

Trajectory of family caregiving to dependent elderly people

Trajetória da prestação de cuidados familiares a pessoas idosas com dependência

Trayectoria de la actividad de cuidados familiares a personas mayores con dependencia

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Abstract

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Resumo

Objetivo: Avaliar o efeito da passagem do tempo no processo de prestação de cuidados nas variáveis do sistema cliente formado pelo cuidador familiar e pessoa idosa com dependência.

Métodos: Estudo observacional longitudinal, tendo por referência o modelo de sistemas de Neuman. A amostra é de 30 diádes avaliadas em 3 momentos durante 8 meses, no domicílio das pessoas idosas com dependência numa comunidade na região de Lisboa, em Portugal. Os instrumentos de avaliação foram um questionário sociodemográfico de caracterização do sistema cliente e a escala de depressão do Center for Epidemiologic Studies.

Resultados: Com o passar do tempo, os cuidadores apresentaram resultados compatíveis com agravamento nas variáveis do core e das linhas que o envolvem, com diferenças estatisticamente significativas ($p < 0,1$) no apoio social recebido ($p = 0,093$), nas atividades em que recebe apoio no cuidar ($p = 0,061$), na categoria atividade somática e retardada da sintomatologia depressiva ($p = 0,052$), constrangimentos financeiros ($p = 0,069$) e internamento temporário do idoso ($p = 0,037$).

Conclusão: A prestação de cuidados quando prolongada no tempo torna difícil a vida do cuidador nas variáveis avaliadas, causando instabilidade no sistema cliente. Face à gravidade do problema é discutida a necessidade de intervenção a nível macro para minimizar consequências da atividade de cuidar.

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Conflicts of interest: none to declare.

Resumen

Objetivo: Evaluar el efecto del paso del tiempo en el proceso de la actividad de cuidar en las variables del sistema cliente formado por el cuidador familiar y la persona mayor con dependencia.

Métodos: Estudio observacional longitudinal, que utilizó como referencia el modelo de sistemas de Neuman. La muestra está compuesta por 30 binomios evaluados en tres momentos durante ocho meses, en el domicilio de las personas mayores con dependencia en una comunidad en la región de Lisboa, en Portugal. Los instrumentos de evaluación fueron un cuestionario sociodemográfico de caracterización del sistema cliente y la escala de depresión del *Center for Epidemiologic Studies*.

Resultados: Con el pasar del tiempo, los cuidadores presentaron resultados compatibles con agravamiento en las variables del core y de las líneas que lo envuelven, con diferencias estadísticamente significativas ($p < 0,1$) en el apoyo social recibido ($p = 0,093$), en las actividades en que recibe apoyo en el cuidado ($p = 0,061$), en la categoría actividad somática y retardada de la sintomatología depresiva ($p = 0,052$), restricciones financieras ($p = 0,069$) e internación temporal de la persona mayor ($p = 0,037$).

Conclusión: Cuando la actividad de cuidar se prolonga en el tiempo, la vida del cuidador se hace difícil en las variables evaluadas, lo que causa inestabilidad en el sistema cliente. Ante la gravedad del problema, se discute la necesidad de intervención a nivel macro para minimizar las consecuencias de la actividad de cuidar.

Introduction

One of the greatest achievements in the 20th century was increasing longevity, but the last years of a person are not always lived with functional capacity. Longer life expectancy leads to higher risks of developing diseases, disability, and dependence, with high costs for patients, families, and society.⁽¹⁾ The increase in dependence and health needs of elderly people requires that someone, either naturally or not, provides care for longer periods, an obligation that usually falls upon the family, with care type determined by how dependence evolves.⁽²⁾

The experience of being a caregiver causes overload and changes in family dynamics.⁽³⁾ The definition of burden encompasses two dimensions: one referring to work, the weight of a task itself, while the other pertains to "norm, responsibility, and the duty of being committed to something".⁽⁴⁾ These dimensions are associated with two meanings: they imply a nonretributive obligation of providing care to a relative with transitory or long-term dependence and the need for delivered care to be continuous and daily. Caregivers who live with care recipients usually provide care intensively and for long periods, having fewer opportunities to rest in comparison with formal caregivers or those who do not share a house with care recipients.⁽⁵⁾ "Continuous care imposes physical, emotional, social, and economic conditions to caregivers and relatives",⁽⁶⁾ and there is an important relationship between the overload perceived by caregivers and sociodemographic condition, patients' clinical characteristics, and care needs.⁽⁷⁾

The effect of caregiving is not limited to family caregivers (FC). Because the user system is a pair, the literature indicates its consequences on dependent elderly people too. Studies have reported⁽⁸⁾ that the overload experienced by caregivers is associated with mortality, hospitalization, abuse, and negligence of dependent elderly people.⁽⁹⁾ Caregiving can be stressful, with the stressing agent being care itself.⁽¹⁰⁾ This overload makes FC predisposed to transitioning from apparently healthy to sick people, increasing their vulnerability and their need for health resources, with implications for health systems and employing organizations.⁽¹¹⁾ The effects of stress related to caregiving are known. However, a small number of studies have explored FC's longitudinal care standards and mental health trajectories.⁽¹²⁾

In face of the increase in this phenomenon around the world, society needs to identify the problem and provide adequate answers. In Portugal, FC account for 80% of the home care load and also need care.⁽¹³⁾ Recent studies have shown depressive symptoms in FC who lived in critical situations.^(14,15) Nursing, as a crucial sector of health care, plays a decisive role by means of interventions to minimize the problem and be part of its resolution.

The following research question was formulated: What is the effect of time on caregiving, specifically on the variables of the user system made up of an FC and an elderly person?

To understand the needs of FC from a comprehensive perspective, it is fundamental to consider that people are permanently changing and reciprocally interacting with the environment, as indicated in systems theory and Neuman systems model,⁽¹⁶⁾ which

guided the present study. This helps understand the stress experienced by FC, and suggests interventions about how it can be managed and prevented.

The results offered answers to the study objective of evaluating the effect of time on the variables of the user system in the caregiving process.

Methods

This was a longitudinal observational study, which lasted eight months and had two follow-ups. Participants were FC who looked after elderly people enrolled in the home support program in the health units of a region of Lisbon, Portugal. By following inclusion and exclusion criteria, a nurse, when planning the home visit, informed the FC about the study, invited them to participate in it, and explained how their participation would occur. The researcher was also present, together with the nurse, in the second visit, to clarify details. After the informed consent, the delivery and collection of the self-completion questionnaires were scheduled.

The recruitment phase happened from January 2015 to April 2017. The user system made up of a single group was evaluated over eight months at three times: initial evaluation (T1); second evaluation, two months later (T2); and third evaluation, eight months after the first (T3).

There were 37 participants at T1, of whom 30 completed the evaluation at T2. During this first interval, 19% of the sample was lost: four elderly people died, one was institutionalized, and two FC dropped out. At T3, 21 participants were evaluated. The loss of 30% in the sample at this stage resulted from three deaths, one institutionalization, loss of contact of two FC, and two dropouts.

The ethical principles existing in health units were applied to the present study. The research protocol was approved by the clinical director of the group of health units. The Health Subregion Ethics Commission issued a favorable report (no. 093/CES/INV/2014). The authors who translated and adapted the scales into European Portuguese agreed to the use of the instruments.

The participants were given clarifications about the study and freedom to drop out at any time

without any consequences. All of them signed informed consent forms, and the ethical principles expressed in the Declaration of Helsinki and the Oviedo Convention were observed.

The data collection instrument was a questionnaire for characterization of the user system. The questions addressed the following aspects:

1. Sociodemographic variables.
2. Activities of daily living (ADL), which were organized into basic activities of daily living and instrumental activities of daily living. The questions were translated and adapted from previous questionnaires.⁽¹⁷⁾ The answer options were items in a scale in which 1 meant "not dependent at all", 2 indicated "little dependent", 3 referred to "very dependent", and 4 symbolized "completely dependent".
3. Social support, which was assessed by means of the following items: gets support to provide care and pays for this support (yes or no); weekly support hours; from whom support is received (relatives, family employee, and home care support); for what activities support is received (hygiene, two activities, three activities, more than three activities, and all activities).
4. Frequency of occurrence of financial limitations. The answer options were a scale from 1 to 5, in which 1 meant "never", 2 indicated "almost never", 3 referred to "sometimes", 4 symbolized "very often", and 5 represented "nearly always".

Frequency of depressive symptoms experienced the week before the evaluation. A version in Portuguese of the Center for Epidemiologic Studies of Depression Scale was applied to assess this variable.⁽¹⁸⁾ The original instrument has 20 items, four of which with an inverse score, grouped into four factors: depressive affect, positive affect, somatic and retarded activity, and interpersonal relationship. The answers could score from 0 to 3, with 0 meaning "never" (less than one day), 1 indicating "occasionally" (one or two days), 2 referring to "with some frequency" (three or four days), and 3 symbolizing "very often" (five to seven days). The scale score ranges from 0 to 60, with the value indicating the intensity of the depressive symptomatology. The authors of the

Portuguese version suggested a cutoff between 20 and 25 to identify possible depression, and three out of the four factors had acceptable values for internal consistency, although lower than those reported for the original instrument.⁽¹⁸⁾ The variables of the system are: physiological, psychological, sociocultural, developmental, and spiritual, and the effect of stressors can be found at different levels: core, lines of resistance, normal line of defense, and flexible line of defense,⁽¹⁶⁾ as shown in Figure 1.

After characterization of the analyzed variables, the following characterization of the user system was obtained:

- Core
 - Physiological variable: age, gender, marital status, and cohabitation of the FC and the elderly person.
 - Psychological variable: degree of kinship between the FC and the elderly person.
 - Sociocultural variable: occupational status of the FC, level of education of both the FC and the elderly person.
 - Developmental variable: elderly person's dependence in ADL.
- Line of resistance
 - Physiological variable: aspects regarding social support (whether the FC gets support to provide care; weekly support hours; from whom support is received; for what activities support is received).

Levels of system	Variable
Core or Basic Structure	Physiological sex, age, marital status, cohabitation of FC and elderly person. Psychological degree of kinship Sociocultural occupational status, level of education Developmental elderly person's dependence in ADL
Lines of Resistance	Physiological support in caregiving, hours of received support, from whom support is received, for what activities support is received. Sociocultural paying for received support
Normal Line of Defense	Physiological daily hours of caregiving, time (in years) acting as a FC Psychological depressive affect, positive affect, somatic and retarded activity, interpersonal relationship, depressive symptoms (total scale score) Sociocultural financial limitations
Flexible Line of Defense	Physiological temporary hospitalization of the elderly person

Figure 1. Neuman systems model applied to caregivers and elderly people

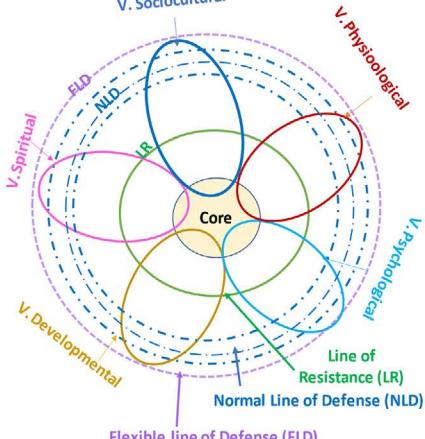
whom support is received; for what activities support is received).

- Sociocultural variable: paying for the received support.
- Normal line of defense
 - Physiological variable: time (in years) acting as an FC, number of daily hours dedicated to caregiving.
 - Psychological variable: depressive affect, positive affect, somatic and retarded activity, interpersonal relationships, and depressive symptoms (total scale score).
 - Sociocultural variable: financial limitations resulting from the caregiving process.
- Flexible line of defense
 - Physiological variable: temporary hospitalization of the elderly person.

Descriptive and inferential statistics was used to compare the variables at the three different times. Cochran's Q test, Friedman test, and analysis of variance were applied to repeated samples when the variables' normality at the three times and homogeneity of variances were verified. Data analysis was carried out using SPSS version 22.0. A level of significance of 10% was adopted for all analyses.⁽¹⁹⁾

Hypothesis

The variables of the user system show worse results as time acting as an FC increases.



Results

The collected data allowed to characterize the physiological, psychological, and sociocultural variables of the core and the physiological variables of the normal line of defense. The user system was 30 FC and the respective elderly people who received care, evaluated at T1 and T2.

Core

The physiological variable indicated that the average age of FC was 68 years, ranging from 44 to 87 years. The modes were female gender (70%), being married (70%), and living with the elderly person (87%). For the elderly people, the average age was 83 years, ranging from 69 to 100 years, and the modes were female gender (73%) and being married (57%). Analysis of the degree of kinship of the psychological variable showed that the mode was being the spouse (60%). Regarding the sociocultural variable, most FC (63%) were retired people. Their level of education varied: 30% had complete high school, and 30% had complete primary school at most. The elderly people had less formal education: 30% and 60% had complete high school and primary school, respectively.

Normal line of defense

In the physiological variable, time acting as an FC was evaluated. The groups that played this role for less than a year, from three to five years, and between five and ten years had approximately the same number of people (17%). The most numerous group was that who had been providing care for one to three years (26%), followed by the group who had been playing this role for over ten years (23%).

Differences between the variables in the core and the lines around the user system at three times (T1, T2, T3)

Core

The developmental variable was evaluated by taking into account the dependence of the elderly person to execute ADL, namely basic and instrumental activities. The differences in the averages calculated for T1 and T3 were not statistically significant, although there was a decrease in the mean and the median. However, over time, the dependence to carry out ADL grew in both total and basic activities, which include carrying out personal hygiene, eating, dressing, ambulating, and transferring. Dependence also increased for instrumental ADL (which include carrying out food preparation, housekeeping, managing finances and medications, shopping for groceries, and using transportation and the telephone). The level of dependence found for basic ADL and ADL as a whole was close to "very dependent", higher than that obtained for instrumental ADL, which was "completely dependent".

Line of resistance

The physiological variable pertaining to social support included the following categories: i) gets support; ii) weekly support hours; iii) from whom support is received; and iv) for what activities support is received. The sociocultural variable addressed the aspect of payment for received support.

Figure 2 shows that, in the category "gets support for caregiving", the percentage of the FC who answered "yes" was higher. The results indicated statistically significant differences ($p=0.093$) between the three times, with an increase in the percentage

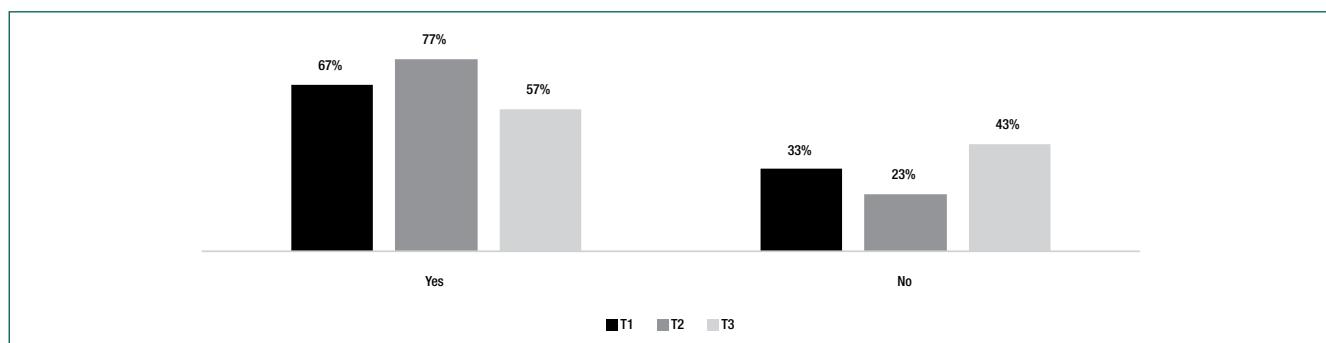


Figure 2. Comparison of the category social support at T1, T2, and T3 in the user system

of FC who received support in T1–T2 and a marked decrease in T2–T3. Overall, in T1–T3, there was a decrease in the obtained support.

Regarding the weekly support hours, the FC received, there was an increase of 80% in the median for the period T1–T3, with no statistical significance, because the averages did not change. The data showed that formal and informal support progressively ceased existing, especially the latter when provided by relatives. For T1–T2, “family” and “full-time family employee” kept their support as at T1, whereas “home care support” and “part-time family employee” increased their contribution (18% and 54%, respectively). For T2–T3, “part-time family employee” increased its contribution to support (50%), whereas “support from relatives” and “home care support” decreased (55% and 25%, respectively), and the percentage of FC with no support grew 74%. For T1–T3, the support offered by “relatives” decreased (55%) and was accompanied by a marked increase in the contribution of “part-time family employee” (13%) and the percentage of FC with no support (21%). The category “full-time family employee” present in one FC – elderly person pair at T1, ceased existing at T2.

Regarding activities for which FC received support, there were statistically significant differences ($p=0.061$) between the three evaluation times (Figure 3): T1–T2 showed an increase in the frequency of the answer “two activities” and a decrease in the frequency of the answer “more than three activities”;

for T2–T3, the number of activities for which FC received support increased, since the answers “more than three activities” and “all activities” were more frequent; and T1–T3 showed a decrease in support in “three activities” and an increase in “all activities”. Over the total analyzed period, the percentage of caregivers who got support in all activities grew.

The sociocultural variable indicated that the percentages of FC who paid for support and those who did not were the same (50%).

Normal line of defense

Physiological variable: The number of daily care hours decreased over time with some intensity, although the differences were not statistically significant. Consequently, the group with less care hours (one to three) gradually increased, and the group with more care hours (ten or more) decreased.

Sociocultural variable: The financial limitations increased over time, and the differences were statistically significant ($p=0.069$).

Psychological variable: The factor positive affect was not shown, since the calculated internal consistency was low, which indicated inappropriate reliability.⁽²⁰⁾

The factor depressive affect improved in T1–T2, but increased in T2–T3 and T1–T3 (43% and 25%, respectively).

Interpersonal relationship varied considerably, but these changes had no statistical significance because the sample was reduced.

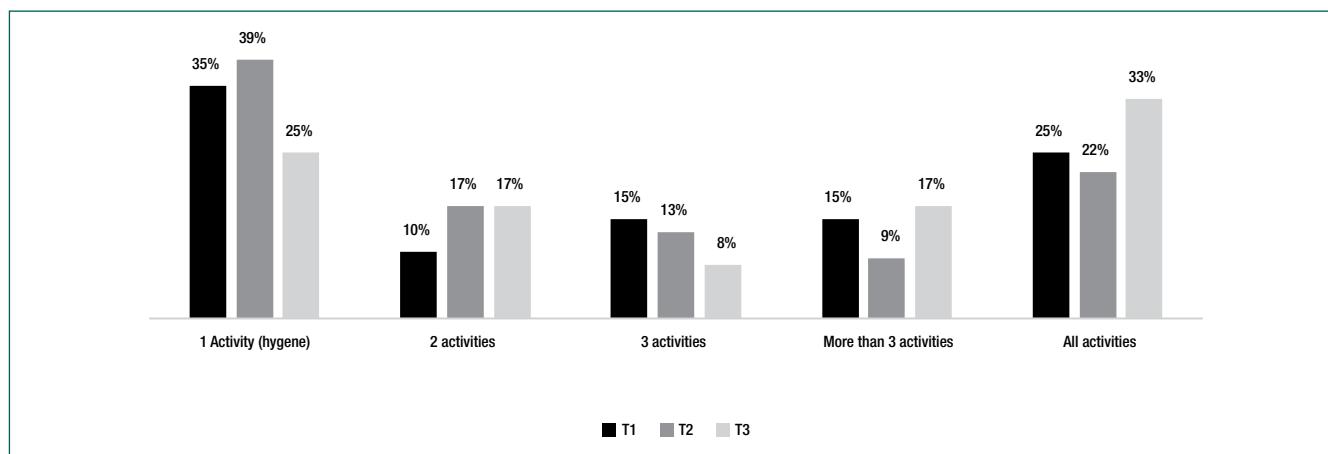


Figure 3. Comparison of the physiological variable (social support: activities for which caregivers receive support) at T1, T2, and T3 in the user system

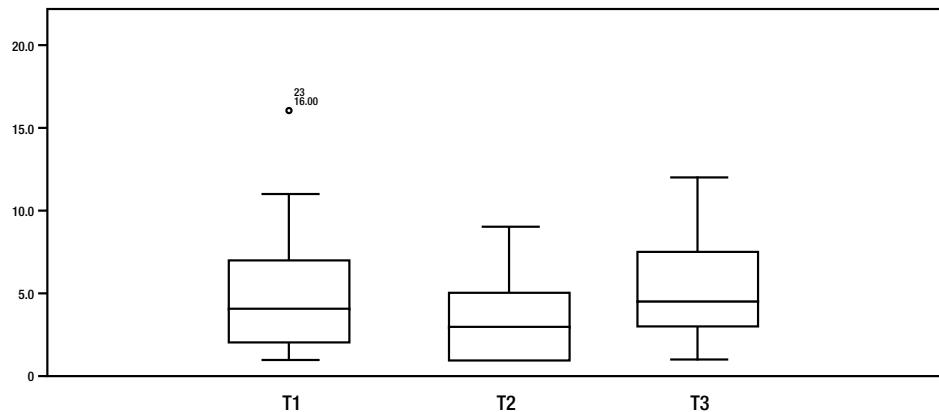


Figure 4. Comparison of the physiological variable in the normal line of defense (somatic and retarded activity) at T1; T2; and T3 in the user system

Depressive symptoms (total scale score) had two successive increases (substantial growths of 47% in T2–T3 and 32% in T1–T3, despite a slight reduction of 11% in T1–T2).

The item somatic and retarded activity was the one that oscillated the most, with two successive increases, the highest found for T2–T3 (50%) and the other for T1–T3 (12.5%), despite the decrease in T1–T2. The differences were statistically significant ($p=0.052$), as shown in Figure 4.

Flexible line of defense

The physiological variable included the temporary hospitalization of elderly people. Comparison of T1, T2, and T3 showed statistically significant differences ($p=0.037$) and a remarkable reduction (60%) in the number of hospitalizations in T1–T3.

Discussion

At T1, the percentage of FC who informed that they had support to provide care was higher than that of caregivers who declared that did not have it. The results indicated statistically significant differences between the three times, with an increase in the percentage of FC who got support for caregiving in T1–T2 and a decrease in T1–T3. The percentage of FC who received support decreased, but those who kept getting it increased the weekly number of hours devoted to care (T2–T3 and T1–T3). Consequently, the expenses with care grew too.

In the group of FC who had support in T1–T3, there was an increase in the help from part-time cleaning ladies and a reduction in “home care support”. The latter result is surprising, indicating that there was a preference for the individualized support offered by cleaning ladies, which may be related to a lack of flexibility in the schedule of formal institutional support in the form of home care support. Although the costs with the family employee may be higher, this professional seems to be the option of FC because of the possibility of getting more personalized care and the existence of working hours that are more compatible with their own needs. Additionally, there usually is an intensification in the instrumental ADL of elderly people, which include housekeeping, walking around the neighborhood, cooking, and preparing meals, and driving a car or using public transportation to go where they need to.

In this group of caregivers, the number of FC that need support in all activities increased from 25% to 33% over T1–T3. The category “activities for which FC get support” showed statistically significant differences at the three evaluated times. A possible explanation is that FC who received support during the caregiving continuum need to ensure that the elderly person receive care from other people (formal support), because they often fail to do it as a consequence of an age-related decline in their functional capacity (the analyzed FC themselves were elderly people, with an average age of 68 years and a maximum age of 87 years).

Exclusion of family as a source of support for caregiving is notorious and compatible with what was reported in the literature, specifically in a study⁽²¹⁾ that identified that sons and daughters who played the role of caregivers of dependent parents experienced abandonment by their siblings, got disappointed, and referred to these siblings as “forgotten people” on whom they could not count. As elderly people’s dependence intensifies, FC get more isolated: relatives, neighbors, and friends stop visiting them, and they have to solve many everyday problems by themselves.

Despite the perceptions of family abandonment, FC do not seek relatives’ support for being afraid of disturbing them or meddling in their care-related decisions. Lack of support increases care load and contributes to a feeling of isolation, which may be one of the causes of the increase in depressive symptoms of the FC.⁽²²⁾

In the present study, as well as indicated in the literature, most FC who provide care to elderly people were elderly people too, and usually spent over ten hours a day (69%) playing this role and faced several difficulties to obtain formal support.⁽²³⁾ Home care support services and formal support are associated with an increase in financial limitations, as shown in the present study.

In face of the influence of multiple variables, the decision of many families is keeping elderly people in the family environment without support, which leads to harmful consequences for FC, because dependence is associated with the cost of received support,⁽²⁴⁾ which means families need a reformulation of financial support policies. It is necessary to analyze the economic dimension of care and find solutions for the problems that emerge.

The issues found in the present study, in which care of elderly people was offered by other elderly people, are difficult to characterize and solve. Another study showed that the user system is made up of young elderly people looking after elderly people and that most of them are spouses of the care recipients.⁽²⁵⁾

The results confirmed that population aging results in an increase in the number of FC who are elderly people.⁽²⁶⁾ This is in agreement with international demographic data and information gathered

in Portuguese censuses, which showed that around 60% of the elderly population live alone or with other elderly people, an increase of 28% compared to the number obtained for the 2000s.⁽²⁷⁾

Over the eight months of the study period, the depressive symptoms increased. The category somatic and retarded activity showed statistically significant differences, but it was also the one that oscillated the most. This activity reduced in T1–T2 and then increased in T2–T3, with a variation of 50%. The final balance was an increase of 12.5% in T1–T3, that is, FC experienced a higher frequency of symptoms such as loss of appetite, annoyance, adynamia, poor sleep, difficulty concentrating, and reduced desire to talk, which corroborated the results of another study on increase of depression in FC.⁽¹⁵⁾

The analyzed variables showed an aggravation of the condition of the participants who were FC. These variables were related to an increased dependence of elderly people to carry out ADL. It was also verified that the components were interconnected and evolved over the caregiving period, in a process that is not stable. Consequently, a change in one of them can result in changes in others.⁽²⁸⁾

The study did not evaluate elderly people’s dependence at the cognitive level. No cognitive assessment was performed because of the reduced sample size, which can be considered a limitation.

The results were consistent to those reported in another study that showed the critical situation experienced by FC in Portugal⁽¹⁴⁾ and reinforced the invisible costs of the trajectory in caregiving provided by FC, with several consequences for the user system. Studies addressing the difficulties faced by FC in the country led to the recognition of the problem and promulgation of Law no. 100/2019, of September 6, which approved an informal caregiver statute and regulated the rights and obligations of caregivers and care recipients.

Conclusion

All the examined variables in the user system showed worse results over the eight months. The variables with the highest percentages were those related to

FC, and some of them showed statistically significant differences. The results allowed to meet the study objective, which was evaluating the effect of time on caregiving, specifically on the variables of the user system, and it was concluded that long-term care brought instability to it.

Caregivers play an important role in the family setting, but it also has social relevance. They are a more vulnerable group because of the stress to which they are subject daily for a long period. For this reason, they need special attention from community health services, especially nursing, which can develop projects to support and look after them.

The results suggest the need for new longitudinal studies to evaluate how other dimensions of the variables of the user system evolve, including caregiver overload, caregiver self-efficacy, budgetary management of family resources, and rewarding aspects and gains (spiritual variable) involved in the caregiving role, so nursing professionals, based on evidence, can implement anticipatory measures to minimize the effects of stressors on long-term FC and leverage family strengths.

Collaborations

Viegas LM and Rodrigues FM contributed to the study conception, data analysis and interpretation, article writing, relevant critical review of the intellectual content, and approval of the final version to be published.

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