

CARE FOR FRAGILE ELDERLY PEOPLE AND THE FAMILY HEALTH STRATEGY: PERSPECTIVES OF CAREGIVERS

O CUIDADO COM O IDOSO FRAGILIZADO E A ESTRATÉGIA SAÚDE DA FAMÍLIA: PERSPECTIVAS DO CUIDADOR INFORMAL FAMILIAR

ATENCIÓN AL ADULTO MAYOR FRÁGIL Y ESTRATEGIA DE SALUD DE LA FAMILIA: PERSPECTIVAS DE LOS CUIDADORES

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Objective: to understand the care for the frail elderly provided by family-related inpatient caregivers, as well as their interaction with the Family Health Strategy, from the perspective of caregivers. **Method:** exploratory-descriptive, qualitative study conducted with 17 informal family-related caregivers of frail elderly from a Family Health Strategy in Minas Gerais, Brazil. Data collected between September/2019 and February/2020, through an interview with semi-structured script and questionnaire. Content analysis was performed, thematic type. **Results:** most caregivers were women, 26-79 years old, white and brown, married and low schooling. Effective communication between the health team and the family/elderly caregiver, to the detriment of high turnover of professionals of the Family Health Strategy, excessive demand for functions and lack of training and technical ability of the caregiver. **Final thoughts:** care for the frail elderly belonged to the female universe and aroused a mixture of feelings. Interaction between caregivers and family health strategy was generally mediated by the Community Health Agent.

Descriptors: Elderly Health. Family Health Strategy. Caregivers. Fragile Elderly. Nursing.

Objetivo: compreender o cuidado com o idoso fragilizado prestado por cuidadores informais familiares, bem como a interação destes com a Estratégia Saúde da Família, na perspectiva dos cuidadores. Método: estudo exploratório-descritivo, qualitativo, realizado com 17 cuidadores informais familiares de idosos fragilizados de uma Estratégia Saúde da Família de Minas Gerais, Brasil. Dados coletados entre setembro/2019 e fevereiro/2020, mediante entrevista com roteiro semiestruturado e questionário. Realizou-se análise de conteúdo, tipo temática. Resultados: maioria dos

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cuidadores eram mulheres, 26-79 anos, brancas e pardas, casadas e baixa escolaridade. Comunicação efetiva entre equipe de saúde e cuidador familiar/idoso, em detrimento de alta rotatividade de profissionais da Estratégia Saúde da Família, demanda excessiva de funções e falta de capacitação e habilidade técnica do cuidador. Considerações finais: cuidado com idoso fragilizado pertencia ao universo feminino e suscitava um misto de sentimentos. Interação entre cuidadores e Estratégia Saúde da Família acontecia geralmente mediada pelo Agente Comunitário de Saúde.

Descritores: Saúde do Idoso. Estratégia Saúde da Família. Cuidadores. Idoso Fragilizado. Enfermagem.

Objetivo: comprender el cuidado de los ancianos frágiles proporcionado por los cuidadores internados relacionados con la familia, así como su interacción con la Estrategia de Salud de la Familia, desde la perspectiva de los cuidadores. Método: estudio exploratorio-descriptivo, cualitativo, realizado con 17 informadores familiares de ancianos frágiles de una Estrategia de Salud de la Familia en Minas Gerais, Brasil. Datos recolectados entre Septiembre/2019 y Febrero/2020, a través de una entrevista con guión semiestructurado y cuestionario. Se realizó un análisis de contenido, tipo temático. Resultados: la mayoría de los cuidadores eran mujeres, de 26 a 79 años, blancas y marrones, casadas y de baja escolaridad. Comunicación efectiva entre el equipo de salud y el cuidador familiar/anciano, en detrimento de la alta rotación de profesionales de la Estrategia de Salud de la Familia, la excesiva demanda de funciones y la falta de capacitación y capacidad técnica del cuidador. Consideraciones finales: el cuidado de los ancianos frágiles pertenecía al universo femenino y despertaba una mezcla de sentimientos. La interacción entre los cuidadores y la estrategia de salud de la familia fue generalmente mediada por el Agente Comunitario de Salud.

Descriptors: Salud del Anciano. Estrategia de Salud de la Familia. Cuidadores. Ancianos Frágiles. Enfermería.

Introduction

The considerable increase of the elderly population in Brazil over the years is notorious. As the statistics predict, the number of elderly between 1950 and 2025 will increase fifteen times, while the total population by five⁽¹⁾. In parallel to the increase in life expectancy, mainly due to technological advances that increase the possibility of life time, Chronic Noncommunicable Diseases (CNDs) have become the main comorbidities and even causes of death of this age group⁽²⁾.

Together with the demographic transition, the aging of the population and the high burden of CNDs in the elderly, there is a greater demand for care inherent to the health of this population. This demand is mainly due to high vulnerability and fragility, with consequent functional decline, which can decrease social interaction, interfere in the quality of life and disrupt the family dynamics of the elderly⁽³⁾.

The definition of frailization of the elderly is still quite controversial in the literature, although it is used to describe the elderly at higher risk of disabilities, institutionalization, hospitalization and death⁽⁴⁾. The multidimensional fragility of the elderly is due to the deterioration of biological,

psychological and social factors throughout life⁽⁵⁾. These factors are related, for example, to aspects such as reduced muscle strength, gait slowing, increasing age, female gender, low socioeconomic status, presence of comorbidities (especially CNDs), global functionality (cognition, mood and communication), as well as other indicators of poor prognosis, such as the presence of polypathology, polypharmacy, recent hospitalization and high socio-family risk (family failure)⁽⁴⁾.

From the perspective of functionality, the presence of functional decline in the elderly is the main determinant of the presence of frailty⁽⁴⁾. Functional decline, in turn, according to the International Classification of Functionality⁽⁶⁾, is the loss of autonomy and/or independence, which restricts the social participation of the individual and compromises the development of daily life activities (advanced, instrumental and basic).

In addition to the interference of CNDs, functional decline in the elderly is mainly caused by the main syndromes associated with aging, known as the Great Geriatric Syndromes: cognitive disability, postural incontinence,

sphincter incontinence, immobility and communicative disability. The presence of these chronic health conditions increases the demand for care and the complexity of clinical management, with consequent risk of iatrogenic. In addition, they are associated with a higher demand for long-term care, usually performed by the family, which, in most cases, is not prepared for this new function, when family insufficiency is presented⁽⁴⁾.

The elderly with chronic, degenerative or disabling disease, when they do not need assistance in health services, whether in primary care, secondary and tertiary care, are cared for at home by a formal or informal caregiver. The formal caregiver is the one who receives remuneration for the services provided, is able to recognize and differentiate the needs of the elderly, to deal with diseases and their cognitive or social symptoms, both personal and family, as well as help in activities of daily living. On the other hand, the informal caregiver is a family member or person of the community, who receives or does not receive remuneration to provide care to people with physical or mental limitations and is not necessarily qualified for such task⁽⁷⁾.

It is very common for this informal caregiver to be a member of the elderly's family. Many families, because they do not have the financial condition to afford the expenses of a professional to perform the role of caregiver, end up choosing to bring the elderly to the family and become the main responsible for their care⁽³⁾. It is worth noting that, predominantly, those who play this role of informal caregiver end up being some female individual with family ties with the elderly, such as a spouse or daughter⁽³⁾. A very common aspect is that this informal family caregiver is already an elderly person⁽⁸⁾.

In fact, meeting this demand for care of the elderly with poor health requires family caregivers to often reorganize their own routine, but this adjustment of daily activities is not always achieved, which leads to feelings of anguish, tension and overload⁽³⁾. The accumulation of domestic activities, the lack of adequate

information for the care and training of skills by the family member who cares provides stress and exhaustion, with consequent increase in the physical and mental overload of this caregiver and family conflicts⁽⁹⁾.

To mitigate these aspects, especially regarding the lack of information and skills for the care of the frail elderly, the Family Health Strategy (FHS), through the longitudinality of care and the multidisciplinary team, can and should support the needs of the elderly and the caregiver/family in the scope of Primary Health Care (PHC), as recommended by the National Primary Care Policy (PNAB in Portuguese) of 2017⁽¹⁰⁾.

Thus, in view of the conformation of PHC with the scope and significant performance in health promotion, disease prevention, disease control and treatment, it is essential to dispense comprehensive health care for the elderly in the management of comorbidities, especially CND, and functional disabilities to improve the quality of life of this population⁽²⁾. Moreover, from the point of view of care for the elderly weakened in the scope of PHC, the FHS plays a fundamental role in the guidance and instrumentalization of family caregivers, so that care, performed assertively, is able to mitigate the health impacts of these caregivers⁽¹¹⁾.

However, broadening the look beyond the elderly and their comorbidities and/or disabilities in the context of PHC is a great challenge in the integrality of care by the FHS. It is noteworthy that professionals need to expand their gaze to the family caregiver⁽¹¹⁾. In this sense, it is extremely relevant to understand the care before the weakened caregiver-elderly binomial and to interact assertively with this family member who cares. In this perspective, it is relevant to investigate the profile of caregivers, as well as to investigate how care is configured for the frail elderly and how the interaction between the FS team and the informal family caregiver takes place, in the perception of this caregiver.

Information from this investigation may guide reflections and discussions among the FHS professionals, especially the nursing team and, consequently, favor the planning and

implementation of actions aimed at improving the health of the frail elderly and the conditions of care of family caregivers. Moreover, the understanding of this care can stimulate the health team to obtain resolution actions in the care of the frail elderly and their caregiver, especially in home visits.

Thus, the aim of this study was to understand the care for the frail elderly provided by family informal caregivers, as well as their interaction with the FHS, from the perspective of the caregivers themselves.

Method

This is an exploratory-descriptive study, with a qualitative approach, developed with family-related inconvenient caregivers of the frail elderly living in the area covered by an FHS located on the outskirts of a municipality in the Midwest region of Minas Gerais, Brazil. The elderly who had some cognitive, mood, mobility and/or communicative inability to perform activities of daily living with autonomy and independence were considered weakened⁽⁴⁾.

The study sample was for convenience, because the proposal was to cover all 21 family caregivers of eligible frail elderly in the area belonging to the aforementioned FHS, of which one of the researchers was a member of the health team. However, 17 caregivers participated, once data collection had to be interrupted due to the onset of the COVID-19 pandemic in Brazil. Inclusion criteria were: being a family caregiver of frail elderly and being older than 18 years. The exclusion criterion adopted was the caregiver being remunerated for the care provided to the elderly.

Data were collected between September 2019 and February 2020 by a nurse residing in Nursing in Primary Care/Family Health working in this FHS, through an interview with the use of a structured questionnaire (completed by the interviewer), to investigate the sociodemographic profile and health and leisure conditions. We also used a semi-structured script with northern questions, which addressed daily care for the frail elderly and the interaction of the informal

family caregiver with the FHS. The interviews lasted, on average, 20 minutes. They were recorded after authorization of the participants, when the semi-structured script approach began. The recordings were transcribed in full.

Before the interview, the caregiver was previously contacted, through a home visit, to be informed about the research. After acceptance, the day and time for data collection were scheduled, which took place in the respective homes, individually and in a private place. The anonymity of the participants was respected, identifying them by the acronym IC (for informal caregiver) followed by the number corresponding to the order of the interview: IC-1, IC-2... IC-15. It is worth clarifying that the interviews conducted, although they did not cover the total number of participants, reached the saturation of the data, ensuring the validity of the sample.

The organization and descriptive analysis of quantitative data from the sociodemographic questionnaire and health and leisure conditions were performed in the Epi Info program version 7.2.3.1, calculating the absolute and relative frequencies for the characterization of the participants.

To analyze qualitative data, thematic content analysis was used⁽¹²⁾. This type of analysis allows identifying the nuclei of meaning of communication and consists of three stages: pre-analysis; exploitation of the material; treatment of results, inference and interpretation. Initially, the interviews were floating reading, from which the units of meaning emerged. In the second stage, the organization of the units of meaning generated two categories.

This study, submitted to the Ethics Committee on Research with Human Beings of the *Universidade Federal de São João del Rei* – Dona Lindu Midwest Campus, was approved by Opinion n. 3,516,178 and Certificate of Presentation for Ethical Appreciation (CAAE) n. 18509019.3.0000.5545. It is noteworthy that all ethical principles of Resolution n. 466/2012 of the National Health Council (CNS – *Conselho Nacional de Saúde* in Portuguese) were respected and that all participants signed the Free and

Informed Consent Form (TCLE – *Termo de Consentimento Livre e Esclarecido* in Portuguese). The quality criteria for qualitative studies, Consolidated Criteria for Reporting Qualitative Research (COREQ), were used in this study.

Results

Among the 17 informal family-related caregivers of frail elderly living in the area covered by the FHS, who participated in the study, the majority were women (15; 88%), married (8; 47.1%), Catholic (10; 58.8%). Self-declared color was: white (6; 35.3%), brown (6; 35.3%), black (4; 23.5%) and indigenous (1; 5.9%). The mean age was 44.5 years, ranging from 26 to 79 years, and low level of education (7; 41.2% with incomplete elementary school). Most caregivers lived with the elderly in the same household (12; 70.6%) and had at least one child (15; 88.2%). Regarding the degree of kinship, 12 (70.6%) were children of the elderly. On the leisure activity of caregivers, there was a predominance of watching television (10; 58.8%) and go to church (5; 29.4%).

Regarding health status, although most caregivers had rated their own health as good or very good (13; 76.5%), still, 8 (47.1%) were diabetics or patients with cardiovascular diseases and this same percentage used at least one medication daily. Among the caregivers, ten (58.8%) reported that they had never had surgery and 12 (70.6%) never needed to be hospitalized. Only three (17.7%) had private health insurance.

Regarding the interviews of the study, which explored the experience of the informal family caregiver of the frail elderly, as well as the interaction with the health team of the FHS, the thematic analysis of the answers showed two categories: relationship of care between caregiver and elderly and Interaction between caregiver and Family Health Strategy.

Care relationship between caregiver and elderly

In the context of the care relationship between the family caregiver and the elderly,

it was possible to identify an important aspect when it comes to respect and the perception of autonomy of the elderly by caregivers. That is, in several discourses, the elderly were compared to a child who did not have and could not decide for him/herself or even who had no desires of his/her own. This finding can be exemplified with the following statements:

[...] besides becoming a child, he doesn't accept the things you talk about. (IC-1).

[...] they become kids again and they don't accept anything you say. (IC-3).

[...] much more complicated than a child, right? Because they're stubborn. Family is even worse, because things, they do not accept much, right? (IC-5).

On the other hand, a characteristic evidenced in the present study is that frail elderly well integrated into family life have their autonomy respected, when it is still preserved. This perspective can be exemplified in the following speech:

[...] the fact that I've known them since I was little, since I was little, so, yes, I know what they like, I know they don't like it, and I try to respect what they like and what they don't like... (IC-4).

In this context of decreased or loss of autonomy of the elderly, the care journey provided by the caregiver becomes even more intense and requires a lot of patience from this individual, especially when the elderly have cognitive impairment. Patience in care was mentioned by some caregivers interviewed:

[...] It's hard work, right, but you have to be patient, right? You have to understand that, as they say, right, they're in their time, because it's a lot, right? So, usually, you're a little wayward, you want to do things you can't, right? (IC-7).

[...] we first have patience, right? Because you need to have a lot of patience, be patient and take care as needed, right, the person, right? ... you have to be very patient. Especially if you're an old man like that, you're my mother with Alzheimer's. First place is patience, calm, very calm, really like taking care, because it wears a lot with us, with the whole family. (IC-15).

Another point addressed by the caregivers was the overload resulting from the role of caring for the frail family elderly, with a consequent feeling of abdication of life projects to assume the role of caring. This context can be perceived in the following statements:

Change, load, bathe. Then you, because your attention has to be all turned to the elderly. You don't, in fact, you don't have a life of your own... so much is that I didn't marry for caring, right? I opened my hand, gave it up too... (IC-1).

We're 11 kids, but there's always plenty for one, right? So I have to give up a lot. (IC-10).

Facilities of this care or difficulties, because I can not leave the house [laughter]. (IC-12).

[...] like it happened to me several episodes of family, of my own children. Sometimes I have to stop paying a little attention to be taking care of more and, especially, the relationship with husband too, which gets complicated. Because he charges things a lot, and sometimes you don't even have time for him. (IC-15).

The lack of training and technical/instructional ability to exercise care with the elderly was another point evidenced in the interviewees' discourses:

I've never received information of anything. It's just practice, isn't it? Day to day. (IC-2).

[...] because i have no training and, besides, not having information [...] (IC-10).

Although the care of the frail elderly is strenuous and can cause difficulties in management and negative feelings, it should be considered that it is a function that also brings positive feelings, especially of gratitude, meaning of life and love, mainly because it is the care of an elderly family member. Some of these feelings can be identified in the following statements:

Useful. I feel useful, because I help a person, right, who is not getting it. For me, it's very good, very rewarding... (IC-4).

Oh! I feel alive! I feel, I feel like I can do something for someone, especially my parents. (IC-6).

I feel good. It's good for us to be useful, right? (IC-7).

It's very gratifying! It's very good for us, for our own ego. (IC-15).

Interaction between caregiver and the Family Health Strategy

The family informally caregivers participating in this research identified pertinent questions about their interaction with the FHS. Among them, the effective communication between the caregiver and the team was highlighted,

especially through the home visit (HV) of the Community Health Agent (CHA), which can be perceived in the following statements:

Look, to tell you the truth, there's the woman at the post, Helena, who had a good time with us here, which she helped, making it easier to make the card of the post. She's making periodic visits, asking how he was. And that helped me a lot, because we saw that he needed some attention, and she was able to give. She got an exam, that helped. The tests were faster with the presence of this woman from the post, Helena. So she helped me a lot. (IC-11).

Look, I think visits are very important, huh? Just like Lena, she comes every time she gives, visits, talks to Grandma. I think this point is very important, because it passes security to us, in a case of extreme need, and also passes confidence, right, that we, that an emergency case, we may be counting on staff of the post. (IC-13).

Why do people say what? What do we have to do, the vaccines that the elderly have to take, time of flu vaccines, right? The care. Oh, your mother has to take the test! Call us, I set up the test for your mother, I set up the doctor for your mother. So I find the staff of the post very considerate up. (IC-14).

In a matter of guidelines that I need, which I don't know, they give me. The care of the venous ulcer wound too, they accompany, bringing medication, the recipes also on time and time, not lacking. Doctor closely follows, nurse. Yes, really, there's nothing to complain about any of them. (IC-15).

On the other hand, as a negative point in the interaction between the caregiver and the FHS, the following discourses highlighted the turnover of the professionals in the team:

[...] because sometimes we go there do not always have a doctor, there is not always a nurse [...] (IC-4).

[...] that the PSF [Family Health Program – Programa Saúde da Família in Portuguese] Santos Dumont is without a doctor for a long time, right? (IC-12).

Thus, as a consequence of the frequent turnover of health professionals, the deficit in care resulting mainly from the scarcity of human resources and the voluminous demand for care drew attention. This fact is evidenced in the discourse of one of the caregivers:

Yes, maybe home visits were like that. See if you're right, how it is, help us, just like you said. Maybe that would be better, right, if it was, right? But it's hard, right, because they're very few professionals. We know the demand as it is. (IC-11).

Discussion

Knowing the characteristics of the informal family-related caregivers of the elderly, especially

those already frail, as well as understanding care and interaction with the health team in the view of these individuals they care for, is an opportunity to envision better conditions of care for the elderly and self-care, since these differ according to the different contexts.

Once it is a population of social and economic vulnerability, in which the caregivers of the study are inserted, it should be considered that social, cultural and economic aspects interfere greatly in the dynamics of care for the frail elderly. The lack of financial resources for formal care, the responsibility of women for the care provided to the elderly and not seeking professional help for this care may favor the perpetuation of a culture of care for the elderly without specific knowledge for this and with excessive physical and emotional burden of the caregiver, even and especially being a family caregiver⁽³⁾.

It is noted in the study the fact that care is mostly exercised by women and daughters of the elderly, which confirms the premise that this activity is centered on the female figure within the family nucleus. With the intensity of the demand for care with the elderly, it can be seen that these caregivers give up the performance of functions, such as studying or working formally and even forming their own family, no more marrying and having children, to dedicate themselves to the provision of care. As in a cascading effect, this priority in the care function also makes it impossible to access leisure and distraction activities. Sometimes, to adapt to the new care routine, the caregiver who is already married and/or resides in an independent home moves into the elderly home or takes him to the family, in order to facilitate the performance of the activities. Aspects such as this, in which most family caregivers are female, give up personal life and present overload of tasks when caring, are factors that meet another study also conducted in Minas Gerais⁽³⁾.

The caregivers of the study really highlighted the physical and mental burden resulting from the function of caring for the frail family elderly, with a consequent feeling of abdication of life projects to perform this function. The informal

family caregiver did not always have the choice or have some knowledge to develop this task⁽¹³⁾. Suddenly, the family caregiver is challenged to reconcile the new function with other activities already inserted in their routine, such as formal employment and domestic activities⁽¹⁴⁾. This situation of physical and mental overload can be aggravated by the lack of adequate training⁽³⁾, besides negatively affecting the health⁽¹⁴⁾.

In fact, over time, the caregiver's health weakens due to its own aging process, when CNDs arise, or due to the exhaustive practice of care for the elderly combined with the performance of other household tasks. Often, this strenuous routine does not allow him to seek care for his own health, leading to the consequent worsening of his condition. The experience of caring for the elderly with poor health, combined with physical overload, can also lead the family caregiver to compromise their emotional health⁽¹³⁾.

In this perspective of high and exhaustive demand for care, statements emerged from the caregivers of the study about the fact that it is necessary to have enough patience in the daily care provided to the elderly. Dementia stemming from cognitive impairment, which brings psychomotor, functional and behavioral alterations, in addition to damage to memory, require a lot of attention and complacency from the caregiver, because, at this stage, the elderly need basic care, such as bathing, personal hygiene and feeding⁽¹⁵⁾.

In the context of the present study, the frail elderly were affected mainly by dementia syndromes, which made them unable to decide on their own lives, as they led them to progressive cognitive decay, compromising the abilities to think, express feelings, perceptions, memories and reasoning⁽¹⁶⁾. This favors the incorporation of the caregiver's paternalism, making the caregiver's own decisions often taken as more ideal and appropriate for the frail elderly, injuring their autonomy⁽¹⁷⁾. Some of the statements of family caregivers showed the loss of autonomy of the elderly precisely due to cognitive disability or even due to the

excessive interference of the caregiver himself in the activities. The decline in the performance of activities of daily living and decision-making by the elderly requires attentive and assertive supervision during the care provided, so that their autonomy is not nullified⁽¹⁶⁾.

Moreover, it was possible to perceive, in the interviews, that the new routine of activities performed during the care of the frail elderly was often unknown by the family caregiver. He sometimes did not have the technical skills or had not received enough information for proper care performance. These circumstances were also evidenced in the study developed in Minas Gerais⁽³⁾, in which family caregivers of patients in palliative care at home were faced with unknown care situations, such as: movement and hygiene of the elderly in bed, preparation and administration of medications and food, handling of drains and probes, dressings, among others. These abilities, when unknown by the caregiver, generate difficulties and anxieties in the act of caring⁽¹⁸⁾. Furthermore, the fact that the caregiver does not receive adequate and sufficient guidance/information to perform the care is indicative of a limitation in the support provided by health teams to these individuals⁽¹⁹⁾.

Among the various feelings expressed by the caregivers of this study, those who refer to the meaning of life, especially the feelings of being useful to the other person and gratitude in the performance of care, were those who drew attention in the interviews. Other studies also corroborate these findings, highlighting that these feelings praise caregivers and motivate them to routine care, in addition to strengthening the relationship of the caregiver/elderly binomial. Moreover, considering that they are family caregivers being able to repay some of what the elderly did in life for the caregiver also brings satisfaction⁽¹⁹⁻²⁰⁾.

In general, with regard to the interaction with the FHS, none of the caregivers in the study mentioned any systematized follow-up by the health team focused on the technical or educational support of the caregiver himself, for the development of the activities inherent to

care. What can be seen is that the actions of the FHS were directed to the demand of the frail elderly and not to the one who takes care of it. It is worth noting that a study of reflection on the integrality of care provided to the elderly reinforces that a special look of professionals beyond the elderly being cared for, that is, a look aimed at the caregiver, becomes essential for the care offered to be of quality and humanized. Likewise, this caregiver should also be assisted with strategies that achieve, or at least minimize, the impacts on their health. When caregivers have structured and continuous support in care, they can remain socially inserted, without feeling nullified by the strenuous burden of care⁽¹¹⁾.

The interviews revealed that the FHS, together with the informal family caregivers to the frail elderly, found challenging situations regarding the management of care to this public, such as the turnover of the team professionals, impairing the creation of bonds and, consequently, bringing as an outcome a deficit in care. On the other hand, a favorable point that can be observed in the caregivers' statements is the performance of the community health agent, which facilitates the communication and interaction of family caregivers with the team, favoring a more quality care.

Communication is part of the human essence. Since its emergence, man has communicated with the available means⁽²¹⁾. In the health context, in addition to qualified listening, communication allows reception, clarification, sharing and exchange of knowledge⁽²²⁾, which favors the bond between the team and the family caregiver of the elderly, as evidenced in the present study.

Regarding the FHS scenario, the first contact between the family caregiver and the health team is often through the CHA, since this professional works directly inserted in the community, as established by the PNAB⁽¹⁰⁾. What was noticed in the present study was that the CHA became a bridge between the caregiver/elderly binomial and the health team. Once the bond was created, this professional became a reference of the team for the caregiver, providing effective communication and continuity of care. These

findings were evidenced in a literature review study, showing that effective communication between the informal caregiver and the health team is extremely relevant to know the context in which the individual is inserted, allowing an effective response to his/her demands and providing resolute care⁽²¹⁾.

According to a study conducted in the interior of São Paulo⁽¹¹⁾, another ally of effective communication between the caregiver/elderly binomial and the health team, also noted in this study, was the HV. Through it, it is possible to identify the singularities presented by the frail elderly, in addition to bringing the team closer to the informal caregiver and building a relationship of trust, enabling a more solid bond.

On the other hand, negative aspects observed, such as the turnover of the FHS professionals, weaken the team's bond with network users, often providing fragmented and non-resolute care. This fact, also evidenced in another study⁽²³⁾, shows that turnover, especially of medical and nursing professionals, compromises the quality of care and the satisfaction of the enrolled population. The reasons for such turnover result from economic, social, political, professional achievement, among others, which leads to negative and unfavorable results for health service users⁽²⁴⁾.

This problem of scarcity of health professionals is really a great challenge in several contexts. In many situations, the FHS has to work with a minimum team, due to the turnover of employees, which leads to the burden of certain team professionals, such as nurses⁽²³⁾. This reality was identified in a reflection research on the complexity of the nurse's work in PHC⁽²⁵⁾, in which work overload was evidenced, due to the accumulation of functions. A team without minimum working conditions, working with a lack of human resources, can be a hinderer of the user's access to the health service. In the case of care for the frail elderly, this occurrence hurts one of the guidelines of the SUS, which is the longitudinality of care.

It is worth noting that, in this perspective of care deficit, especially of human resources, the

objectives of PHC, as proposed by the PNAB, are compromised. That is, the set of actions in the individual and collective spheres, which covers the promotion and protection of health, prevents injuries, diagnoses, treats, rehabilitates and promotes the maintenance of health, will not be developed as recommended⁽¹⁰⁾.

Understanding this scenario and the perceptions of family caregivers, whether negative or positive, as well as the potentialities and challenges that these individuals face in their daily care is extremely relevant so that the FHS can plan its actions, even if it is with a small study population, as occurred in this research. Therefore, it is emphasized as limitations of the study to have involved only one team of FHS in the municipality and having as interviewer a professional working in the FHS, which may have interfered in the discourses about the relationship with the institution. Therefore, it is suggested that future studies involve all teams of the FHS in the municipality and that the interviewers are not part of the team.

The present study contributes to health knowledge by providing support for a better understanding of the interaction between the FHS and the informal family caregiver of the frail elderly, contributing to the restructuring of the work process and, consequently, to the improvement of the care provided to the caregiver/elderly binomial. Specifically in relation to the nursing context, this study denotes weaknesses and potentialities regarding care for the elderly population and their family caregivers, which may lead to nursing actions aimed at the elaboration of more effective singular therapeutic plans.

Final thoughts

From the perspective of the informal caregivers, the study allowed us to understand that the care provided to the frail elderly raises a mixture of feelings in the daily routine of care, with predominance of gratitude for performing this function, but also overload and tiredness with daily care. Even though it is grateful to be

able to perform this care, the study showed that the caregiver shares the understanding that it is necessary to have patience in caring for the frail elderly and all their challenges, especially when cognitive disability advances. Moreover, it was observed that the caregivers belonged to the female universe and experienced changes in their daily routines that eventually generated physical and mental overload, in addition to the abdication of their life projects.

The study has also showed that the lack of training and technical skill on the part of the family caregiver were factors that implied insecurity to perform the care of the frail elderly. In this context, the caregivers' statements drew attention to the annulment of the autonomy of the elderly during care. However, on the other hand, when the informal caregiver was a member of the family and the elderly were well inserted in family life, their autonomy was preserved.

Regarding the interaction between the FSS and the informal family caregiver of frail elderly in the area studied, it was evidenced that this interaction happened, yes, and that sometimes it occurred through effective communication between the team and the caregiver, mediated by the CHA. It is worth noting that this professional is seen as fundamental in the construction of the link between the health team and the caregiver/elderly binomial in the area studied. It was also observed that the high turnover of the team professionals, together with the excessive demand for functions performed by certain members, were factors of dissatisfaction of the care provided to the elderly and their caregivers.

Collaborations:

1 – conception, design, analysis and interpretation of data: Mírian Aparecida de Lacerda, Liliane de Lourdes Teixeira Silva and Kellen Rosa Coelho;

2 – writing of the article and relevant critical review of the intellectual content: Mírian Aparecida de Lacerda, Liliane de Lourdes Teixeira Silva, Flávia de Oliveira and Kellen Rosa Coelho;

3 – final approval of the version to be published: Kellen Rosa Coelho.

References

1. Sampaio SN, Esteves AVF, Oliveira APP, Franco PC, Lima ES. Visão da pessoa idosa sobre o atendimento do enfermeiro da Atenção Básica. *Rev baiana enferm.* 2018;32:e27618. DOI: 10.18471/rbe.v32.27618
2. Medeiros KKAS, Coura AS, Ferreira RT. O aumento do contingente populacional de idosos no Brasil e a atenção primária à saúde: uma revisão de literatura. *Arq Cienc Saúde UNIPAR.* 2017;21(3):201-7. DOI: <https://doi.org/10.25110/arqsaude.v21i3.2017.6034>
3. Pessalacia JDR, Silva AE, Araújo DHQ, Lacerda MA, Santos KC. Experiências de cuidadores nos cuidados paliativos e redes de suporte. *Rev enferm UFPE on line.* 2018;12(11): 2916-22. DOI: <https://doi.org/10.5205/1981-8963-v12i11a236208p2916-2922-2018>
4. Moraes EN. Atenção à saúde do idoso: aspectos conceituais [Internet]. Brasília (DF): Organização Pan-Americana da Saúde; 2012 [cited 2020 Nov 23]. Available from: <https://apsredes.org/pdf/Saude-do-Idoso-WEB1.pdf>
5. Freire JCG, Nóbrega IRAP, Dutra MC, Silva LM, Duarte HA. Fatores associados à fragilidade em idosos hospitalizados: uma revisão integrativa. *Saúde Debate.* 2017;41(115):1199-211. DOI: <http://dx.doi.org/10.1590/0103-1104201711517>
6. Organização Mundial de Saúde, Organização Panamericana de Saúde. CIF – Classificação Internacional de Funcionalidade, Incapacidade e Saúde [Internet]. São Paulo: EdUSP; 2003 [cited 2020 Nov 23]. Available from: <http://uniapae.apaebrasil.org.br/wp-content/uploads/2019/10/CLASSIFICA%C3%87%C3%83O-INTERNACIONAL-DE-FUNCIONALIDADE-INCAPACIDADE-E-SA%C3%9ADE.pdf>
7. Santos SMC, Oliveira LS, Santos MCS, Carneiro SR, Santos LLS, Teodori RM. Avaliação da sobrecarga de trabalho e da qualidade de vida de cuidadores de idosos institucionalizados. *Fisioter Brasil.* 2017;18(4):433-41. DOI: <http://dx.doi.org/10.33233/fb.v18i4.1203>
8. Oliveira NA, Souza EM, Luchesi BM, Inouye K, Pavarini SCI. Stress and optimism of elderlies who are caregivers for elderlies and live with

- children. *Rev Bras Enferm.* 2017;70(4):697-703. DOI: <http://dx.doi.org/10.1590/0034-7167-2017-0088>
9. Messias LAS, Gazetta FADA, Barbosa PMK, Calamita Z. Conhecimento prático e sobrecarga na vida de cuidadores de idosos com demência. *Sci Med.* 2018;28(3):ID30569. DOI: 10.15448/1980-6108.2018.3.30569
 10. Brasil. Ministério da Saúde. Portaria nº 2436, de 21 de setembro de 2017. Aprova a Política Nacional de Atenção Básica, estabelecendo a revisão de diretrizes para a organização da Atenção Básica, no âmbito do Sistema Único de Saúde (SUS) [Internet]. Brasília (DF); 2017 [cited 2020 Nov 23]. Available from: https://bvsms.saude.gov.br/bvs/saudelegis/gm/2017/prt2436_22_09_2017.html
 11. Santos SC, Tonhom SFR, Komatsu RS. Saúde do idoso: reflexões acerca da integralidade do cuidado. *Rev Bras Prom Saúde.* 2016;29(Supl): 118-27. DOI: <https://doi.org/10.5020/18061230.2016.sup.p118>
 12. Bardin L. Análise de conteúdo. São Paulo: Edições 70; 2011.
 13. Nunes DP, Brito TRP, Duarte YAO, Lebrão ML. Cuidadores de idosos e tensão excessiva associada ao cuidado: evidências do Estudo SABE. *Rev bras epidemiol.* 2019;21(Suppl 2). DOI: <https://doi.org/10.1590/1980-549720180020.supl.2>
 14. Rabelo ES, Lopes SC. A demência na terceira idade: a família no enfrentamento da doença, tendo como referência a ABRAZ de São Luís, MA. *Rev Bibliomar* [Internet]. 2017 [cited 2020 Nov 23];16(2):7-28. Available from: <http://www.periodicoeletronicos.ufma.br/index.php/bibliomar/article/view/8806>
 15. Silva LB, Souza MFS. Os transtornos neuropsicológicos e cognitivos da doença de Alzheimer: a psicoterapia e a reabilitação neuropsicológica como tratamentos alternativos. *Pretextos - Rev Grad Psicol PUC Minas* [Internet]. 2018 [cited 2020 Nov 23];3(5):466-84. Available from: <http://periodicos.pucminas.br/index.php/pretextos/article/view/15987/13037>
 16. Scherrer Júnior G, Simão M, Passos KG, Ernandes RC, Alonso AC, Belasco AGS. Cognição prejudicada de idosos em instituições de longa permanência pública de São Paulo. *Rev Enferm Brasil.* 2019;18(3):339-48. DOI: 10.33233/eb.v18i3.3085
 17. Santos RAAS, Corrêa RGCF, Rolim ILTP, Coutinho NPS. Atenção no cuidado ao idoso: infantilização e desrespeito à autonomia na assistência de enfermagem. *Rev Pesq Saúde* [Internet]. 2016 [cited 2020 Nov 23];17(3):179-83. Available from: <http://www.periodicoeletronicos.ufma.br/index.php/revistahuufma/article/view/6793/4335>
 18. Silva MS, Beuter M, Benetti ERR, Bruinsma JL, Donati L, Girardon-Perlini NMO. Situações vivenciadas por cuidadores familiares de idosos na atenção domiciliar. *Rev Enferm UFSM.* 2019;9:e10. DOI: 10.5902/2179769232528
 19. Coppetti LC, Giardon-Perlini NMO, Andolhe R, Dalmolin A. Produção científica da enfermagem sobre o cuidado familiar de idosos dependentes no domicílio. *ABCS Health Sci.* 2019;44(1):58-66. DOI: <https://dx.doi.org/10.7322/abcshs.v44i1.1119>
 20. Gutierrez LLP, Fernandes NRM, Mascarenhas M. Caracterização de cuidadores de idosos da região metropolitana de Porto Alegre (RS): perfil do cuidado. *Saúde debate.* 2017;41(114):885-98. DOI: <http://dx.doi.org/10.1590/0103-1104201711417>
 21. Andrade GB, Pedroso VSM, Weykamp JM, Soares LS, Siqueira HCH, Yasin JCM. Cuidados Paliativos e a importância da comunicação entre o enfermeiro e paciente, familiar e cuidador. *Rev Fund Care Online.* 2019;11(3):713-7. DOI: <http://dx.doi.org/10.9789/2175-5361.2019.v11i3.713-717>
 22. Cariolano-Marinus MWL, Andrade RS, Ruiz-Moreno L, Lima LS. Comunicação entre trabalhadores de saúde e usuários no cuidado à criança menor de dois anos no contexto de uma unidade de saúde da família. *Interface.* 2015;19(53). DOI: 10.1590/1807-57622013.0552
 23. Tonelli BQ, Leal APR, Tonelli WFQ, Veloso DCMD, Gonçalves DP, Tonelli SQ. Rotatividade de profissionais da Estratégia Saúde da Família no município de Montes Claros, Minas Gerais, Brasil. *RFO UPF.* 2018;23(2):180-5. DOI: <https://doi.org/10.5335/rfo.v23i2.8314>
 24. Mayer BLD, Hupper RE, Silva FS, Weiller TH, Poll MA. Profissionais de saúde da atenção básica e a avaliação: revisão integrativa da literatura. *Saúde (Santa Maria)* [Internet]. 2015 [cited 2020 Nov 23];41(1):19-28. Available from: <https://periodicos.ufsm.br/revistasauade/article/viewFile/9209/pdf>

25. Ferreira SRS, Perico LAD, Dias VRGF.
A complexidade do trabalho do enfermeiro
na Atenção Primária à Saúde. *Rev bras enferm.*
2018;71(supl1):752-7. DOI: <http://dx.doi.org/10.1590/0034-7167-2017-0471>

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