

RESEARCH ARTICLE (ORIGINAL) 

The dependent person, the family caregiver, and the resources used: A study with standard families


A pessoa dependente, o cuidador familiar e os recursos utilizados: Estudo com famílias clássicas

La persona dependiente, el cuidador familiar y los recursos utilizados: Un estudio con familias clásicas

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Abstract

Background: Demographic aging and the increase in chronic diseases are reflected in high levels of dependence for self-care.

Objective: To characterize the Dependent Family member (FM), the Caregiving Family Member (CFM) and the resources used, in the context of classic families.

Methodology: Quantitative and descriptive study. A Snowball sample was used. The “Families that Integrate Dependents in Self-care” form was used in 60 CFM.

Results: The FM are mostly female. Caregivers are predominantly elderly women with low education. The most basic care (e.g. feeding, giving drink and dressing) are carried out with some ease by the CFM and are guaranteed. Care with a more differentiated intervention, such as performing exercises for the lower and upper limbs and activities to stimulate memory, do not are carried out. The main resource used is the health center.

Conclusion: This study reveals the need for Family Nurses to intervene in family care at home through teaching and implementing more differentiated care (motor rehabilitation and cognitive stimulation), as well as promoting accessibility to care and health resources.

Keywords: ageing; family nurse; dependency; self-care; caregiver

Resumo

Enquadramento: As transições demográficas, epidemiológicas e sociais têm implicações na (in)dependência para o autocuidado.

Objetivo: Caracterizar o familiar dependente (FD), o Membro Familiar Prestador de Cuidados (MFPC) e os recursos utilizados, no contexto das famílias clássicas.

Metodologia: Estudo transversal e descritivo. Amostragem de *Snowball*. Utilizou-se o formulário “Famílias que Integram Dependentes no Autocuidado” em 60 MFPC.

Resultados: Os FD são maioritariamente do género feminino. Os cuidadores são predominantemente mulheres idosas com baixa escolaridade. Os cuidados mais básicos (e.g. alimentar, dar de beber e vestir) são realizados com alguma facilidade pelo MFPC e estão garantidos. Os cuidados com intervenção mais diferenciada, como a realização de exercícios dos membros inferiores e superiores e a estimulação das funções cognitivas não são realizados. O principal recurso utilizado é o centro de saúde.

Conclusão: Este estudo revela a necessidade do Enfermeiro de Família intervir nos cuidados à família em contexto domiciliário através do ensino e da implementação de cuidados mais diferenciados (reabilitação motora e estimulação cognitiva), assim como, promover a acessibilidade aos cuidados e recursos de saúde.

Palavras-chave: envelhecimento; enfermagem familiar; dependência; autocuidado; cuidadores

Resumen

Marco contextual: Las transiciones demográficas, epidemiológicas y sociales repercuten en la (in)dependencia de los autocuidados.

Objetivo: Caracterizar al familiar dependiente (FD), al familiar cuidador (MFPC) y los recursos utilizados, en el contexto de las familias clásicas.

Metodología: Estudio transversal y descriptivo. Muestreo de bola de nieve (*snowball*). El formulario “Famílias que integran a personas dependientes en el autocuidado” se utilizó en 60 MFPC.

Resultados: Los FD son mayoritariamente mujeres. Los cuidadores son predominantemente mujeres mayores con bajos niveles de educación. Los cuidados más básicos (por ejemplo, alimentar, beber y vestirse) los realizan con cierta facilidad los MFPC y están garantizados. Los cuidados con intervención más especializada, como ejercitar los miembros inferiores y superiores, y estimular las funciones cognitivas no se realizan. El principal recurso utilizado es el centro de salud.

Conclusión: Este estudio pone de manifiesto la necesidad de que el enfermero de familia intervenga en los cuidados familiares en el domicilio enseñando y aplicando cuidados más especializados (rehabilitación motora y estimulación cognitiva), así como promoviendo la accesibilidad a los cuidados y recursos sanitarios.

Palabras clave: envejecimiento; enfermería de la Familia; dependencia; autocuidado; cuidadores

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Introduction

The changes observed in the Portuguese resident population, mainly due to the low birth rate and the increase in longevity in recent decades, suggest a continuation of demographic aging. Between 2015 and 2080, the Portuguese aging index is estimated to more than double, from 147 to 317 older adults for every 100 young adults (Instituto Nacional de Estatística, 2022). The literature has demonstrated a relationship between aging and disability (Chen et al., 2018) and a significant association between multimorbidity, which is frequent among older adults, and functional decline and/or dependence (Wang et al., 2017). All these factors contribute to a greater need for care provided by families in community settings (Sequeira, 2018). However, many family caregivers report not having the support needed in different areas (emotional, care delivery, financial) to care for their family members. Chen et al. (2018) report that many older adults with some type of disability present at least one unmet need, with the prevalence of unmet needs ranging from 4.6 to 77.2%. Family Nurses (FNs) are on the frontline of care for dependent people and their families, focusing on training them for self-care (Melo, 2018; Shajani & Snell, 2019). Thus, knowing the dependent person's self-care abilities and assessing the type and degree of dependence is crucial (Costa, 2013; Gonçalves, 2015). By knowing the dependent person's needs, nurses can better understand how the person should be cared for and which interventions are the most appropriate for them to achieve self-care independence (Dixe et al., 2019).

The lack of data on the number of community-based families with older adults dependent in self-care and how each family responds to the care needs of their dependent members is alarming. The lack of knowledge hinders understanding the problem's actual dimension and, therefore, the effective organization of the care resources that families need to ensure greater well-being and health for all stakeholders involved (Costa, 2013; Gonçalves, 2015). Moreover, this lack of knowledge may explain why society and healthcare systems undervalue the caregivers' importance in recovering and rehabilitating dependent people's health.

Hence, this study aims to describe the dependent person (DP), the family caregiver (FC), and the resources used within the context of standard families.

Background

The scientific community currently defines "aging" as a process resulting from biological, psychological, and social factors. Older adults' health status results from their past experiences regarding lifestyles, the exposure to their environments, and the health care received. Also, their quality of life is influenced mainly by their ability to maintain autonomy and independence. Multimorbidity, polymedication, domestic and traffic accidents, bereavement, institutional admissions, social isolation, desertification, financial fragility, family structure chan-

ges, and poor housing conditions are some of the factors affecting older adults' health, autonomy, independence, and quality of life, and require a multidisciplinary, integrated, and teamwork-based assessment and interventions (Direção-Geral da Saúde, 2017).

The issue of dependence in self-care is not a recent concern for Nursing. Logan et al. (2000) declare that it is the nurse's responsibility to assess the person's degree of dependence and emphasize that it is vital to establish the most appropriate type of care for the DP, aiming to achieve maximum autonomy in activities of daily living. However, Melo (2018) and Shajani & Snell (2019) agree that the effectiveness of health care is enhanced when the focus extends from the individual and includes the DP's family. One of the principles guiding Family Nursing is including the family in care planning and delivery, bearing in mind the family's needs as a whole and not just the DP's (Melo, 2018; Shajani & Snell, 2019).

Considering that the aging process is associated with caring for a dependent older adult, it is essential to recognize that providing care is a complex and demanding process that may encompass physical, emotional, psychological, social, and/or financial changes (Nicolau, 2018), with burden and anguish being widely reported outcomes associated with care provision (Dixe & Querido, 2020; Nicolau, 2018).

Two exploratory population-based studies conducted by Costa (2013) and Gonçalves (2015) in the Portuguese districts of Lisbon and Porto, respectively, reveal the high dependence of the person under care, specifically on Feeding, Grooming and Bathing, and that many DPs do not participate in their medication regime management. Other authors have also found that the self-care domains with the highest level of dependence were Taking medication, Dressing and undressing, Bathing, and Walking (Dixe et al., 2019; Machado et al., 2020). In addition, several studies show that FCs are mostly older women (wives and daughters), which increases the likelihood of caregiver burden due to age and physical condition (Dixe & Querido, 2020; Nicolau, 2018). However, the study conducted by Chen et al. (2018) shows a slightly different characterization, with older DP's caregivers being predominantly middle-aged and showing moderate burden. Caring for a DP and/or the needs of the FC should be understood from a systemic family perspective. FNs must consider the family as a care unit to know and understand it better (Shajani & Snell, 2019). Knowing and assessing the family unit allows for identifying its weaknesses and enhancing its abilities and strengths, fostering collaborative interventions in partnership with the families. This way, nurses promote families' health and empower them to solve their crises, thus contributing to the quality and well-being of the DP and the family as a system (Dixe & Querido, 2020; Nicolau, 2018).

Research questions

What is the DP's degree of dependence? What are the characteristics of the FC and the resources used, within

the context of standard families, in a parish of the central region of Portugal?

Methodology

This quantitative, observational, cross-sectional, and descriptive study was conducted within the scope of the project of the Nursing School of Coimbra *Famílias que integram Pessoas Dependentes no Autocuidado: estudo exploratório de base populacional no concelho de Coimbra* (Families with Self-Care Dependent Members: an exploratory population-based study in the municipality of Coimbra), approved by the Ethics Committee of the UICISA: E - Health Sciences Research Unit: Nursing (opinion no. 634/11-2019).

This study's target population was standard families with members dependent in self-care. The following inclusion criteria were defined: to be from a standard family from a parish in the central region of Portugal; to be 18 years or older; to be a FC of a family member dependent in self-care; and to agree to participate voluntarily in the study. The exclusion criteria were: to care for a DP who was not a family member; and to care for a dependent family member whose dependence is inherent to their age/stage of the life cycle, such as children.

The study used a non-probability snowball sampling technique. First, the families were identified through the User list of the Health Center of the study's geographical area. Next, these families' FCs were asked to identify other families in the same area with members dependent in self-care. In the end, the snowball sampling technique allowed including 60 families in the study's sample.

Data were collected using the Portuguese form *Famílias que Integram Dependentes no Autocuidado* (Families with Dependents in Self-Care; Costa, 2013; Gonçalves, 2015). The form is organized into two parts: Part I - Preliminary survey/characterization – including questions on the type of accommodation and family, the household's socioeconomic conditions, and the FC's sociodemographic description; and Part II - Caregiver/Dependent – including questions on the DP's social characterization, degree of dependence, and health condition, the FC's perception of self-efficacy, and the description of the care provided and the resources used in care provision. Studies using this form achieved good reliability scores, with Cronbach's Alpha coefficients in the different self-care domains between 0.881 and 0.997 (Costa, 2013; Gonçalves, 2015). In this study, Cronbach's Alpha coefficients ranged between 0.743 and 0.997.

Data were collected in two phases from March to July

2020. In the first phase, the researcher, the FN of these households, contacted the families by telephone. After confirming that the families met the study's inclusion criteria and their consent was provided, the researcher scheduled a day and time to administer the form at home according to the FC's availability. In the second phase, the form was interviewer-administered at the FC's home and complemented with direct observation. The data analysis was based on descriptive statistics. It used the Statistical Package for the Social Science (SPSS) software, version 25.0, to calculate the percentage and frequency of nominal categorical variables, the mean, and the standard deviation, maximum and minimum values for quantitative variables.

Results

Regarding the families' description, the study observed that most were standard families with one nucleus (55%), of less than three members (46.7%), and with monthly incomes between 501 and 1000 euros (33.3%). Most (86.3%) lived in a house, of which 63.4% needed minor (31.7%) or medium (31.7%) repairs. More than two thirds of the buildings had no access for people with reduced mobility (73.3%). They all had a toilet and bath or shower facilities, 98.3% had running water, and 55% had heating.

Considering the DP's description, more than half (60%) were pensioners/retired and female. The mean age was 81.88 ± 11.77 years, ranging from 48 to 100 years. Half of the DPs were widowed and at least 85 years old. The majority (51.7%) had a primary school education level, and 36.7% were illiterate. Among the reasons for dependence, 73.3% were due to "aging" and 68.3% to "chronic illnesses." When asked about the onset of dependence, 78.3% considered it was gradual, with the mean time of dependence being 6.18 ± 4 years. In the analysis of the self-care domains, Bathing (63.3%) and Taking medication (56.7%) were those in which the DP did not participate. On the other hand, the self-care domain Turning showed more independence (48.3%). The self-care domains in which the DP needed more assistance were Feeding (80%), followed by Walking (58.3%), Grooming (58.3%) and Dressing or undressing (55%). The need for devices/equipment was most reported in the self-care domain Wheelchair use (13.3%), followed by Transfer (6.7%; Table 1). Overall, 15% of the DPs were non-participants in self-care, and 85% needed someone's assistance.

Table 1*Number and Percentage Distribution of the Degree of Dependence by Self-Care Domain*

Self-care domains	Non-participant dependent <i>n</i> (%)	Needing someone's assistance <i>n</i> (%)	Needing devices/equipment <i>n</i> (%)	Completely independent <i>n</i> (%)
Bathing	38 (63.3)	21 (35.0)	- (0.0)	1 (1.7)
Dressing or undressing	24 (40.0)	33 (55.0)	1 (1.7)	2 (3.3)
Grooming	25 (41.7)	35 (58.3)	- (0.0)	- (0.0)
Feeding	12 (20.0)	48 (80.0)	- (0.0)	- (0.0)
Use of toilet	20 (33.3)	37 (61.7)	- (0.0)	3 (5.0)
Standing	18 (30.0)	26 (43.3)	3 (5.0)	13 (21.7)
Turning	12 (20.0)	16 (26.7)	3 (5.0)	29 (48.3)
Transferring	15 (25.0)	27 (45.0)	4 (6.7)	14 (23.3)
Wheelchair use	29 (48.3)	16 (26.7)	8 (13.3)	7 (11.7)
Walking	20 (33.3)	35 (58.3)	2 (3.3)	3 (5.0)
Taking medication	34 (56.7)	19 (31.7)	- (0.0)	7 (11.7)

Note. *n* = Number % = Percentage.

Concerning the FC's description, most were married women (wives and daughters) (86.7%), aged 65 or older (53.3%), with primary education levels (46.7%), that lived with the DP. Only 11.7% of the participants were relatives-in-law (daughter-in-law, stepfather, brother-in-law, or other similar), and an equal percentage corresponded to father/mother and brother/sister. Half of the FCs were pensioners, 13.3% were homemakers, and 13.3% were unemployed.

None of the FCs interviewed considered themselves incompetent in the various self-care domains. However, the self-care domains in which the FCs perceived themselves as less competent were Walking and Taking medication, both with 5%, followed by Turning and Use of toilet, both with 3.3% and, finally, Bathing, Dressing or undressing, Feeding and Transferring, with 1.7%.

Regarding daily care, Feeding (4.3%) and Hydrating (2.77%) were the most frequent care activities provided. The least frequent were: "examining bony prominence areas" (0.82%), "massaging skin and bony prominences" (0.77%), "teeth brushing" (0.63%), "exercising lower limbs" (0.05%) and "exercising upper limbs" (0.05%). Considering the care provided weekly, the most regu-

lar care activities were "applying moisturizing creams" (2.58%), "bathing" (2.57%), and "hair washing" (2.48%). On the other hand, "cognitive stimulation" was the least frequent (0.03%).

Concerning the use of devices/equipment, the most reported were in the self-care domains "taking medication" (100%), "walking" (74.5%), and "use of toilet" (54.7%), and the less used were in the domains "dressing or undressing" (4.6%), "grooming" (7.7%), and "wheelchair use" (8.7%). As for other resources, all participants indicated they could resort to the Health Center/Family Health Unit. Moreover, the study observed that all participants resorted to the physician and that 71.7% had access to nursing care. Within the scope of non-professional resources, 96.7% of the FCs had the support of a family member.

Regarding overall health status (where higher scores correspond to worse health status), a mean of 2.17 points was observed, with 61.7% of the scores between 1 and 2 points (Table 2). The DP's health conditions that FCs most reported were signs of joint stiffness (83.3%), changes in mental status (56.7%), signs of compromised skin integrity (21.7%), and falls (21.7%).

Table 2*Health Status Assessment*

Health Status	<i>n</i>	%
Presenting apparent signs of:		
dehydration	1	1.7
malnutrition	2	3.3
joint stiffness	50	83.3
compromised skin integrity	13	21.7
respiratory compromise	11	18.3
poor hygiene and cleanliness	5	8.3
poor clothing conditions	1	1.7
falls (last month)	13	21.7
changes in mental status	34	56.7
Overall health status		
0	1	1.7
1 – 2	37	61.7
3 – 4	19	31.7
5	3	5.0
<i>M</i> = 2.17 <i>SD</i> = 1.2		

Note. *M* = Mean; *SD* = Standard deviation.

Discussion

This study characterized the DP's needs and the FC's care provision. It observed that the studied families with members dependent in self-care were composed of one or two nuclei, with monthly incomes between 501 and 1000€. Other studies conducted in urban areas, specifically in the Portuguese districts of Lisbon and Porto, found that most families were considered standard without a nucleus or with one nucleus and a monthly family income below 500€/month (Costa, 2013; Gonçalves, 2015). The fact that these studies were conducted in urban settings, unlike this study, which occurred in rural settings, may account for the differences found.

The FC's profile constructed in this study aligns with that described in the literature (Bento et al., 2021; Dexi & Querido, 2020; Machado et al., 2020; Nicolau, 2018), as the FC was predominantly female, with low education levels, married or in *a de facto* union. These data show that most FCs are wives, confirming the feminization associated with informal caregiving (Amaral et al., 2021). Also, more than half (53.3%) were older adults, underlining the phenomenon of "older people taking care of older people" reported in the literature (Amaral et al., 2021; Nicolau, 2018; Santos-Orlandi et al., 2017). Increasing age limits the FC's functional abilities. Thus, older FCs are expected to have greater difficulty performing their role. Also, there is a significant association between "frailty" and the variables "gender" and "age," with a higher prevalence in older women with less education, as well as greater vulnerability to psychological and physical illnesses and emotional and financial problems (Santos-Orlandi et al., 2017). In this sense, FCs in this study may be at an increased burden risk as most are older women. Furthermore, these FCs have low education levels, which may suggest difficulties understanding the DP's entire disease

process and providing care. This causes the FC to suffer greater emotional tension and stress (Nicolau, 2018; Santos-Orlandi et al., 2017). Thus, the FC's profile may highlight a type of caregiver more vulnerable to adverse events arising from caregiving.

This study also observed that most DPs are widowed women of advanced age, similar to that reported in other studies (Costa, 2013; Dixe et al., 2019; Gonçalves, 2015; Machado et al., 2020). These data may be explained by the fact that older age is a risk factor for dependence.

As mentioned in the literature, this study found that many DPs do not participate in self-care activities that require greater fine and gross motor skills, greater manual dexterity, muscle strength, body balance, and movement coordination, such as the activities Dressing or undressing, Walking, Use of toilet, Transferring and Standing (Machado et al., 2020). Also, more than half of the DPs studied did not participate in their medication regime management. This may be because this activity implies a specific set of psychomotor and cognitive skills (Costa, 2013; Dixe et al., 2019; Gonçalves, 2015). In this study, "turning" was the self-care domain in which less assistance was required, which may indicate that most DPs were not bedridden, thus reducing the number of potential complications, such as the risk of pressure injuries. Future studies should analyze this self-care domain in detail because if, on the one hand, the DP may not be bedridden, on the other hand, the FC may need less assistance due to lacking adequate information on this self-care domain, specifically regarding its technique and frequency (Costa, 2013; Gonçalves, 2015; Machado, 2020).

This study's FCs considered themselves very competent in the various self-care domains, particularly those related to activities of daily living, which may be reflected in the health assessment, in which dehydration, malnutrition, and lack of clothing were the least mentioned regarding

the person dependent in self-care. However, it was evident that the care domains in which the FC feels less competent (turning, transferring, and mobilizing) are carried out less often (Petronilho, 2015). Although signs of altered mental status were identified in more than half of the DPs, the performance of memory-stimulating activities was practically null. These results may be associated with the FCs' low education levels, lack of knowledge about cognitive stimulation, and difficulties performing these activities, particularly older FCs. Also, FCs may prioritize other areas, such as hygiene and feeding, because they are unaware of the importance of stimulation or how to integrate it into other self-care activities (Silva et al., 2021). Moreover, as these self-care activities have greater complexity, FCs may not feel competent to perform them and require specialized professional help (Petronilho, 2015; Silva et al., 2021). This study's findings also strengthen the significance of health professionals' monitoring, specifically FNs. Due to the restrictions imposed by the COVID-19 pandemic, FNs were less available to monitor families with DPs through home visits. Furthermore, although FCs consider themselves competent, their daily confrontation with their family member's physical and psychological decline and the lack of social and economic support may contribute to their physical, emotional, and social burden as well as that of the families (Dixe et al., 2019).

The most commonly used equipment to perform the DP's different self-care activities were in the self-care domains of "taking medication" and "walking." The DP's loss of cognitive and motor skills and the complexity of many medication regimes may promote the use of support devices/equipment (Costa, 2013; Gonçalves, 2015) commonly used by this population. On the other hand, support devices/equipment were least used in the domains of "standing," "dressing or undressing," "grooming," and "wheelchair use." These results may be explained due to the vast range of equipment/devices existing in these domains, the costs associated with their acquisition, and the FC's and/or older adult's lack of knowledge and/or training on them (Costa, 2013; Gonçalves, 2015; Petronilho, 2015). These data underscore Gonçalves's (2015) idea that care activities that demand more differentiated skills from FCs are not adequately addressed, thus falling short of what is needed.

Considering the use of health services, the most used were Health Care Centers/Family Health Units (100%), followed by the Portuguese National Health Service 24-hour health line (78.3%) and hospitals (70%). These results suggest the significance of the geographical proximity of healthcare, particularly in rural settings, in which Health Care Centers are the most accessible resource for caregivers and/or DPs, as opposed to urban settings, in which Hospitals are the most used resource (Costa, 2013; Gonçalves, 2015). Also, these results may reflect the period in which the study took place (during the COVID-19 pandemic), in which the indications and guidelines of the Portuguese Directorate-General of Health were for people first to call the 24-hour health line or use the

Health Care Centers. The physician and the nurse were the most reported professional resources, which may reflect the FC's demands for health care based on the DP's needs. On the other hand, the most often used non-professional resources were other family members, as reported by Sequeira (2018), according to whom family represents one of the main supports in care delivery to DPs. Similarly to that observed by Stojak et al. (2019), a positive relationship was evidenced between long-term nursing care at home and the situation of informal caregivers of dependent older adults at home. FCs with long-term nursing care at home experienced less stress, more support, and greater satisfaction in their caregiving role than FCs who did not receive such support. The same study concluded that long-term nursing home visits could facilitate and improve the care delivered to DPs and help FCs to provide better care while improving their situation. Therefore, it is essential to identify users' health needs and develop practices that allow for research, guidance, and intervention in situations identified in home settings (Nicolau, 2018; Stojak et al., 2019).

This study has some limitations. The first is related to the geographical area where the study was conducted (a parish in the central region of Portugal) that hindered the generalization of the results. Second, the form was not administered to all families as initially planned to avoid contacting a large number of people and putting the families' health at risk. Thus, this study opted for a snowball sampling technique, which does not allow for identifying the exact number of families with members dependent in self-care. And third, despite providing detailed information, the form needed a mean of 60 minutes to be administered, and this amount of time restricted the entire data collection process.

Conclusion

This study observed that most DPs are older women that have a gradual onset of dependence and present a higher degree of dependence in the self-care domains "bathing," "medication regime self-management," "feeding," "walking," "grooming," and "dressing or undressing." The FCs are mostly married women with low education levels who live with the DP. Of these, more than half are older adults (65 or older), and the health center is the primary resource used. FCs prioritize the care provided to satisfy the activities of daily living and undervalue the care activities aimed at preventing functional decline and the consequences of dependence, such as the loss of independence in self-care. FCs need support through educational interventions and assistance in more complex care areas, such as mobility and cognitive stimulation. FNs should direct care delivery to teach and help FCs in motor rehabilitation and memory stimulation activities. This way, FNs' interventions will become more effective, promote access to existing care resources, and optimize favorable health outcomes for FCs and DPs, specifically through Primary Health Care home visits.

Authors contributions

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