The experience of family caregivers of older people with depression

VIVENCIA DE LOS CUIDADORES FAMILIARES DE ADULTOS MAYORES QUE SUFREN DEPRESIÓN

VIVÊNCIA DOS CUIDADORES FAMILIARES DE IDOSOS QUE SOFREM DEPRESSÃO

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ABSTRACT

The objective of the study was to understand how family caregivers experience the depression of older people in their care, within their cultural context. This is a qualitative study of ethnographic trajectory, performed using Spradley as the framework. The cultural universe consisted of relatives who performed the role of caregivers, who provided informed consent. Caregivers perceived the disease as a deep limitation on their way of living, involving loneliness, sadness and pity. The feelings of the depressed patients extend to the caregiver, who also faces the risk of suffering from depression. The responsibilities of caring also generate feelings of guilt that produce more suffering. Relatives recognize the onset of the disease, their attributes, the forms of treatment, and the social stigma associated with this mental disease and that they have a fundamental role in providing support and care in the recovery process.

KEY WORDS

Depression. Aged. Caregivers. Family.

RESUMEN

La investigación tuvo como objetivo comprender cómo los cuidadores familiares vivencian la depresión de los adultos mayores, en su contexto cultural. Se realizó un estudio cualitativo de travectoria etnográfica utilizando el referencial de Spradley. El universo cultural se constituyó con familiares, quienes ejercían el rol de cuidador, obteniéndose su participación a través de consentimiento informado. La enfermedad es percibida por los cuidadores como una limitación profunda en la calidad de vida del anciano, sumando soledad, tristeza y dolor. Los sentimientos de los pacientes deprimidos se hacen extensivos a los cuidadores, quienes también corren el riesgo de deprimirse. Las responsabilidades propias del cuidado también generan en los cuidadores sentimientos de culpa, lo cual los expone a un mayor grado de sufrimiento. Los familiares reconocen las formas de inicio de la enfermedad, sus atributos, las formas de tratamiento, y el estigma social asociado a la enfermedad mental y su rol fundamental de apoyo y cuidado en la recuperación.

DESCRIPTORES

Depresión. Anciano. Cuidadores. Familia.

RESUMO

O objetivo da pesquisa foi compreender como os cuidadores familiares vivenciam a depressão dos idosos, no seu contexto cultural. Realizou-se um estudo qualitativo de trajetória etnográfica, utilizando-se o referencial de Spradley. O universo cultural constituiu-se de familiares que exerciam o papel de cuidador, obtendo-se sua participação através de consentimento informado. A doença é percebida pelos cuidadores como uma limitação profunda no seu modo de vida, com solidão, tristeza e dó. Os sentimentos dos pacientes deprimidos extendem-se aos cuidadores, e estes tem também o risco de tornarem-se deprimidos. As responsabilidades próprias do cuidado geram nos cuidadores sentimentos de culpa que produzem mais sofrimento. Os familiares reconhecem o início da doença, seus atributos, as formas de tratamento e o estigma social associado à doença mental, e seu papel fundamental de apoio e de cuidado no processo de recuperação.

DESCRITORES

Depressão. Idoso. Cuidadores. Familia.

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INTRODUCTION

Mental illnesses are a large public health problem in Chile and internationally nowadays, permanently demanding policies, plans and programs that seek the best possible solution.

Sequelae of mental illnesses are not limited to the country's economy, considering workdays lost due to leaves of absence and decreased productivity, among others, but also include their impact in the lives of patients and their close environment⁽¹⁾.

Depression is a pathological alteration of a person's state of mind and a decline in one's mood which ends in sadness, accompanied by different vegetative and emotional symptoms and signs, related to thinking, behavior and life rhythms, which tend to continue over a long period. It frequently manifests itself during life, with different episodes, in a physical and recurring course with a trend towards recovery between these episodes⁽²⁾.

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2020. Mortality rates among depressive patients are twice as high as in the general population and patients suffer greater limitations in terms of psychosocial functioning than patients with chronic physical diseases like hypertension and diabetes⁽³⁾.

Depression is one of the most frequent psychiatric disorders in elderly patients. Several North American epidemiological studies describe prevalence rates of 1-5% for major depression and 8-27% of significant depres-

sive symptoms among community-based elderly. Prevalence rates are even higher among hospitalized elderly patients and elderly living in long-stay institutions⁽¹⁾.

In Chile, depression is the second cause of potential years of life lost (PYLL^(a)) among women. This disease is at least twice more frequent among women than men and entails high direct and indirect costs. It is responsible for one third of workdays lost due to disease, concentrating more than 40% of medical leaves and representing at least 25% of general medical appointments in Primary Health Care⁽⁴⁾.

Among the 20 specific disorders most relevant for their contribution to PYLL in Chile, for 2002, major depression and alcohol-related disorders rank first and second, with 9.9% and 5.1%, respectively. Disorders associated with drugs consumption and schizophrenia also figures among the 20 most important. The weight of specific psychiatric disor-

ders is also higher when considering only patients between 15 and 59 years of $age^{(2,4)}$.

Depression is the most common affective or emotional disorder in old age and usually responds to treatment. Nevertheless, it is important to consider how this disease affects quality of life, increasing the risk of suicide. Moreover, it can be seen as an early sign of chronic disease and a result of physical illness, with both physical and psychological possible causes. Cognitive deficiencies can be more due to depression than to old age or dementia. When depression coexists with medical diseases, lack of treatment delays physical recovery. Symptoms can be secondary to medication interaction or to an undiagnosed physical problem^(3,5).

Adults entering a depressive period tend to describe their state of mind as sad, without hope, dark and useless. Low self-esteem and decreased physical and psychic energy lead to apathetic withdrawal from the environment. There is another dimension of depression, however, experienced by a significant number of adults who express anxiety, irritability, agitation and feelings of anguish.

Depression prevalence rates in the community among

people over 65 years of age ranges between 2 and 3% in the United States, while rates for the last six months in Santiago de Chile correspond to 5.6%, which is lower than for the general population. In institutions like asylums or homes for the elderly though, prevalence levels rise up to 17-20%, with between 28 and 40% of dwellers showing depressive symptoms⁽⁴⁾.

On the other hand, according to followup studies, the presence of depression in ge-

riatric patients hospitalized due to non-psychiatric causes constitutes a risk factor for death within 30 months after the diagnosis⁽⁴⁾.

Another aggravating factor is the double stigma that rests on elderly people with depression. One relates to the mental illness and the other to the patient's biological losses. In the context of the body culture in the West, elderly people are considered aged, which contributes to a lack of independence, isolation, and solidness and often to the development of depression itself or relapses. Fortunately, research is being done with a view to healthy old age, evidencing advantages that can be stimulated, mainly at the affective level⁽⁶⁾.

This highlights the need to reassess nursing's practical function in elderly care, traditionally based on a curative focus. The focus needs to be moved to health promotion, considering the biological, social, psychological, cultural and spiritual areas as necessary elements of balance to reach wellbeing.

Care for elderly patients is usually long-term; it is about offering quality of life, enabling them to use their physi-

⁽a) Compound indicator that assessed the number of years a person lives without any kind of healht problem. It is obtained by adding up the years lost by premature death and years lived with disability, after discounting the number of years that person could live in a given time and place.



cal, psychological and social abilities to the maximum, with the support of relatives and friends, until the end of their lives.

Getting to know the experiences of people close to a depressive person and observing how the family interacts and mutually relates in the context of the disease and daily life can contribute to the exercise of nursing's professional role.

OBJECTIVE

This research aimed to understand the meanings family caregivers of depressive patients attribute to the disease in its cultural context.

Chart 1 - Cultural Universe of the Research - 2008

| M | EΤ | Ή | O | D |
|---|----|---|---|---|

This is a qualitative ethnographic research⁽⁷⁾. The cultural universe of the research comprises nine family caregivers, between 28 and 65 years of age, with different socioeconomic and educational conditions (Chart 1).

The following inclusion criteria were adopted: Relatives of patients with a diagnosis of depression, under treatment at a care center in Santiago, whose disease has been controlled for at least six months, informants able to communicate and, finally, who accepted to sign the informed consent form. Exclusion criteria were: relatives with depression younger than 60 years and an insufficient support network.

| Family Relationship | Age | Education Level | Profession | Socioeconomic Condition | Identification |
|------------------------|-----|------------------------|------------------------|----------------------------|----------------|
| Husband | 65 | Unfinished Secondary | Retired | Low | E1 |
| Niece | 28 | Unfinished Basic | Housewife | Medium | E2 |
| Wife | 65 | Unfinished Secondary | Retired | Low | E3 |
| Sister | 50 | Unfinished Basic | Housewife | Medium | E4 |
| Niece | 28 | Finished Secondary | Housewife | Medium | E5 |
| Niece | 25 | Professional Technical | Paramedical Technician | Medium | E6 |
| Wife | 65 | Unfinished Basic | Housewife | Low | E7 |
| Daughter-in-law | 40 | Professional Technical | Housewife | Medium | E8 |
| Daughter | 28 | Unfinished Secondary | Housewife | Medium | E9 |

The following data collection tools were used: participant observation, in three steps: descriptive observations, which should be broader and aimed at getting a picture of the cultural context; focused observations, which analyze the previous observations and are narrower; and selective observations, aimed at narrowing down the observation field even more. This allowed us to get to know the relatives' activities, the physical characteristics of the daily social situation and the satisfaction with participating in the cultural context.

In-depth interviews were used to get access to the meaningful contents; it is the single event that occurs between two people: the informant and the interviewer. These aimed to understand the family caregivers' perspectives on their lives and experiences, seeking their vision on the world. The interviews were held at the families' homes, fully taperecorded and transcribed to preserve the discourse, respecting the meaning of the informants' expressions⁽⁸⁾.

Next, taxonomic analysis was performed, which is the second data analysis level. It aims to deeper elaborate and demonstrate the internal organization of a domain. Hence, like a domain, a taxonomy reveals subsectors of popular

terms and the way these are related to a domain as a whole, finally constructing 7 taxonomies: Describing depression, perceiving the impact of depression in the family, taking care of a relative with depression, care and treatment for relatives with depression, the onset and relapse of depression, seeking solutions, relation between patients and relatives.

For discourse analysis, first, Domain analysis was performed, which refers to a category of cultural meaning that includes other minor categories. This first analysis level starts with the discourse notes, resulting in 21 Cultural domains. It should be highlighted that the description of cultural domains always involves the use of language, hidden terms, included terms and semantic relations; these are all words and phrases that define and give meaning to objects, events and activities. Like the domains identified in a culture, they should be validated by the informants, through questions structure according to the principles used to formulate this type of questions, with a view to confirming or denying hypothetical domains⁽⁷⁾.

And finally, thematic analysis was performed. Themes correspond to some tacit or implicit cognitive principle that is recurrent in different domains and serves as a relation



among subsystems of cultural meaning. Thus, cultural themes are large units of thought and consist in a number of symbols used within relations among meanings.

PRESENTING THE CULTURAL THEME

Data analysis, aimed at understanding the cultural meaning in its peculiarities, provided an understanding of the meaning of depression for family caregivers of elderly depression patients. Experiencing the impact of depression is described through two themes: *Perceiving the disease* and *Taking care of the depressive relative*.

Experiencing the Depression of a Relative

Perceiving the disease

The disease is acknowledged as something complex: this mainly refers to the way care is delivered, the relative's inborn feeling of wanting to give support, but perceiving many obstacles and impediments to provide it. This perception is considered based on the lack of training, with sufficient knowledge for care delivery to family members.

Dealing with these patients is very complicated..

[...] a person with a physical illness, a headache, he is given an aspirin of course and calms down for a while, so the situation is under control at least for a couple of hours, but this kind of patient, one cannot, because one has not been trained, if the doctors don't see them, imagine one without any skill, no study... so it's not that easy [...] (E4).

Through their discourse, the family caregivers describe the disease as something difficult to understand and accept different manifestations by distinct people.

[...] a depression can it be like this?, can it be silent without crying? Because I want to cry, I go to bed and feel desperate, and I cry and it scares and frightens me, so that's what I though, and as I see him so timid, not crying or anything [...] and it may have come up some time ago? And he didn't know [...] (E3).

I call it depression because the sadness is so big, the will to sleep, she didn't feel like doing anything (E2).

In the patients' discourse, family caregivers highlight inexplicable changes of mood, disinterest in life, and at other times similar to the loss of a meaning in life. They always say the same thing, showing difficulties to describe their suffering. Thus, the idea of suicide is perceived in their discourse.

A person who's ill sees everything as a problem, doesn't want to know about anything, doesn't get up, doesn't want to sleep, and the only thing he feels like is dying.

They get anguished because they don't know why they feel so bad, as if they had no reason to live.

The world does not interest me, I think I'd relax more if I were dead, I think I am carrying an intolerable torment.

It's something nobody understand because it's like a mark you carry with you in your life, it's a disease like a punishment we carry and we'll carry it forever (E7).

The following statements suggest the phases in which patients' state of mind alters between depression and euphoria.

Anyone who knows her would never once think she is a depressive person, because she's been happy for days, sociable, but we know that is a disguise, because we see her closed up without wanting to get up.

[...] she feels alone although she's accompanied, she feels old and that she's no use for anything, but I tell her she does (E1).

These statements reveal the feelings that flourish in patients about their disease, through their caregivers, their emotions about the end of the lifecycle, the loss of family members, physiological changes, or simply because the feel they have reached the final phase of their life. Caregivers express the causes for the onset of depression as follows.

He's like that because he's alone there, well, his disease started when his wife died (E4).

She was a happy, joyful woman, her life changed when her son moved abroad and she felt so sorry because he took her grandchildren, she was always sad, wanting to sleep and to cry, she never conformed.

She had problems with her husband, it was very strange because she always hid it, I always felt sorry for her, I heard her crying at night and she didn't sleep (E8).

These statements reflect how caregivers identify solitude as a predominant factor for the onset of their relative's depression. Solitude is undoubtedly a reality for many elderly, either because they are actually alone or because they simply feel alone. This is a very painful process, all the more when associated with the loss of one's partner, considered one of the main conflicts in a human being's life.

Moreover, reaching old age implies a period of changing goals and purposes, as one starts to reassess the events of life. In this search, one faces difficulties from a past that was often protected, hidden. Bringing these memories to the present favors depressive states.

He had many problems when he was a child, had problems with his father, when his father came home, came home from work he was very drunk, you see [...] and he had to hide under his bed, because he used to take his mother, take all of them [...] he tells me that he has so many problems because of what my father did to us [...] (E3).

On the other hand, the cultural universe identifies depression as a disease that goes through different stages, as they see different manifestations of the disease over time in their relatives' actions:

[...] only sometimes she feels down, I don't know how, as if she doesn't want to talk, but not all day, for a moment, then she suddenly feels animated, she walks, talks, we talk, we



watch TV, so it's not as if she's there all day [...] She used to say: I feel as if I wasn't part of the home, and, I didn't want to wake up and I used to feel all day as if I hadn't slept at night, I was in hospital and they did not find anything (E6).

Different causes can be attributed to depression, but the main one is also connected to the phase of the lifecycle they are in, during which they go through countless changes, with regard to themselves as well as in the social dimension; like changed roles for example; in addition to the *losses* of people they are closest to. That makes this into a complex period in their lives and if one does not have adequate adaptation or coping tools, this can lead to a depressive disorder.

The disease involves different phases, such as feeling a stranger among one's family at home, sleepiness although one sleeps a lot and, in a more advanced stage of the disease, the somatization of anguish.

Caregivers clearly recognize the results or consequences of having depression. The relatives determine some characteristics of the disease, which are attributed to depression.

He doesn't say anything, locks himself up in his world, gets upset really quickly (E4).

According to what is *socially* acknowledged as a depressive patients, relatives attribute value, sustenance and meaning to the disease, without knowing that manifestations of depression differ according to the patient's culture, type of personality, gender and stage in the lifecycle.

As a result of the family caregivers' experiences and of sharing daily life with a depressive patient, the caregiver or closest relative undoubtedly recognizes and identifies the disease in different ways.

Throughout the research, the cultural universe permitted indicating depression by its name in most cases. In others, however, relatives refer to the disease by its evolution or some characteristic their relative manifests, which they attribute to depression, giving the impression that they do not consider or perceive the patient as depressive.

Pure nerves, that's it, this thing (E9).

Although families know and identify some aspects of the disease, denial is being expressed as part of the description in different ways, as a defense mechanism, a form of preventing it from affecting their loved ones with depression. Perhaps by denying its existence they protect themselves from suffering and from adding pain to their experience. Seeing what is happening is much more difficult, it means facing life and knowing how to continue; perhaps it is easier to simply live "blinded" from what is happening around, resulting in some kind of protection, as there is less sorrow.

Another important aspect the informants manifest is related to the appearance of new depressive episodes, given the lack of adherence to medication treatment. That is one

of the main problems in patients' recovery, as treatment abandonment tends to lead to relapses⁽⁹⁾.

In this context, family support is vital, as elderly people with depression demand a solid support network from people they are close to, not only to help them to follow treatment and care, but mainly to feel affection, understanding and support by people they most want support from.

Taking care of the depressive relative

Taking care of a depressive person at hoe demands family participation in the care process. Whoever plays this role faces a new responsibility in care for that person. In a way, the family adapts, reorganizes to assume the attitudes they should take towards the ill patient.

Finding family caregivers willing to help them in these circumstances is a complex task in this phase, mainly considering that elderly people may have been alone already due their phase in life. Often, only one or two people follow patients in their disease process, while the rest of the family does not participate. Their economic and presential support in depression treatment is important, but one has to take into account that the type of care demanded covers different tasks that imply daily dedication, as well as follow-up and other tasks characteristic in cases of depression, such as listening, observing and giving support when necessary.

I go with her everywhere, prepare her food, have lunch with her, take her to the toilet, take her upstairs, cheer her up, give her medicine, listen to her burdens, pay attention to her changes (E2).

To play this caregiving role, one needs to dedicate time to this activity, which often implies redistributing time, daily activities, physical spaces, including conditions that strongly influence the caregiver's life, who delays certain aspects of his/her daily life and own health to dedicate time to the depressive relative⁽⁹⁾, arousing feelings of guilt and obligation, as this provokes a rupture in life and family organization on many occasions.

It is increasingly burdensome to go to work, because I do few things because of her, I ceased participating in church because I did not want to leave my mother alone (E9).

The whole family dynamics goes through a big change, everyone suffers due to the depression, it seems as if the disease affects everyone's life (E7).

In the case of elderly people who do not live with their family, this fact becomes even more tangible, as the economic costs and efforts to take care of their relatives are even greater. The sense of oppression, despair and stress the family members perceive are the common factor in this cultural universe under analysis. The caregivers acknowledge that the disease has affected them both physically and psychologically. Informants mention feelings like *it has really affected me (E5), it makes me feel anguished (E8), it concerns me (E6), it makes you feel desperate(E5).*

Stefanelli MC



When they acknowledge the impact of their relative's depression on their own wellbeing, a certain family comorbidity seems to exist. The expressions the informants use coincide with a study⁽¹⁰⁾ that appoints that, at the same time as home caregivers see themselves as people who take care of others, they also perceive that they cannot take care of themselves. Hence, their physical, emotional and social needs, such as sleeping and relaxing, lead to such exhaustion that their health is affected.

It is exhausting, sometimes I go through great pains to sleep (E7);

I fell into a depression, I had a lot on my mind, I am nervous, I got a bit careless with my health (E3).

These assertions confirm that depression really affects health, especially in emotional and psychological terms, feeling the fear that the disease will pass on to them.

It cooperates for the environment to get ill (E6), her disease is passing on to me (E1).

Thus, depression is dimensioned as a family disease. This suggests that a non-infectious disease from the biomedical paradigm is linked up with a risk of transmission in the context of the anthropological theory of contagion⁽¹¹⁾. According to caregivers, the possibility of contagion is related to representations of depression as a mental and physical illness and its consequences for family, professional and social relations patients face in daily life⁽¹¹⁻¹²⁾. When addressing the theme of depression, it is related with social pollution, that is, danger, in this case due to the dimension of the disease that is established and continues for years, causing suffering⁽¹³⁾.

Hence, caregivers are concerned with themselves and, simply listening to their discourse, one can observe the fatigue and psychic exhaustion they also carry in their daily reality. While they are a source of support, they are also turning into subjects who demand care.

Concern with the rest of the family should be highlighted, as they often live with small children at home, or with other elderly people, which is a source of concern for relatives, reflected in the following statements:

So, it's as if one does not enjoy the day because of great concern (E2).

So it's really difficult for my mother as well, very difficult (E9).

So that's a concern for my mother, it's a cross she carries, a burden. My sister cries her heart out (E9).

The emotional impact evidenced so far is underlined by the following statements, which express the caregiver's suffering.

One needs strength to be here (E4).

The other option would be to take distance, forget and act as if it doesn't exist and I cannot [...] (E8).

I have to continue until the end, that's it [...] (E1).

I cannot take care of him but I don't want to leave him either (E3).

One would like to be colder and say well, that's it, no more, but the fact is that feelings surpass many things [...] it is complicated (E6).

This desire to often give up the role of caregiver is complicated by the feelings involved in these relatives' relationship. These give the impression that caregivers experience a feeling of obligation, of guilt about having to assume this responsibility, which not only implies having to modify their own life to dedicate time to care, but also a psychological and emotional burden that may lead to total exhaustion⁽¹³⁾.

The feelings of anguish and suffering become permanent, strengthening the desire to give up one's role. Obligations towards the family member contain this dual feeling of, on the one hand, not feeling able to continue one's role and, on the other, having to stay with one's relative who depends on care, as there is no other alternative. That is how one lives ambivalence.

Hence, the feeling of guilt is intense, not as a consequence of having committed something bad, such as ignoring some aspect of care, but of having the intent to abandon the commitment of love and concern with the other. As a result, they feel sanctioned by their conscience and, as historical subjects, they can judge their thoughts and actions.

The group of caregivers indicates that affective bonds in the patient-family relation are what makes them continue this work. The theme values good and evil, that love and moral conscience demand self-sacrifice, that despite the problems that may result from care delivery to a depressive patient, they are motivated to continue playing their role, even when this makes them annul their own wellbeing. Families often do not see any *real* solution for their relative's disease or simply prefer not to think about a future that includes living with depression.

We don't see a way out of the situation, I haven't thought about what the future is going to be like (E9).

The cultural universe identifies other sources than psychiatric and pharmacological treatment, mainly provided by faith and the family. God, Jesus, the Bible play a protagonist role in this search for solutions, a way of seeking answers to their disease or a way of finding emotional support at difficult times.

He got involved with the evangelical church, I read him paragraphs from the Bible, verses and he calms down (E1).

The family is identified as an important source of support in the search for solutions, despite a certain ambivalence, because they know that the family is their main means of support and therefore long for this support but, on the other hand, the feeling of being a nuisance or burden predominates, which often makes them not want to play their roles as caregivers.



This evidences the need for guidelines and support from health professionals and associations working with affective disorder, mainly through psycho-educative programs⁽¹⁴⁾ or other forms of healthcare⁽¹⁵⁻¹⁶⁾, which permit the perception that caregivers of elderly patients are not alone in their experience. In the case of depression, relatives, whether they are caregivers or not, suffer due to the disorder or family comorbidity, including both caregivers and patients.

FINAL CONSIDERATIONS

This research permitted understanding the meanings of the experiences of caregivers to elderly patients with

depression, showing the repercussions of care for the relative and the caregiver, as the direct responsible for care

Caregivers' perception of the disease is accompanied by a lack of knowledge, causing profound limitations in their way of life. They indicate that the depressed patients' feelings extend to themselves, which is why they are also at risk of depression.

The study contributes to the strengthening of educative programs on nursing and health team competencies, as well as on research and family and community health programs.

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