinking and questioning of personal goa ls, their own projects are not consolidated, having a significant impact on the meaning of life and therefore on the ap pearance of suicidal behavior. The awareness of your own problems is always negative, so it does not allow you to fi nd appropriate solutions and assume, if necessary, new challenges to the problems that arise in your daily life.
In general, personality is affected in its entirety because this new level of self-consciousness goes through all the pers onological formations, printing stability, development, independence, autonomy, which in depressed people are affected; and therefore this influences the appearance of clinical pictures where symptoms related to these configurations preva il such as: anxiety, hypervigilance, alterations in the course and content of thought (suicidal ideas), hypotimia, hypoab ulia, anorexia, hypoerotism, insomnia, among others that may have an acute or chronic course depending on how the subject assumes them and the influence of the environment.
In the caretaker this picture can be aggravated due to the perception of physical and psychic overload they present (Roca and Blanco, 2007; Araya, Guzmán and Godo, 2007; Taset and Marante, 2009; López, Orueta, & Gómez, 2009; Segura, Peña, & Eloy, 2014; Alfonso, 2016; Hidalgo, Turtós, Caballero, & Martinola, 2017; Bayarre, 2017).
Hence the need to conduct research that explores the level of depression in this population group on which the most dramatic effect of this task gravitates.
In this sense, this research work aims to determine the main manifestations of depression in family caregivers of elde rly people with dementia. It is of vital importance as it will lay the foundations for future research on the subject as well as for the implementation of a psychological intervention strategy in order to reduce the level of depression of c aretakers and thus improve their quality of life and quality of the work they offer.

2. Method

Participants:
The *inclusion criteria of* the universe were:
- ✓ Being city prays family of an elderly man with d emencia
- ✓ Willingness to participate in the investigation.

1 One of the diseases that more functional deterioration and therefore, greater stress provides the caregiver is dementia. This is a disease of the central nervous system, given by alterations of the higher mental processes, which modifies the personality and behavior of the people who suffer from it. Dementia causes a progressive loss of the autonomy of the patient, who becomes dependent on other people to perform their activities of daily living. This dependence, together with behavioral problems such as delusions, hallucinations, aggressiveness, disinhibition and other behavioral symptoms, leads to the appearance of alterations in family dynamics and in particular, in the quality of life of caregivers.

The research universe was made up of 26 family caregivers of elders with d emencia of the town of Guise. It was decided to work with the universe as long as the figure is considered to allow quantitative and qualitative techniques to be adequately applied, so that sufficient results are obtained from the analysis and interpretation of the data to determine the presence of depression in caregivers. Family members of elderly people with dementia.

Variable under study: Conceptual and operational definition.

3. Depression

" **Depressive** mood (sadness), decreased interest and pleasure in enjoying things, consequent decrease in the level of activity and other secondary, given by significant changes in appetite and due to weight, sleep disorder, agitation, psy chomotor slowing Exaggerated fatigue, loss of energy, difficulty in concentration, difficulty in making decisions, think ing of death or suicide. "(ICD-10).
To study this Variable in this research assumes n d os dimensions of expression:

4. Dimensions

4.1. Somatic

A group of somatic manifestations that occur in the body affecting their health and causing discomfort due to the pre sence of symptoms to the person that affect their behavior .

4.1.1. Indicators

- P oss of interest or ability to enjoy activities that were previously pleasurable .
- P oss of emotional reactivity to pleasant events and environmental circumstances .
- Alterations in sleep.
- P objective resence psychomotor inhibition or agitation .
- P oss marked appetite .
- P oss weight .
- P oss of sexual desire .
- Irritability .
- Muscle tension .

4.2. Psychological Ps

Set of effects that occur in the subjective world of the subject as a result of the action of harmful elements of the environment and that affect their psychosocial development.

4.2.1. Indicators

- Feelings of unmotivated sadness that causes discomfort and suffering .
- To nsiety .
- S entrances of disability, of cul pa.
- D isminución attention and concentrated tion .
- P oss of self - confidence and feelings of inferiority .
- Ideas of guilt and of being useless.
- Pe rspectiva grim future .
- P entimentations and suicidal acts or self-aggressions.

5. Methods and techniques used

5.1. Methods

D the theoretical level of knowledge: the historical-logical, the analytical-synthetic and the inductive-deductive were used throughout the investigation.
From the empirical level of knowledge: scientific observation was a cardinal method to capture data from family ca regivers in their own social environment. Behaviors, decisions, expressions, gestures, arguments in daily practice, dom estic activities carried out, family constitution, interpersonal relationships between family members, insane caregiver-ol d relationship were observed.

5.2. Techniques used

Initial interview: It was the first contact with family caregivers of the elderly with dementia . Its main objective is t o present the research and know its attitude towards the process. It also seeks to obtain a general impression of the li fe of each caregiver because it allowed to measure sociodemographic variables (age, sex, marital status, schooling) an d other data related to kinship, number of family members living at home, the time spent on the patient . It is possibl e to establish rapport and empathy.
In-depth interview: It was applied in order to know in depth the general characteristics of the caregivers and determ ine which are the main manifestations that speak in favor of the existence of depression . It was assessed on the phys iological reactions and personal well-being, that is to say the discomforts and sufferings that the interviewed subject h as, as well as the connection of these discomforts and sufferings with the existence of psychological stress. In additio n, it was sought to determine the individual potentials that it has to face this problem and the knowledge it has on th e subject in question and its personal health. Other general characteristics were also evaluated. Evaluates the social int egration of the individual with their environment, that is, the quality of interpersonal relationships with those around t hem.
Beck Inventory: It was used to assess the depth of depression in family caregivers of the elderly with dementia. The content of the items clearly reflects the importance attached by the authors to the cognitive component of depression, only one third of the items refer to physiological or behavioral aspects The score range obtained is from 0 to 56. Th e 21 dimensions of those that consist are:

A. Mood
B. Pessimism
C. Failure
D. Discontent
E. Guilty feeling
F. Need for punishment
G. Self hate
H. Self accusations
I. Suicidal impulses
J. Crying
K. Irritability
L. Social isolation
M. Incapacity of decision
N. Image of the body itself
O. Inability to work
P. Sleep disorders
Q. Fatigability
R. Pé loss of appetite
S. Pé loss of weight
T. Hypochondria
U. Loss of Li Bido

The use of this technique allowed to evaluate the depth or intensity of depression of family caregivers quickly and objectively through the quantitative and qualitative qualification of said instrument.

5.3. Procedures

The research was carried out from three stages:
1) Pilotage of research to know the quantitative growth of the elderly with dementia in the Los Cocos community of the Guisa municipality and of these which are cared for by relatives .
2) Application of the techniques to family caregivers of the elderly with dementia, divided into two work sessions.
Session 1: The initial interview was applied.
Session 2: The Beck Inventory and the in-depth interview were applied.
3) Interpretive analysis of the data, with the intention of determining the presence of depression in family caregivers of the elderly with dementia.

6. Results

One was achieved climate of rapport, family caregivers reported feeling motivad to s by research which was carried out and expressed their willingness to collaborate in everything necessary, as this l a s benefited them as caregivers relatives. Which gave the possibility of obtaining excellent results through the methods and techniques applied. The analysis was carried out by work stages :

6.1. Stage 1

In the first stage was conducted r eview of documents, such as family records of doctors ' offices Family 6 and 7 comprising the study area, it was not counted on them with a medical classification of the elderly with dementia. There is no correspondence between: the number of older adults in the community registered in the files, the figure obtained in the Department of Health Statistics in the municipality (2016) and the data that could be obtained from the registration of the Health Center Mental (also from 2016 as it is updated annually). For what it was necessary to visit, with the help of the nurses and assistants of the offices, 100% of the elders of the community, being defined that there are in the area 38 elderly people with diagnosis of dementia and of these, 26 have as primary caregiver to a relative. After concluding with this stage, the universe of study was defined.

6.2. Stage 2

6.2.1. Session 1

Initial Interview: With the application of this technique, general data were obtained from family caregivers of the elderly with dementia such as:

The analysis of the data confirms that the woman configures the basic pillar in the care and care of older adults with dementia, on which the fundamental weight falls. In this community, 100% of caregivers are female.

The average age of caregivers is 54.1 years, here it is important to highlight that 65.4% corresponds to average adulthood as a stage of development, and of these 27% are between 55 and 59 years of age. 30.8% of all caregivers are over 60 years old, that is, they are older adults and only one caregiver, which represents 3.8%, is young.

The analysis of the level of schooling reports significant differences. The highest number of school caregivers have completed twelve grade (38.5%), appreciating other forms of education, basically in the middle (15.4%) and university (23.1%) levels. It is important to note that there are caregivers with very low levels (primary 11.5%) and even 7.7% do not present any expired school level.

It is seen as a tendency in caregivers to be accompanied maritally, 65.4% evidenced having a formal or informal relationship, however the presence of frequent couple conflicts is exhibited. These conflicts are significant as caregivers perceive them as a direct consequence of care. It is also important to note that, of 34.6% of the caregivers who are divorced, 7.7% directly link their separation with the work they do.

The study also reveals different results in the employment situation of these caregivers, however they have a common element, the cause that leads to the fact that 84.6% do not have a work relationship, is the performance of their role as primary caregiver of the relative with dementia, this demand for continued day and night care that makes it impossible for them to meet a work schedule. The 15.4% of caregivers who keep working correspond to those responsible for the care of

the elderly in the initial stages of the disease, which allows them to be left alone, for a certain time, to the extent that they have some independence, or leave it under supervision of relatives (for example, grandchildren, friends or neighbors) , for a short time.
Different attitudes are perceived between caregivers who do not have a defined occupation (50%) and those who studied a career and have an occupation that is related or that allows them to perform this work better (50%).
There is a superiority of extended families over nuclear and extended families, while the former reach 69.2%, the latter and third represent 23.1% and 7.7% respectively. The results confirm that the family is responsible for the care of the elderly with dementia, expressed in that 65.4% are daughters, followed by wives, who represent 23.2% and sister, niece and daughter-in-law, who express the same level percentage (3.8%). (See annex 1):
Session 2:
Beck Inventory: The application of this technique showed that the 26 family caregivers of the elderly with dementia had an overall score between 10 and 18 points, which indicates that 100% of the caregivers have a mild level of depression. This constitutes an alarming situation due to the rapid progress that this pathology has and its consequences for both the caregiver and the patient. In Annex 2 the behavior of the main dimensions of the depression obtained in this technique is shown.

This inventory corroborated data obtained in other techniques that speak in favor of the presence of depression in caregivers. It is also appreciated, how all spheres of the caregiver's life are affected which, being a sustained situation, can lead to severe depression.

As in other techniques, the influence of age, level of education and the stage of the disease on the subjective well-being of family caregivers was observed, since the lowest-scoring caregivers are those at the university level.
In - depth interview: It was found that e l 100% of caregivers assess their state of regular health or bad , a lthough are notable distinctions, there is a tendency for the onset of chronic non - communicable diseases, especially arterial hypertension, which is related with the state of intense labor they present. It also highlights the frequent presence of other psychosomatic diseases, where stress becomes, in most cases, the driving force behind its appearance. The musculoskeletal pains achieve significant results while they are a sign of the physical stress they suffer from trying to make the patient's care and manipulation compatible, with other household responsibilities.
In interviews l was obtained as allocations from the genre are the ones that have the greatest influence on the assumption of lifestyles that limit and often cause feelings of guilt for not complying with assigned , showing a p e rspectiva grim of the future and lack of interest in activities previously they were pleasant .
It was appreciated that in the majority of extended families, the caregiver is solely responsible for the care of her family member, even though there are consanguineous ties and filial relationship between the elder and the rest of the members. Although they express, they receive financial aid, they do not have a support network that in certain occasions assume this role, even to devote time to attend to their state of health, perceiving their life restricted exclusively to the care of their relative. This situation causes the caregiver to feel irritable, tense with loss of appetite and sleep disturbances. It is often also the presence of feelings of sadness and p oss of emotional reactivity to pleasant events and environmental circumstances.
Caregivers have dissatisfactions regarding the care of the elderly with dementia due to the health system. Although the House of Grandparents could contribute to the improvement of the quality of life of these caregivers, it is not possible, since the entrance to it corresponds to mentally healthy older adults who are self-worthy.
In 100% of the interviewees it was obtained that they feel committed to their family member, because they think it is their duty, they also allege that they suffer a lot when they see how their loved one is “tearing apart”, “destroying”, “crumbling”, “collapsing” 71% of family caregivers know techniques that help with the management of their family member and 100% have ever attended specialized consultations with psychologists and psychiatrists for help because they have felt tense, depressed, anxious.
In general, 86% consider their performance as a good caregiver although they express that sometimes it could be better, and 14% value their actions as very good, perceiving that they have given their best.

7. Discussion and Conclusions

With the research carried out, it is clear that informal care configures the basic pillar of care that elderly people with dementia receive, the only source of care comes from the family, with the fundamental weight on women. Defining as family caregiver the family *woman responsible for the care of the dependent elderly, who participates in the decision-making, supervision and support of basic activities (food, hygiene, bathroom, clothing, personal mobility, sleep and rest)*

and instrumental (has greater cultural bias, and refer to the use of communication systems, maintenance of one's own health, money management, establishment and care of the home, use of security procedures and emergency response) of its daily life. He lives mostly with the elderly and does not receive financial compensation for the work he does.

The mental health of caregivers is affected, with depression being one of the main discomforts that afflict them. P or one hand the multiplicity of roles to which women are exposed that causes high levels of stress. P or other attributes assigned own gender, tempered by patriarchal societies condition that carers t i Jan n to deal with a lot of tasks that go beyond frequently their real possibilities, these tasks and demands are changing (so that what is useful today may be totally useless tomorrow requiring a readjustment of the daily routine), continuous (they take up a large part of the caregiver's time) and long-term (it is often prolonged for months and even years).

In l a s caregiver to s informal often limited their free time and leisure activities, social life is affected presenting difficulties in work and family sphere as well as health problems both physical are presented as emotional or psychological, which, although they can affect all the relatives of the dependent elderly person, they become especially accused in the main caregiver. That being the case arises in the caretaker to a subjective perception given load have to feel confused, overwhelmed, trapped and excluded.

When care is conceived as an unexpected task, imposed by the problem of the elderly and the levels of dependence that it is progressively reaching, and often in a prolonged way, through stages, together with the other obligations and responsibilities that caregivers usually have and the physical and mental discomfort caused by the performance of this role , caregivers are subject to a long-term risk situation, for which they are not prepared, causing high levels of overload that directly influence the state of sadness, decreased interest and pleasure in enjoying things, consequent decrease in the level of activity and other secondary, given by significant changes in appetite and due to weight, sleep disorder, agitation, psychomotor slowing, exaggerated tiredness, loss of energy , difficulty in concentration, difficulty in decision making, thinking of furniture rte or suicide presented by family caregivers of elderly people with dementia under study.

After the theoretical analysis and the practical verification carried out, it is concluded that:

The main manifestations of depression in caregivers relatives of elderly with dementia are: Poss of interest or ability to enjoy activities that were previously pleasurable , p oss of emotional reactivity to events and environmental circum stances pleasurable , sleep disturbances, pmarked loss of appetite, loss of weight, irritability, muscular tension, entices of unmotivated sadness that produce discomfort and suffering, nsiety, entrances of handicap, of cul pa, loss of self-co nfidence and feelings of inferiority , gloomy perspective of the future .

7.1. It can also be seen that

Family caregivers of elderly people with dementia coexist in a community rooted in patriarchal precepts and rural livelihoods that give women and family all responsibility for the care of the home and dependent people, with women being the responsible figure of the care of the elderly with dementia.

Family caregivers of elderly people with dementia become a sensitive group from the logic of socioeconomic life, physical and psychological health due to the work they do.

In family caregivers of elderly people with dementia, adaptive coping strategies predominate, whose background is the predominance of the filial relationship (daughter-mother / father), defined by gender stereotypes and social norms of allocation and compensation of care that define to daughters as solely responsible for parental care.

Age, level of schooling, kinship and stage of the disease determine the caregivers' perception of care, family environment and themselves.

Caring for an elder with dementia has on the caregiver to family the presence of chronic non - communicable diseases like Hypertension and Diabetes Mellitus affecting the quality of life of the caregiver and the quality of care they offer.

7.2. Recommendation

7.2.1. To the Psychology and Psychiatry consultations of the municipality of Guisa

Design psychological intervention strategies aimed at family caregivers of the elderly with dementia, in order to reduce the manifestations of depression they present.

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Appendix 1:

Table: Characteristics of family caregivers of elderly people with dementia.

Cuidadora	Edad	Est. mar.	Niv. escolar	Profesión	Vínc. lab	Parentesco	Años de cuid.	No. Miemb. fam	Tipo. Fam	Relac. Interp
C1	30	Casada	Universit	Lic. Derecho	No	Nuera	5	4	Nuclear	Buena
C2	42	Casada	Universit	Lic. Enferm.	No	Hija	2	6	Extensa	Buena
C3	43	Casada	Bachiller	Ama de casa	No	Hija	6	6	Extensa	Buena
C4	46	Casada	Bachiller	Ama de casa	No	Hija	3	5	Extensa	Buena
C5	46	Casada	Bachiller	Ama de casa	No	Hija	3	6	Extensa	Buena
C6	47	Divorciada	Universit	Lic. ESC	No	Hija	3	4	Extensa	Buena
C7	47	Casada	Bachiller	Ama de casa	No	Hija	2	5	Extensa	Regular
C8	47	Divor./ cuid	Universit	Lic. Maestra	No	Hija	9	4	Extensa	Buena
C9	50	Divorciada	Universit	Lic. Contab	No	Hija	2	3	Nuclear	Buena
C10	52	Casada	Bachiller	Ama de casa	No	Hija	10	7	Extensa	Buena
C11	54	Divor./ cuid	Universit	Lic. Enferm.	No	Hija	8	2	Nuclear	Regular
C12	55	Divorciada	Téc.medio	Gastronóm	No	Hija	20	2	Nuclear	Buena
C13	56	Casada	Téc.medio	Manicure	No	Esposa	2	2	Nuclear	Regular
C14	57	Casada	Téc.medio	Cocinera	No	Sobrina	9	3	Ampliada	Buena
C15	57	Casada	Téc.medio	Peluquera	No	Hija	6	6	Extensa	Mala
C16	58	Divorciada	Bachiller	Sec. Marmol	No	Hija	2	3	Extensa	Buena
C17	59	Divorciada	Bachiller	Corte y costu	No	Hija	5	5	Extensa	Buena
C18	59	Casada	Bachiller	Ama de casa	No	Hermana	5	6	Ampliada	Buena
C19	63	Casada	Bachiller	Ama de casa	No	Esposa	4	7	Extensa	Buena
C20	63	Divorciada	Bachiller	Ama de casa	No	Hija	10	5	Extensa	Mala
C21	63	Casada	Bachiller	Ama de casa	No	Esposa	4	3	Extensa	Buena
C22	69	Casada	Secundario	Ama de casa	No	Esposa	7 meses	3	Nuclear	Buena
C23	71	Casada	Primario	Ama de casa	No	Hija	2	3	Extensa	Buena
C24	77	Divorciada	Primario	Ama de casa	No	Hija	8	2	Nuclear	Buena
C25	78	Casada	Ninguno	Ama de casa	No	Esposa	8	5	Extensa	Regular
C26	80	Casada	Ninguno	Ama de casa	No	Esposa	11	4	Extensa	Buena

Appendix 2:

Table: Major dimensions d EPRESSION in caregivers relatives of the elderly with dementia.

Dimensions d EPRESSION	Do not give Family caregivers	Percent than represent (%)
Discontent	26	100
Crying.	26	100
Irratibility	26	100
Sleep disorder.	26	100
Fatigability	26	100
Loss of appetite	26	100
Weight loss	26	100
Inability to work.	26	100

Mood	13	fifty
Guilty feeling.	26	100
Hypochondria.	6	25