

FUNCTIONING OF FAMILIES WITH FULLY DEPENDENT ELDERLY

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ABSTRACT

Introduction: The total dependence of the elderly is a condition that requires full-time caregivers to perform the basic activities of daily living and can cause changes in family dynamics. **Objective:** To analyze the functioning of families with totally dependent elderly. **Methodology:** A descriptive study, developed in Cuiabá, Mato Grosso, Brazil, with four families assisted in the Family Health Strategy, using the Calgary Family Assessment Model. The data were collected in the families' homes through an interview with the main caregiver and were submitted to content analysis and interpreted using as reference the functional category of the Calgary Family Assessment Model. **Results:** They are presented in three categories: family characterization; internal functioning to care for the elderly; and functioning of families with the external family. The families were characterized as multigenerational, with inbred members and lived with the elderly. Internal functioning is influenced by total dependence on the elderly. The functioning of families with the external family is not completely effective due to communication problems. **Final considerations:** The results of this study have implications for health professionals, as it shows aspects of family functioning, suggesting ways to intervene in improving communication among their members.

Keywords: Family. Caregivers. Frail elderly.

INTRODUCTION

The aging process occurs in a dynamic and progressive way, followed by biological, psychological, functional and social changes that reflect in the life and health conditions of the elderly⁽¹⁾. Although some elderly people do not develop any incapacity, some of them may present some degree of functional incapacity, mainly due to the presence of chronic conditions to perform basic activities of daily living (BADL) and instrumental activities of daily living (IADL)⁽²⁾.

Fully dependent elderly people for BADL and IADL are not yet in large numbers. A study, conducted in Ceará, evaluated the functionality of the elderly and showed that, in relation to BADL, 14.5% were totally dependent⁽³⁾. The study, which evaluated the functional capacity of 820 elderly people assisted by the Pelotas Family Health Strategy (ESF), found that only 2% of the elderly were totally dependent⁽⁴⁾. However, this number

tends to grow, as the number of older people reaches more advanced ages increases, a period in which dependency sets in more frequently⁽³⁾.

The number of studies with families in the most diverse areas is increasing. Some address family care⁽⁵⁾, analyze the quality of life of family caregivers⁽⁶⁾, and others assess nursing interventions in the stress of the family caregiver of the elderly dependent⁽⁷⁾. An integrative review aimed at identifying the delineations and themes addressed in studies with dependent elderly showed that the content of the research is focused on describing the sociodemographic characteristics of caregivers, quality of life and work overload⁽⁸⁾.

Surveys with fully dependent elderly are still scarce^(9,10). A study that aimed to verify the association between functional capacity of the elderly and the caregiver overload identified that 71.4% of the elderly had severe dependence and 46.4% of their caregivers

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presented moderate overload. The functional capacity of the elderly and the overload of the caregiver were therefore correlated, for example, the greater the dependence of the elderly, the greater the burden on the caregiver⁽¹⁰⁾.

An investigation carried out with fully dependent elderly people, aimed at knowing the emotional characteristics, the context of the work and the sense of caring for home caregivers, showed that care is taken suddenly by the family, without preparation to deal with the caring role and there is no sharing of care tasks, physically and emotionally burdening the family caregiver⁽⁹⁾.

When a family member becomes totally dependent, there are changes that involve the caregiver's routine, reorganization of living spaces, family finances and demand rearrangements and family cohesion^(8,9). As the degree of dependence increases, family dynamics becomes permeated by feelings such as fear, sadness, insecurity, worry, conflicts and tensions⁽⁸⁾.

This way, there is a need to understand the functioning of families when the elderly become totally dependent. The Calgary Family Assessment and Intervention Model (CFAIM) consists of a multidimensional tool, which enables families to know and evaluate their families in order to solve problems. The CFAIM has an organized structure that covers three main categories: structural, that allows to evaluate the structure of the family; of development, which refers to the progressive transformation of family history during the phases of the life cycle; and functional, which relates to the way individuals in the family interact⁽¹¹⁾.

When considering that the total dependence of the elderly is a differentiated condition that can cause changes in the family dynamics, the following question comes up: How do families with totally dependent elderly work?

In this sense, the objective of this study was to analyze the functioning of families with totally dependent elderly.

METHODOLOGY

An exploratory and descriptive study, with a qualitative approach, developed with families of fully dependent elderly people attended by ESF in Cuiabá - MT. The municipality has, in its urban area, 63 units of Basic Attention, which are distributed in the four regions: North (20); South (21); East (11) and West (11). Through a lottery, one ESF from each region was selected to participate in the study. In sequence, the nurse in charge informed which families could meet the inclusion criteria (having an elderly person totally dependent on the BADL and living in the same household for more than 1 year). Four families were indicated and were part of the study. In order to analyze the functioning of families, the functional category of CFAIM was used, since it makes it possible to explore the instrumental functioning, referring to activities of daily life and expressive functioning, such as communication styles, problem solving, roles, beliefs, rules and alliances⁽¹¹⁾.

Data were collected by the main investigator, through an interview, at the family's home, preferably with the primary caregiver. To evaluate the degree of dependency of the elderly, the Katz Index was used. The elderly were considered totally dependent when they reached the G classification⁽¹²⁾. After this evaluation, the families were invited to participate in the study. The genograms, scripts with questions about the sociodemographic data of the elderly and family members (birth year, gender, marital status, education, religion, occupational situation, income, health problems), biological relationships, affective proximity and events as pregnancy and death, were built. In addition, there were questions about family functioning in daily life activities, particularly in the care of the elderly. In these issues, roles played by family members, communication between them, and problem solving were explored.

For analysis, the technique of content analysis, specifically the thematic analysis, was used⁽¹³⁾. Content analysis aims to analyze speech and has three different phases: 1) pre-analysis - organization and/or planning; 2) exploration of the material - coding,

decomposition or enumeration, and 3) treatment of results, inference and interpretation. The categories emerged from the analysis process were: family characteristics; internal functioning; external functioning.

The results were discussed and interpreted in the light of the theoretical reference on the functioning of families and the relevant literature on the subject.

This research was approved by the Research Ethics Committee of the Júlio Müller University Hospital and, during its development, all the ethical precepts were respected at the national and international levels. All participants signed the free and informed consent form in two copies.

RESULTS E DISCUSSION

Characteristics of families

The first family consisted of an elderly, 81-year-old widower, who has three sons and a daughter, who lives with him and is the main caretaker. The second family is an elderly woman, 72, a widow, with four sons and three daughters; she lives with grandchildren and one of the daughters, who is the main caretaker. The third family is an elderly, 90-year-old widow, mother of four sons and three daughters; she resides with grandchildren, son-in-law and her daughter, who is the main caretaker. The fourth is a 69-year-old man, married, with three daughters and a son; he resides only with his wife, who is the main caretaker.

Of these, three were affected by stroke and one has Alzheimer's disease. The main disease that led these elderly people to total dependence was stroke, which reflects the high incidence of cardiovascular diseases in the elderly. The National Health Survey, conducted in 2013, showed that approximately 2.2 million (1.5%) of people reported a diagnosis of stroke, with a higher incidence in the age group of 75 years or more⁽¹⁴⁾.

Before total dependence, all the elderly lived with their families, except one, who lived alone. They were active people, they helped financially in the family income and with the domestic activities. This situation is found in

several Brazilian households and dependence represents a financial decline for the family^(9,10,14).

Regarding the structures of the families of the elderly under study, it was possible to notice that most of the elderly lived with other members of the inbred family (Figure 1). This result evidences a type of family structure that is increasingly frequent in Brazilian households, in which multigenerational families are found, composed of the elderly, children and grandchildren⁽²⁾.

In only one family, the elderly lived with a spouse alone (Figure 1). This arrangement may possibly be explained by the fact that the elderly person is younger than the others (69 years). In the Brazilian population, in the group of 60 years or more, the family arrangement composed only by the couple represents 35.8%, while the couple and children comprise 25.3%⁽¹⁵⁾.

In these families, women are the main caregivers, as found in a study in which 75% of caregivers of dependent elderly were women. This situation occurs mainly because of the social and cultural role that women play as a mother, wife, daughter. This way, their choice to be the caregiver predominates⁽¹⁶⁾.

Apparently, the designation of the primary caregiver is also related to certain conditions, such as kinship, gender or physical proximity⁽⁸⁾. In old age, children are expected to assume the responsibility of caring for their parents, providing them materially and affectively, according to their conditions and needs^(9,10,16). For couples, caring for the spouse is an expected task with aging, however, when the spouse is deceased, responsibility for care becomes the obligation of the children⁽¹⁰⁻¹¹⁾.

When analyzing the arrangement of these families, it is observed that they have a structure in which the elderly necessarily live with a relative and there is always a primary caregiver. This result may show that totally dependent elderly people have had the opportunity to be with their families, regardless of their functioning. This situation is positive for the care of the dependent elderly, because the family, in taking care of this, avoids his/her institutionalization.

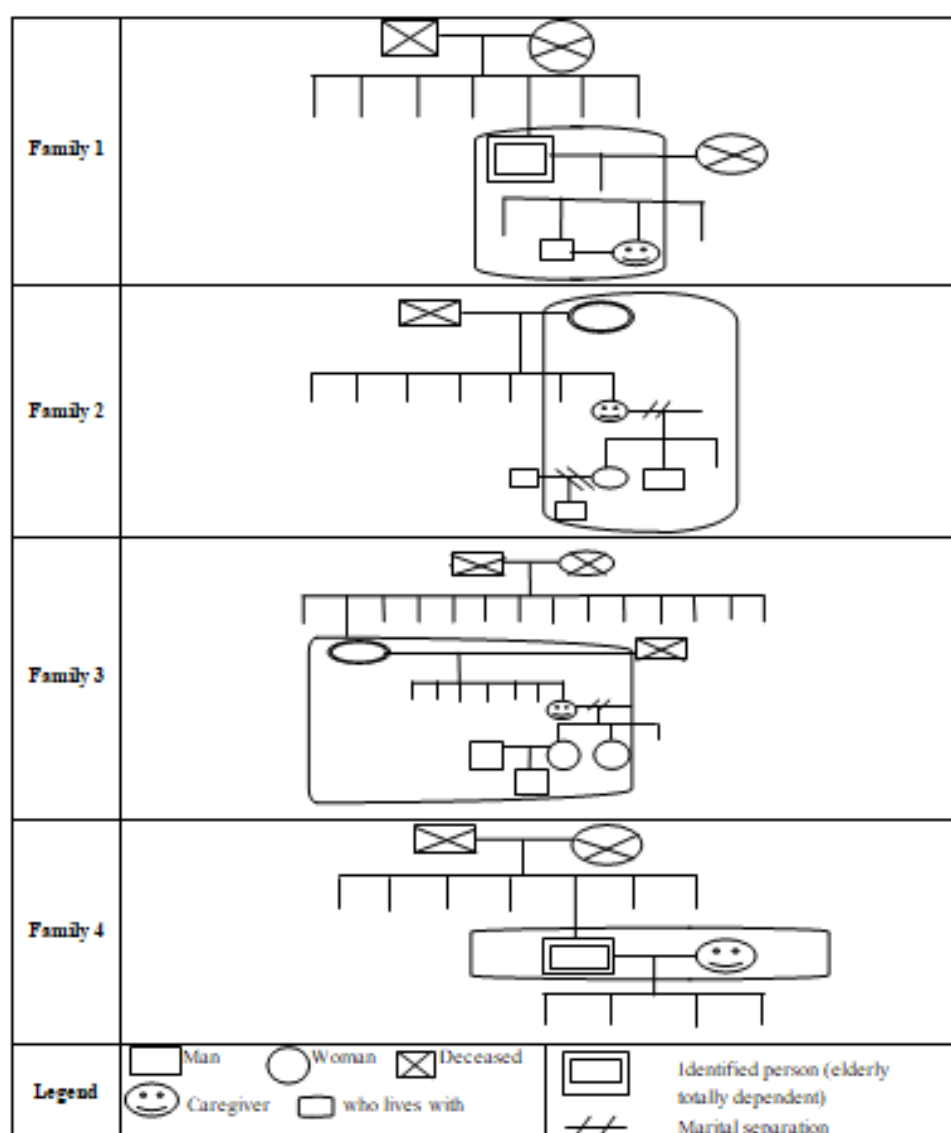


Figure 1. Genograms of the families participating in the research. Cuiabá - MT, 2011.

Internal family functioning to care for the elderly

The analysis of the interviews with the families allowed to analyze that the instrumental and expressive functioning of these families is strongly influenced by the total dependence of the elderly.

In fact, dependency on an elderly family member causes significant changes in various areas of family life, such as finances, affection, and health of caregivers. In addition, it causes loss of freedom of the family that cohabits with the elderly and overwork the caregiver^(6,11,17). These changes in families with fully dependent elderly seem to have an even greater impact as

drastic changes in their functioning occur due to the demand for uninterrupted care.

Families with fully dependent elderly need caretakers for twenty-four (24) hours to assist them in activities that maintain their survival. A partially dependent elderly person, although needing help for certain activities, is not incapable and can continue to perform other tasks. Worsening of the degree of dependency of the elderly represents an increase in the demand for care^(9,11).

The results of this study showed that the organization and functioning of families occurs around the care provided to the elderly. The family works in the sense that there is always a responsible caregiver so that their health needs

are met. Among these caregivers, the main ones were the women, daughters and wife of the elderly. They are responsible for care, such as preparing meals and food, bathing, changing clothes and diapers, supervision, among others. A role that, according to the reports, was established to them or by them, as if it were natural:

Most of the day it's me [...] I put him in the chair to take him to the bathroom to take a shower, I put on a diaper, I give him food in his mouth, I put him to bed. [...] I have three brothers[...] the care with him is more for me right now, that I am an only daughter. (Family 1).

I do everything for her, food, bath. I put her outside to get a little sun ... [...] for everything it's me ... She is my mother, I have an obligation with her. (Family 2).

Thus, for them, assuming this role of caretakers seems to be not an option, but a condition defined based on certain criteria such as kinship level, unavailability of other caregivers, gender, cohabitation, bonding and commitment^(6,17).

Another element that particularizes totally dependent elderly families is the overload that daily care entails, generating demand from other caregivers. Studies have shown that caregivers of dependent elderly people generally perform their function in a "solitary" way, as there is a separation from other family members, who, for the most part, do not offer to help, leading to the overload and health care, as well as in care provided^(8,16-18). In this research, it became evident that care is centered on only one family member and there is a need for more caregivers' support to alleviate the burden of the primary caregiver.

In the family nucleus, it is hoped to find help in the care, understanding, sharing and union to face the difficulties. The fully dependent elderly requires the primary caregiver's ongoing dedication so that care is taken to ensure that all of their basic needs are met. Such care, when shared with others, can mitigate the impact of the burden of tasks⁽¹⁶⁻¹⁹⁾.

The relationship of the caregiver and the elderly totally dependent with the other family members contributed to the family functioning, determining whether it will be effective or not. If the relationship is good, family functioning is

effective. On the other hand, families do not function effectively when the relationship between their members is bad.

In this study, through the reports, it was noticed that the way in which the majority of families organize themselves internally to care for the elderly denotes an effective functioning, because there is collaboration in the relationship among the members of the house. Although there is a family member who generally takes most of the responsibilities for caring for this elderly person, everyone else, some more than others, tends to become involved in care, taking the role of the caregiver or a helper:

... my husband helps me a lot. He is the one who gives me strength every day and helps me. [...] I have a brother who helps me a little, he also takes my father for a walk (Family 1).

... the Tulip washes and irons, that I do not do not, she who has to take care of it. (Family 2).

... my mother, in the case, cooks, in the morning, then we arrive, see if my grandmother has already eaten. Then we have to cook her food, which is different from ours. Then, if you have to change your diaper, we'll do it ... we take turns... (Family 3).

This sharing of tasks is recognized by family members as a positive element for the effectiveness of their functioning, because although it is not directly linked to the care of the dependent elderly, it can minimize the physical and financial burden. With shared care, through the division of roles, there is a lower overhead of the primary caregiver, and can bring greater satisfaction to him because he knows that he is not the only one responsible for the caring of the totally dependent elderly.

In addition, the involvement of family members favors support between them, either because family ties become narrower or by shared search for problem resolutions. Otherwise, when there is insufficient help within the family, there may be, in addition to overloading, conflicts between family members^(11,20).

Family functioning in relation to communication among its members is not always satisfactory. From the reports, it was verified that this communication does not happen in a totally harmonious way when there

is a need for elderly care and relief of the caregiver's overload:

It is clear, sometimes she [sister] does not need to speak, but the gestures, the face she makes, [...] I need to change diapers and ask for help, my sister already makes a face of who does not want to do it, but she has to go, because she knows there is no one and it is difficult to change alone, so she will, but with that face (Family 3).

Communication is a process that favors effective functioning among members, as it can help in understanding family rules, in the best possibility of conflict resolution, and also allows the clarification of the nonverbal messages transmitted by the behavior.

In the example presented, the primary caregiver, through non-verbal language, requests support from secondary caregivers, which potentiate the effectiveness of care for the dependent elderly⁽¹¹⁾.

Functioning of families with the external family

Differently from what occurs in these families, the relationship between their members and those who do not reside with the fully dependent elderly shows that their functioning is not completely effective.

While family collaboration occurs according to the demands, there are times when needs and difficulties arise, whether financial or for the care of the elderly, which members of the inner family cannot afford. The costs, generated with expenses to meet the needs of the totally dependent elderly, are high. The income of the families surveyed is not enough to cover their expenses and that of the elderly, even with the help of the benefits received from retirement.

... she has a daughter and a son and they almost do not come here at home ... I sometimes call to know how she is, but you think they care? ... (Family 2).

... everyone helping would not be so hard for me by myself, right ... I could work ... because I need to, right? life is very difficult, everything is very expensive and has her pension and my son's money, because I am not retired, I have no income, so I think it would be less difficult ... (Family 2).

... Because it is expensive, diaper, food that is

special ... The major emphasis is on the financial part, and second, would be the care, help in the care ... (Family 3).

Reconciling work and continuous and permanent care for the elderly is a difficulty that the primary caregiver usually finds and which forces him to stop working or reduce his workload drastically. This situation, together with the costs generated by materials and medicines, makes the family income decrease and not always be supplied with other resources^(17,18). At these times, they need the help of other family members:

... the second [son] older, he is the one who gives diapers, he gives the supplement to add in the milk that is expensive. (Family 3) ... he is retired, and every once in a while, my daughter comes here and gives something too (Family 4).

The expressive functioning of the family is related to the interactions among its members. Sometimes they need to face a combination of instrumental and expressive issues. From the reports, it was learned that the expressive functioning suffers from loss, because there is difficulty of communication between the members of the families that live with the elderly totally dependent and those who do not reside with them.

Some people are resistant to asking for help from other family members:

... is not everything I tell either, because no one seems to want to know, if they wanted, they would come here, they would call, so I'll tell them when I remember, and when they wonder too ... (Family 4). -... I sometimes call to see how she is, but do you think they care? That they call to know if I need anything? Nothing, they do not even want to know ... (Family 2).

However, when families find themselves facing problems that they cannot solve on their own, they ask outside help for the needed help:

... when he really needs something, we soon get in touch with them [other members of the family] (Family 1)

Only if she gets sick, there's the cooperation ... we call the uncles, because there's no car in the house, so we'll call someone who can take her ... (Family 3).

All this situation awakens feelings in caring families, such as anger and sadness, not only

because of the situation they are in, but also because of the condition of the elderly:

... I get very sad, and sometimes it makes me angry too, because nobody knows what I do, nobody helps me ... and how she understands everything, she suffers more from seeing all this (pause) and I, to see her in this situation and no one to help me (Family 2). - I get angry too because no one helps me ... there are days I wake up angry (Family 4).

These feelings are common in caregivers, mainly due to the low participation of family members in the division of care provided to the elderly. When adopting strategies in which family members help to care for the dependent elderly, there is relief in the primary caregiver's tension and decreased sense of caregiver overload. In this way, care can be permeated by feelings of affection, solidarity and gratification⁽¹²⁾.

This situation is not evident in the families of this study, because the communication between them is not always easy and is permeated by misery feelings worn out generated when there is a need to request help.

Sometimes, in urgent situations, when families do not have the possibility of obtaining help from relatives who do not live with them, they use the collaboration of neighbors or health units:

I thought until she was going to die, she was out of breath, breathing weird. Then I called my neighbor who owns a car and he took me to the hospital. [...] he [neighbor] says that when we need anything for my mother, we can call him, no matter what time it is, he takes me ... (Family 2). - I asked the neighbor in front to watch him [...] ... when he needs something really bad, I go myself to the clinic (Family 4).

This type of collaboration was found in a study with family members and professionals of family health teams. The results showed that the families used support services to meet the health needs of the elderly totally dependent at home. It is important that in such situations, families can count on the support of professionals to establish a routine of care for the dependent elderly, with a view to the distribution of tasks with family members, as well as, where possible, help of friends and neighbors^(9,12).

FINAL CONSIDERATIONS

The results of this research are important because they show the functioning of families with elderly people totally dependent and evidence elements little explored, allowing to broaden the vision about this phenomenon.

This study showed that the life of families with fully dependent elderly is distinct from the lives of other families whose elderly are not totally dependent. They are strongly impacted by the changes and demands arising from the total dependence of the elderly. Caring for fully dependent elderly implies the need for financial support and other caregivers, arrangements in the physical and spatial structure of households, time and knowledge for care.

The instrumental and expressive functioning of these families is influenced by the total dependence of the elderly. With regard to instrumental functioning, there is effectiveness, since members who live with the totally dependent elderly participate more actively in their needs and share direct care to the elderly with the primary caregiver. However, expressive functioning is adversely affected by communication problems, both between the caregiver and the elderly, as well as with relatives who do not live in the household.

The use of the Calgary Family Assessment Model was fundamental, since the data generated through the analysis of the reports allowed to understand the families surveyed and revealed important aspects of their structures and the instrumental and expressive functions.

Finally, it is considered that the results of this study have implications for health professionals who work with families, since they show significant aspects of family functioning, which are not always visible in practice, suggesting ways of intervening to the improvement of communication among family members. The results of this study are also important in that they show that care to be provided by health professionals should be differentiated and better suited to their needs.

It is suggested that future research be carried out in order to evaluate interventions to meet the needs of these families who are experiencing a situation as peculiar as having fully dependent elderly people under their care.

FUNIONAMENTO DE FAMÍLIAS COM IDOSOS TOTALMENTE DEPENDENTES

RESUMO

Introdução: A dependência total do idoso é uma condição que requer cuidador em tempo integral para realização das atividades básicas de vida diária e pode ocasionar modificações na dinâmica familiar. **Objetivo:** Analisar o funcionamento de famílias com idosos totalmente dependentes. **Metodologia:** Estudo descritivo, desenvolvido em Cuiabá, no Mato Grosso, com quatro famílias atendidas na Estratégia de Saúde da Família, utilizando o Modelo Calgary de Avaliação de Famílias. Os dados foram coletados nos domicílios das famílias por meio de entrevista com o cuidador principal e foram submetidos à análise de conteúdo e interpretados utilizando como referencial a categoria funcional do Modelo Calgary de Avaliação de Famílias. **Resultados:** Estão apresentados em três categorias: caracterização das famílias; funcionamento interno para cuidar do idoso; e funcionamento das famílias com o núcleo familiar externo. As famílias eram caracterizadas como multigeracionais, com membros consanguíneos e habitavam com os idosos. O funcionamento interno é influenciado pela dependência total dos idosos. O funcionamento das famílias com o núcleo familiar externo não é completamente efetivo por problemas na comunicação. **Considerações finais:** Os resultados deste estudo têm implicações para os profissionais de saúde, pois mostra aspectos do funcionamento familiar, sugerindo modos de intervir na melhora da comunicação entre seus membros.

Palavras-chave: Família. Cuidadores. Idoso dependente..

FUNIONAMIENTO DE FAMILIAS CON ANCIANOS TOTALMENTE DEPENDIENTES

RESUMEN

Introducción: la dependencia total del anciano es una condición que requiere cuidador en tiempo integral para la realización de las actividades básicas de vida diaria y puede ocasionar modificaciones en la dinámica familiar. **Objetivo:** analizar el funcionamiento de familias con ancianos totalmente dependientes. **Metodología:** estudio descriptivo, desarrollado en Cuiabá, Mato Grosso-Brasil, con cuatro familias atendidas en la Estrategia de Salud de la Familia, utilizando el Modelo Calgary de Evaluación de Familias. Los datos fueron recolectados en los domicilios de las familias por medio de entrevista con el cuidador principal y fueron sometidos al análisis de contenido e interpretados utilizando como referencial la categoría funcional del Modelo Calgary de Evaluación de Familias. **Resultados:** están presentados en tres categorías: caracterización de las familias; funcionamiento interno para cuidar al anciano; y funcionamiento de las familias con el núcleo familiar externo. Las familias eran caracterizadas como multigeneracionales, con miembros consanguíneos y vivían con los ancianos. El funcionamiento interno es influenciado por la dependencia total de los ancianos. El funcionamiento de las familias con el núcleo familiar externo no es completamente efectivo por problemas en la comunicación. **Consideraciones finales:** los resultados de este estudio tienen implicaciones para los profesionales de salud, pues muestran aspectos del funcionamiento familiar, sugiriendo modos de intervenir en la mejoría de la comunicación entre sus miembros.

Palabras clave: Familia. Cuidadores. Ancianos dependientes.

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