



ORIGINAL ARTICLE

OLDER PEOPLE CARING FOR OLDER PEOPLE: A CHALLENGE TO THE ORGANIZATION OF HOME CARE

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ABSTRACT

Objective: To identify the nursing care needs of individuals who live in their homes and are dependent on others for self-care, who cares for them, and how often.

Methods: Cross-sectional, observational, quantitative, descriptive study conducted in central Portugal. The sample consisted of 130 individuals dependent on others for self-care who were admitted to home care services by the Continuous Care Teams of a Cluster of Healthcare Centers in central Portugal between July 2019 and March 2020. Data were analyzed using descriptive and inferential statistics.

Results: The majority of caregivers were women, spouses, over 75 years of age; 15.6% of caregivers were over 80 years of age. They were often unable to ensure the dependent person's care needs.

Conclusion: The study points to the need to design professional care delivery strategies to reduce care omissions.

DESCRIPTORS: Nursing; Aged; Self-care; Home care; Caregiver, Family.

ANCIANOS QUE CUIDAN DE ANCIANOS: UN RETO PARA LA ORGANIZACIÓN DE LOS CUIDADOS DOMICILIARIOS

RESUMEN:

Objetivo: saber qué cuidados de enfermería necesitan las personas dependientes en el autocuidado que viven en su domicilio, quiénes los prestan y con qué frecuencia. **Métodos:** estudio observacional, cuantitativo y descriptivo, realizado en la región central de Portugal. **Muestra** compuesta por 130 personas dependientes en el autocuidado, admitidas para atención domiciliaria en los Equipos de Cuidados de Larga Duración de un Agrupamiento de Centros de Salud de la Región Centro de Portugal, entre julio de 2019 y marzo de 2020. Los datos se analizaron a partir de los resultados de las estadísticas descriptivas e inferenciales. **Resultados:** predominan los cuidadores mayores de 75 años, el 15,6% mayores de 80 años, son mujeres y cónyuges, y no presentan, en muchos casos, capacidad para garantizar los cuidados necesarios a la persona dependiente. **Conclusión:** el estudio revela la necesidad de pensar en estrategias que permitan una oferta de cuidados profesionales, para reducir las omisiones de asistencia.

DESCRITORES: Enfermería; Anciano; Autocuidado; Asistencia Domiciliaria; Cuidador Familiar.

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INTRODUCTION

The latest demographic projections place Portugal as the sixth oldest country worldwide and the European country with the highest burden of the “oldest-old” by 2080, with people over 80 years of age representing 16.1% of the population⁽¹⁾.

Over the past few decades, although Portugal’s average life expectancy has increased and is now higher than the European average, the majority of extra years of life are lived with disability⁽²⁾, making older people more vulnerable and more likely to be dependent or require the help of others for self-care⁽³⁾. In response to this situation, health and social policies have been based on a familial perspective, holding citizens and their families accountable for their care. On the other hand, family and lifestyle changes tend to reduce the possibilities of the family, per se, to ensure the delivery of care from an informal perspective⁽⁴⁻⁵⁾.

Continuous care responses should give priority to home care and community-based care⁽⁶⁾, keeping people who are dependent on others for self-care or at risk of transition to dependence in their homes, as long as they can receive the necessary health care and social support to maintain their well-being and quality of life⁽⁵⁾. This option is more cost-effective and highly valued by many citizens who consider institutionalization as a last resort. Despite the importance of these measures, in Portugal, it is estimated that about one-third of individuals dependent on others for self-care who live in their homes depend entirely on the family caregiver to survive because they are bed-ridden and at risk of compromising their bodily processes⁽⁷⁾.

Studies have shown that the majority of family caregivers are women, employed, with a low education level and an unfavorable situation regarding available support, often living with a per capita income/month below the national minimum wage⁽³⁻⁷⁾. Moreover, many situations of self-care dependence require not only full availability from family caregivers but also motivation, capacity, knowledge, and skills to perform the caregiver’s role and meet the dependent person’s care needs, which are expected to become increasingly complex⁽³⁾.

The reflection on the current home care model posed a set of questions that led to the development of a broader study on the reality of dependent people referred to the Integrated Continuous Care Teams. This article aims to answer the following questions: Who are the primary caregivers? Is the primary caregiver capable of performing the caregiver’s role?

Therefore, this study aimed to identify the nursing care needs of individuals dependent on others for self-care who live in their homes, who cares for them, and how often.

METHOD

An observational, quantitative, descriptive, and cross-sectional study was conducted. Data were collected through a form designed for this research. This form was used because it allows collecting a wide variety of complex data that require clinical judgments directly from the interviewees (through interview or observation).

The first part of the form consisted of questions for the sociodemographic characterization of the family caregiver/primary caregiver (spouse, partner, relative, or friend of the dependent person who provides them regular care, lives with them, and is not remunerated for the care provided). The items in the second part aimed to assess the

dependent person's needs and the family caregiver/primary caregiver's ability to perform the caregiver's role, including housekeeping (shopping; cleaning the house; storing food) and accompanying the family member to health services.

The sample consisted of all people dependent on others for self-care who were referred and admitted to home care in the Continuous Care Teams of a Cluster of Healthcare Centers (ACES) in central Portugal and their family caregivers between July 2019 and March 2020, in a total of 130 individuals. Data were collected from all people who accepted to participate in the study (four people did not accept to participate, and two people withdrew from the study).

Data were collected by a team of three independent specialist nurse researchers who, based on their clinical judgment and the form application guide (including the clinical assessment criteria agreed upon by the experts' panel), assessed the care needs of each person and collected information about the patient, the family caregiver, and the family caregiver's ability to provide the necessary care. Each form took, on average, 60 minutes to complete. Data were analyzed using descriptive and inferential statistics. Non-parametric methods were used because the vast majority of variables were nominal (Chi-square and Mann-Whitney tests).

The research was submitted to the Ethics Committee of the Health Sciences Research Unit: Nursing (UICISA: E) and approved under opinion no. 546/01-2019.

RESULTS

The following profile emerged based on data analysis. First, 6.2% (n=8) of participants do not have a caregiver. Of those with a family caregiver, 80.3% (n=87) had a female caregiver, aged between 35 and 86 years, with a mean age of 67.2 years and a standard deviation of 11.6 years. Moreover, 15.6% (n=19) of caregivers were over 80 years of age and 31.1% (n=38) over 75 years of age. In the majority of cases, the primary caregiver was a family member (94.6%): 50.8% (n=62) were spouses, 21.3% (n=26) were daughters, 7.4% (n=9) were mothers, and 6.6% (n=8) were children. The option "others" was chosen by 13.1% (n=17) of participants: three daughters-in-law (2.3%), two sisters-in-law (1.53%), aunt, niece, goddaughter, sister, and partner (one of each; 0.76%), five domestic workers/contracted persons (3.84%), and two neighbors (1.53%).

Regarding marital status, 91 (70.0%) of dependent persons were married. Concerning the caregiver, 97 (79.5%) were married or cohabiting. Of these, 62 (63.9%) were spouses of the dependent person, 10 (8.2%) were divorced, eight (6.6%) were widowed, and seven (5.7%) were single. As with dependent people, the caregivers' education level was low: 69 (56.6%) of them had completed the 1st cycle of basic education, 14 (11.5%) had completed the 3rd cycle of basic education, and 10 (8.2%) had completed six years of schooling (2nd cycle of basic education). Only 11 (9.0%) caregivers had completed secondary education, with the same number completing higher education. The percentage of illiterate people in the group of caregivers was lower than in the group of dependent people (5.7%; n=7).

Regarding occupation, most caregivers (52.5%; n=64) were retired, which is in line with this group's mean age. The fact that 27 (22.1%) of caregivers were domestic workers or unemployed is in line with the fact that they were mostly women (the majority of the population served by this ACES and enrolled in the Portuguese Institute for Employment and Vocational Training were women) who had to perform the caregiver's role. The reconciliation between this role and work has been identified as a problematic issue. It should be noted that 31 (25.4%) caregivers accumulate this role with their professional activity: 12 (9.8%) were non-skilled workers, six (4.9%) were specialists in intellectual and scientific professions, four (3.3%) were intermediate-level technicians and professionals,

three (2.5%) were administrative and similar staff, and two (1.6%) were service personnel and sales workers.

Most families consisted only of the couple (47.7%; n=62), followed by families with a single parental figure (mother, father, or other caregiver), and one or more children or other dependents (25.4%; n=34). Extended families with more than three people were the exception. As shown in Figure 1, based on the researchers' (nurses') judgment, 41.5% (n=54) of primary caregivers were unable to give a bath, 40.0% (n=52) were unable to transfer the dependent person, 29.2% (n=38) were unable to help lifting the dependent person, 27.7% (n=36) were unable to position the dependent person, and 26.9% (n=35) were unable to dress/undress the dependent person.

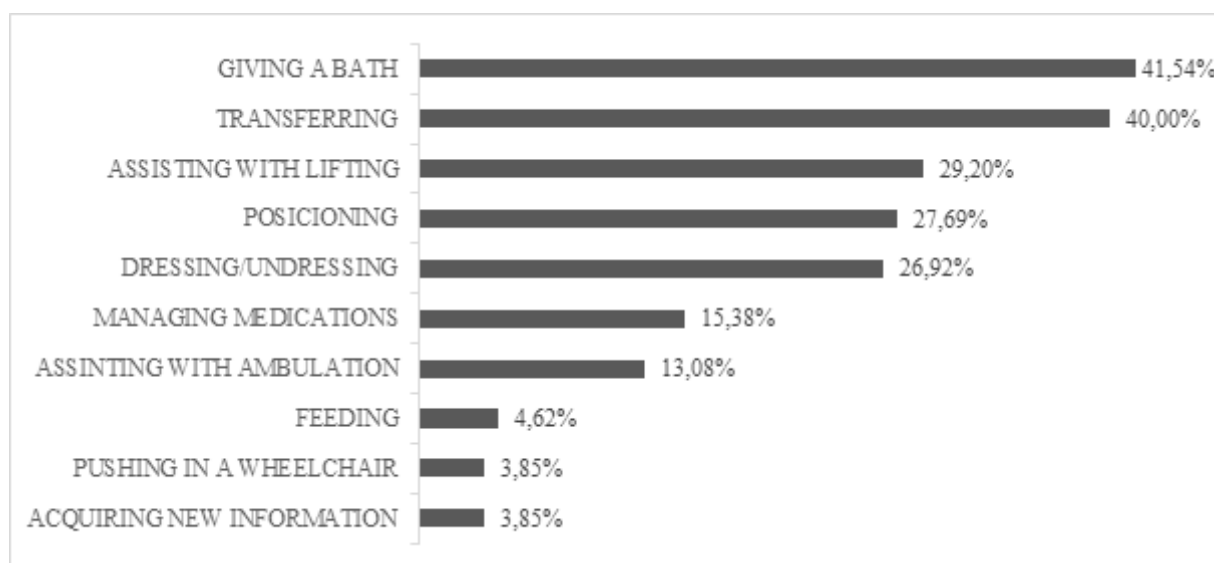


Figure 1 – The caregiver is unable to provide care. Coimbra, Portugal 2020
Source: Authors (2020)

Twenty (15.4%) primary caregivers could not manage medications, and 17 (13.1%) could not assist with ambulation. The majority of caregivers were able to provide help with "feeding" and "pushing the dependent person in a wheelchair". Only six (4.6%) and five (3.8%) caregivers were unable to do so, respectively. Most primary caregivers were also able to acquire new information, with only five (3.8%) of them having difficulties in this area.

As shown in Figure 2, 32 (24.6%) caregivers had difficulties in housekeeping and meal preparation, 30 (23.3%) had difficulties in accompanying the dependent family member to health services, 28 (21.7%) in shopping, and 19 (14.6%) in ensuring storing food.

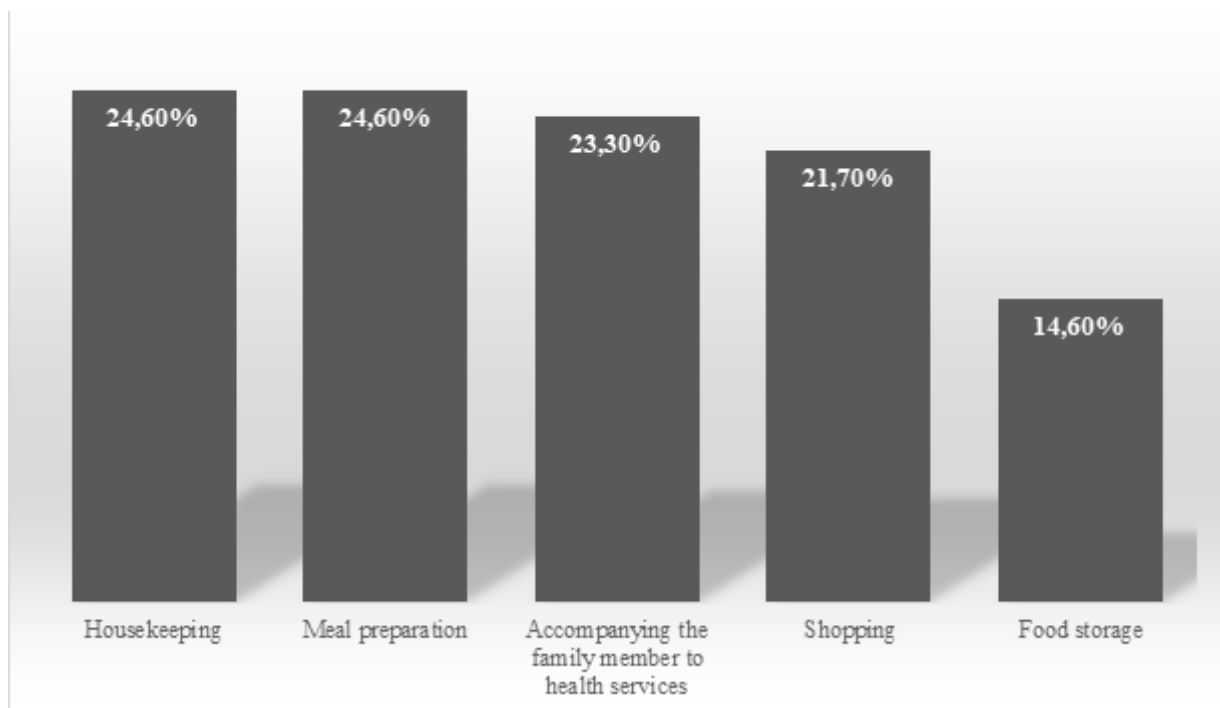


Figure 2 – What the family does not provide. Coimbra, Portugal, 2020
Source: Authors (2020)

The relationship between the variables related to the family process and those related to the characteristics of the dependent persons and their caregivers was analyzed to better understand the observed reality, revealing a statistically significant association between the ability to feed the person, the onset of dependence ($p=0.02$), and the type of referral to care ($p=0.032$). Thus, when caregivers were physically unable to feed the dependent person, all of those (100%) for whom they cared for had a gradual onset of dependence, and the same was true of the situation that caused it, chronic disease (100%), and 83.0% were referred to nursing care.

The age difference between those who were able and those who were unable to give a bath was statistically significant ($p=0.013$). According to the data, caregivers over 70 years of age are expected not to be able to give a bath, requiring help from others. Married or cohabiting caregivers had more difficulties in transferring (86.0% $p=0.038$), which is not surprising given that most of them were spouses of the dependent person and close in age to them. On the other hand, physical inability to dress/undress is associated with age ($p=0.022$) and the situation that caused dependence ($p=0.029$), being more frequent in caregivers over 71 years of age. The results also show that the caregiver's inability to dress/undress is more frequent if aging was the reason for dependence, with a statistically significant difference ($p=0.003$).

The likelihood of being unable to position the dependent person was higher when the family consisted of only the couple (69.0%; $p=0.016$), aging was the reason for dependence (61.0%; $p=0.009$), and the caregiver was older than 71 years ($p=0.032$). The likelihood of being physically unable to assist with lifting was higher ($p=0.001$) in caregivers aged 72 years or older, when the caregiver was married/cohabiting (92% $p=0.005$) and retired (74%; $p=0.038$), the family consisted only of the couple (71%; $p=0.005$), the onset of dependence was sudden (61%; $p=0.036$), and the caregiver was a spouse of the dependent person (74%; $p=0.005$).

The likelihood of being unable to manage medications was higher ($p=0.004$) when the caregiver was 73 years of age or older. The likelihood of being physically unable to assist with walking was also higher ($p=0.003$) if the caregiver was older than 75 years, and

the physical inability to push the dependent person in a wheelchair was higher ($p=0.04$) when caregivers were 77 years of age or older.

A statistically significant association was also found between not being able to acquire new information and not ensuring shopping (80.0%; $p=0.003$), housekeeping (80.0%; $p=0.001$), meal preparation (80.0%; $p=0.0$), accompanying the family member to the health services (80%; $p=0.01$), and the referral to nursing care (80.0%; $p=0.028$). Thus, the likelihood of not ensuring shopping, housekeeping, meal preparation, and accompanying the family member to the health services is expected to be higher if the caregiver is over 81 years of age and/or unable to acquire new information.

Figure 3 shows the association between the mean ages at which the caregiver can no longer help the dependent person in their self-care activities, by domains.

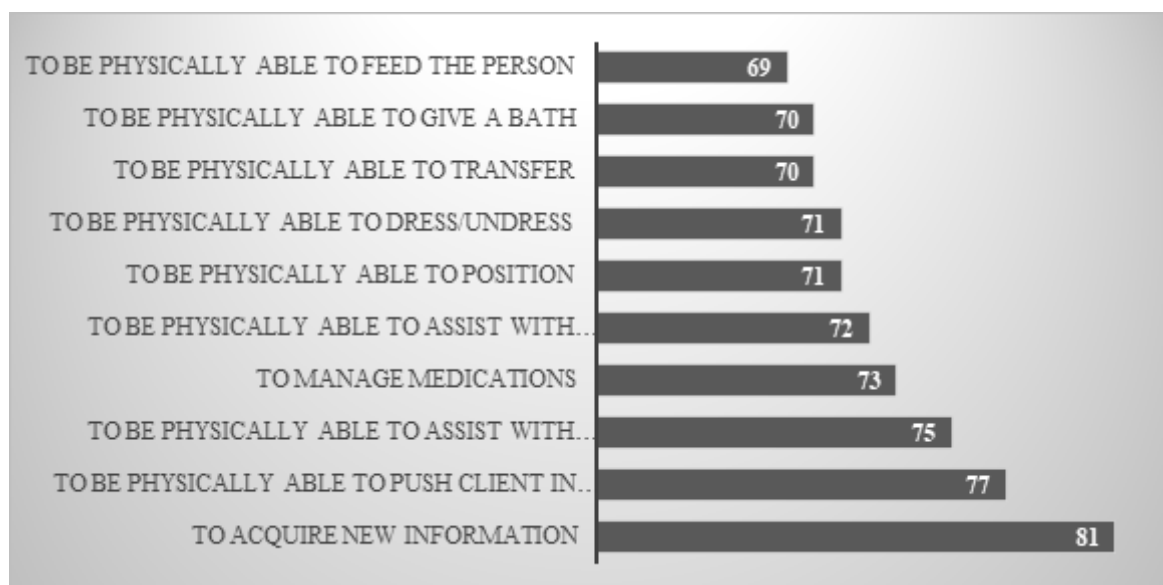


Figure 3 - Mean age of the caregiver who is unable to provide care. Coimbra, Portugal 2020
Source: Authors (2020)

DISCUSSION

This study shows that a significant percentage of caregivers are older people with a mean age higher than 65 years, with 15% of them being over 80 years of age, women, and spouses. This finding is in line with the demographic evolution and reflects the aging of the global population. The caregivers' advanced age and female gender result in a percentage of individuals who are unable to ensure the basic activities of daily living, which can be seen in the statistically significant association ($p<0.05$) between the variables of age, family consisting only of the couple, and activities such as giving a bath, positioning, and managing medications⁽³⁾. It should be noted that these data are in line with those found in studies conducted in Portugal, showing that the direct care provided by the family caregiver to the dependent person is a source of major difficulty⁽¹³⁾.

Despite the participants' willingness to become caregivers, which is very important, the capacity or ability to perform the caregiver's role must be present and evaluated⁽⁸⁾. In

dependency processes, many family members are pushed to become proficient in providing care that requires nursing skills within a relatively short period of time after admission to home care and the assumption of this role⁽⁹⁾. These results reveal the need to redesign the home care model, which holds mostly the families accountable, and consider a model that assesses the conditions of potential caregivers to perform the caregiver's role and the need for greater support from the professionals, namely family nurses.

The results of this study show that there is a set of aspects of care that are rationed or not provided often due to the caregiver's inability or the high percentage of individuals who do not have a caregiver. International studies on care provided by family caregivers have identified the prevalence of unmet self-care needs based on dependent people's self-reports⁽¹⁰⁾. Some studies indicate that about 20% of necessary care is not delivered, and the higher prevalence of unmet needs is associated with higher levels of dependence on others for self-care⁽¹¹⁾.

An unexpected finding is the existence of dependent people without a caregiver (6.2%) because the referral to Integrated Continuous Care Teams implies the existence of a "social support network"⁽¹²⁾. However, a future care model must consider that 55% of people aged 65 years and over in Portugal live alone to give a universal response to people dependent on others for self-care who want to continue living in their homes⁽⁴⁾.

In this study, about a quarter of caregivers kept their professional activity, which may influence the availability for performing the caregiver's role. This data is in line with those of the available studies on family caregivers⁽³⁾.

The reflection on these data points to an unavoidable problem related to the organization of care delivery to dependent people living in their homes, and it is important to analyze the true meaning of family support. Is it enough to have a family member with affective availability to perform the caregiver's role to say that family support exists? This study says "no" because the caregiver is often physically unable to provide care.

In fact, the population faces a situation characterized by a large percentage of "older people caring for older people". It is clear that there is an association between this situation and the lack of ability to provide the necessary care. A statistically significant association was found between feeding and positioning the person, managing medications, and giving a bath and the caregiver's age, the onset of dependence, and being a couple.

Although it may seem controversial to suggest that continuing to live at home with the spouse (or other older family members) ensures affective support and maintains identity references, it is also true that caregivers older than 70 years are increasingly more likely not to be able to manage the processes associated with self-care dependence⁽¹⁴⁾. The need for professional support, especially nursing care, is imperative in these situations.

Based on Orem's Theory of Nursing Systems, the reality unveiled by this research allows concluding that a Supportive-Educative System (in which the caregiver only needs support, guidance, and training) is insufficient to ensure the safety, health, and well-being of both dependent people and caregivers.

The results point to the need for a new care organization that will transition progressively from a "partially compensatory system" (in which some caregiver limitations are compensated and some activities that the caregiver cannot do for the dependent person on a daily basis are performed) to a "wholly compensatory system" as the caregiver gets older and reaches the age of 80 years⁽¹⁵⁾.

The current system of home care delivery by integrated continuous care teams in Portugal is based on the existence of a family caregiver who performs the caregiver's role and on the complementary role of health professionals, particularly within a Supportive-Educative System. This study shows that the vast majority of family caregivers are older people who, despite being emotionally available to provide care, do not have the necessary

conditions to deliver the required care. Therefore, caregivers need the help of health professionals, particularly nurses, not only within a Supportive-Educative System but also a Wholly Compensatory System that ensures the necessary care to the dependent person.

A limitation of this study was that it was carried out in a single Cluster of Healthcare Center, which may have limited the generalization of results. This study should be replicated in other Clusters of other regions in Portugal.

CONCLUSION

Throughout this study, the phenomenon of the care needs of people dependent on others for self-care who live in their homes and the need to meet them have been characterized as complex and multidimensional realities that are often associated with aging, both of the dependent person and the family caregiver, leading to the omission of care.

This study revealed that one of the factors contributing to the omission of care to the dependent person is the high percentage of family caregivers who are unable to provide care in different self-care domains and the fact that the caregivers' inability increases gradually with age. This inability to ensure the necessary care increases gradually with age, especially after 70 years of age.

Although family caregivers play a critical role in delivering care and maintaining the health and well-being of their dependent family members, the truth is that today "older people care for older people" in many situations. The need for professional support, particularly nursing support, is imperative in these cases.

Therefore, this study reinforces the need to design a Home Care Model that can provide a professional response, throughout the trajectory of dependence, to different types of needs: promotion of self-care ability and prevention of autonomy loss; recovery of the potential for autonomy and prevention of complications associated with the dependence on others for self-care; maintenance care and prevention of complications, stimulation, well-being promotion, and palliative interventions.

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