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RESEARCH

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PROFILE OF CAREGIVERS OF DEPENDENT ELDERLY IN A PANDEMIC CONTEXT: IMPACTS ON THE HEALTH AND WORK OF CAREGIVERS IN PORTUGAL

Perfil de cuidadores de idosos dependentes em contexto de pandemia: impactos na saúde e no trabalho de quem cuida em portugal

Perfil de los cuidadores de personas mayores dependientes en un contexto de pandemia: impactos en la salud y el trabajo de los cuidadores en portugal

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ABSTRACT

Objective: to know the profile of formal and informal caregivers of the elderly with functional dependence in Portugal. **Method:** online survey conducted in June-November 2021 by the National School of Public Health-NOVA of Lisbon. The questionnaire was published on social networks and in institutions that work in the care of dependent elderly. Protocol approved by the Ethics Committee of the School. **Results:** females prevailed (91.4% formal and 88% informal caregivers). Higher education level predominated in both categories. Formal caregivers were in a younger age group than family caregivers. 51% of formal caregivers and 63.7% of informal caregivers reported suffering from a chronic back problem. Feelings of isolation, sadness and depression predominated among formal and informal caregivers. **Conclusion:** caring work is predominantly female and the Covid 19 pandemic has had important impacts on the health of caregivers, especially mental health.

DESCRIPTORS: Elderly caregivers; COVID 19 pandemic; Portugal.

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RESUMO

Objetivo: conhecer o perfil dos cuidadores formais e informais de idosos com dependência funcional em Portugal. **Método:** inquérito online realizado em junho-novembro 2021 pela Escola Nacional de Saúde Pública-NOVA de Lisboa. O questionário foi divulgado em redes sociais e em instituições que atuam nos cuidados a idosos dependentes. Protocolo aprovado pela Comissão de Ética da ENSP. **Resultados:** o sexo feminino prevaleceu (91,4% cuidadoras formais e 88% informais). Predominou o nível superior de escolaridade em ambas as categorias. Os cuidadores formais situavam-se numa faixa etária mais jovem que os cuidadores familiares. 51% dos cuidadores formais e 63,7% dos cuidadores informais relataram sofrer algum problema crônico de coluna. Os sentimentos de isolamento, tristeza e depressão predominaram entre os cuidadores formais e informais. **Conclusão:** o trabalho de cuidar é predominantemente feminino e a pandemia de Covid 19 trouxe impactos importantes para a saúde dos cuidadores, em especial para a saúde mental.

DESCRITORES: Cuidadores de idosos; Pandemia COVID 19; Portugal.

RESUMEN

Objetivo: conocer el perfil de los cuidadores formales e informales de ancianos con dependencia funcional en Portugal. **Método:** encuesta online realizada en junio-noviembre de 2021 por la Escuela Nacional de Salud Pública-NOVA de Lisboa. El cuestionario fue difundido en redes sociales y en instituciones que trabajan en el cuidado de ancianos dependientes. Protocolo aprobado por el Comité de Ética de la Escuela. **Resultados:** predominó el sexo femenino (91,4% cuidadoras formales y 88% informales). El nivel de educación superior predominó en ambas categorías. Los cuidadores formales estaban en un grupo de edad más joven que los cuidadores familiares. El 51% de los cuidadores formales y el 63,7% de los cuidadores informales reportaron padecer un problema crónico de espalda. Los sentimientos de aislamiento, tristeza y depresión predominaron entre los cuidadores formales e informales. **Conclusión:** el trabajo de cuidado es predominantemente femenino y la pandemia de Covid 19 ha tenido impactos importantes en la salud de los cuidadores, especialmente en la salud mental.

DESCRIPTORES: Cuidadores de personas mayores; Pandemia de COVID-19; Portugal.

INTRODUCTION

Population ageing in Europe and, in particular, in Portugal, is a reality that is imposing deep reflections on the directions of public policies, so that this portion of the population can enjoy quality of life in their old age.

The association between greater longevity of the population and the occurrence of multiple chronic diseases and functional disability is well grounded in scientific evidence. ¹⁻³ Such association translates into an increase in the contingent of elderly people who require care and/or support to perform their daily activities, usually at home, with the support of informal caregivers, family or not.

Since the beginning of the state of emergency in Portugal on March 18, 2020, throughout the year 2020 and until mid-2021, hygiene and social contact restriction measures have been adopted to control the spread of the contagion. With the start of vaccination of the population in December 2020, some of these measures were progressively adapted depending on the increased vaccination coverage of the population.

However, the social isolation/removal measures taken during the peak periods of the pandemic, if on the one hand, proved effective in mitigating the spread of the disease, on the other hand, brought harmful consequences for physical and mental health, especially for the population at older ages. ⁴⁻⁷ The decrease or even absence of contacts that previously represented an essential social support for the life of a considerable number of elderly people (such as neighbors, friends, or social and health

services), further contributed to the feeling of loneliness and social isolation.8

In this context, formal and informal/family caregivers have been a key resource for the health of a significant portion of care-dependent elderly individuals.

Formal caregiver is the person who provides care under contract in institutions (hospitals, geriatric clinics, group homes, shelters, day centers, etc.) or at home, when hired by the user or the family itself. Thus, the formal character is expressed by subordination to economic and legal regulations proper of the market. For the purposes of this study, we distinguish the higher level professionals who work in the health and social assistance sectors from those who have basic or secondary schooling and who perform caregiver activities for remuneration.

From the perspective of the training processes, according to the National Qualifications Catalogue,³ the following professional categories fit into these levels: geriatric agent, family and community support assistant, family and community support technician, and geriatric technician. However, some professional careers existing in the labor market may have similar attributions to the professionals trained in the areas described above. Examples are the categories of Direct Action Auxiliary, General Services Assistant, and Home Helpers.³ It is noteworthy that the tasks performed by formal caregivers are little differentiated and cumulative among the different professional categories.⁴ Besides the help in basic activities of daily living such as personal hygiene, getting out of bed, and helping with feeding, these professionals also assume, in many situations, other tasks such as health mo-

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nitoring, participation in the implementation of care plans, and in the maintenance of health records.⁵

The informal/family caregiver, in turn, is defined as any person who has a parental or close relationship (friend or neighbor) and provides unpaid care to a person with functional dependence. 1,6 Informal/family caregivers in Portugal were only recognized in a law establishing the Caregiver Statute in the year 2019,7 after more than two decades of organizing specific social movements.8 In this law, informal caregivers are recognized as "the spouse or unmarried partner, relative or kin up to the 4th degree of the direct or collateral line of the person being cared for, who accompanies and cares for the person being cared for on a permanent basis, who lives with the person in a communal dwelling, and who does not earn any remuneration for their professional activity or for the care they provide to the person being cared for. ⁷ They can be identified as primary caregiver – the one who accompanies and cares for the person being cared for on a permanent basis and lives under the same roof as the person being cared for, or as non-primary caregiver - the one who accompanies and cares for the person being cared for on a regular but non-permanent basis, and may or may not receive remuneration from a professional activity or for the care they provide to the person being cared for.⁷

The present study aimed to know the profile of formal and informal caregivers of the elderly with functional dependence in Portugal, their needs and demands aggravated by the pandemic and impacts on their work process.

MATERIAL AND METHODS

This is a survey study, with the application of an online questionnaire, originally designed and applied by the team of researchers of the Oswaldo Cruz Foundation in Brazil.

The sample was of the random and snowball type. The questionnaire link was sent to 73 hospital units, 51 health center groupings, 2874 parish councils, 2243 residential structures for the elderly, 56 patient or elderly-related associations, 360 long-term care units. These institutions, in addition to the link, were provided with information about the research objectives and asked for wide dissemination.

The data collection instrument (questionnaire) was composed by closed questions that sought to evaluate the following dimensions: a) sociodemographic; b) profile of insertion in the caregiver activity; c) characteristics of the work developed in the daily pandemic; and d) health conditions.

After formalizing a joint work plan with the Brazilian team, the original questionnaire was submitted to cultural adaptation; conceptual equivalence assessment and reading by researchers with experience in surveys; translation of the concepts from Brazilian Portuguese; semantic equivalence assessment; pre-testing to 5 formal and 5 informal caregivers to assure the instrument's adequacy to the sample in order to verify the understanding and interpretation of the questions, objectivity and clarity. Only after the necessary adjustments were made, the questionnaire was

made available via link during the period from June 30, 2021 to November 30, 2021.

The research protocol was approved by the Ethics Committee of the National School of Public Health-NOVA of Lisbon (ref. CE/ENSP/CREE/1/2021), on May 20, 2021.

RESULTS

During the period in which the questionnaire was available, 873 responses were counted. Of this number of respondents, 6 did not agree to participate. Of the remaining 867 questionnaires, it was found that 93 respondents, despite having agreed to participate, did not answer any of the other questions, with 774 responses at this initial stage of analysis. Of these 774 initial responses, 618 responses were validated for analysis. The invalidated answers were those whose respondent did not agree to participate and those that were only about the characterization of the respondent, leaving most of the questions blank.

First, we sought to know the insertion profile in the caregiving activity of the respondents before the pandemic onset, in the following categories: a) did not work as caregivers; b) worked as paid caregivers and; c) worked as unpaid caregivers.

The analysis of the data referring to paid caregivers (382 individuals) took into account the respondents who a) did not act as caregivers before the pandemic and moved to the paid caregiver category (43 responses); b) maintained their paid caregiver status (329 responses) and; c) those who provided unpaid care before the pandemic and moved to the paid status (10 responses).

Regarding the data on unpaid caregivers (236 individuals), we considered the respondents who: a) were not caregivers before the pandemic and became unpaid (43); b) maintained their situation of unpaid (190) and; c) stopped being paid caregivers and became unpaid during the pandemic (3).

Regarding the sociodemographic profile, it was observed the predominance of females, both among the informal caregivers (88%) and among the formal caregivers (91.4%). The higher education level prevailed in both work situations with a percentage above 60% (63.68% of the informal caregivers and 61.3% of the formal caregivers). Analyzing the mean household income, it can be observed that the income of 44.31% of the informal caregivers was concentrated in the range of 1,500.00 to over 2,000.00€ while almost half of the formal caregivers (49.1%) had an average income a little below this range, from 651.00 to 1,500.00€.

Regarding the age bracket, 64.1% of the formal caregivers were under 45 years old. Among the informal caregivers, in turn, 62.8% of the respondents were in the age bracket above 46 years old.

Portuguese nationality predominated among both the informal (97.4%) and the formal (94.2%).

Regarding the caregivers' residence status, it is observed that there was a greater concentration of responses, in both situations, in the region of Lisbon and Tagus Valley (informal -47.4%; formal -43.9%).

The time of work as a caregiver was higher among the formal caregivers, 81.7% said they had more than 3 years of service. In the informal caregivers this percentage was 53.1% (Table 1).

The activities performed in the act of caring are common to both informal and formal caregivers and concern the management of personal hygiene and medication, entertainment, and assistance with feeding (Table 2).

When asked to make a self-assessment of their health, among the informal caregivers there was a predominance of "moderate" self-assessment (57.2%), while among the formal caregivers there was a predominance of "good" (48.1%) (Table 3).

When asked if they had any back problems, chronic back or neck pain, low back pain, sciatica, vertebral or disc problems or other, most of the informal caregivers (63.7%) and formal caregivers (51%) said yes.

Those who answered "yes" regarding the presence of some back problem were asked if the pain reported was affected by changes in usual activities. The categories "increased a lot" and "increased a little" were noted by 64.2% of the informal caregivers and by 62.8% of the formal caregivers.

When asked if they suffer from any illnesses, both informal and formal caregivers checked "none of the options" with the highest percentage (43.6% and 62.9% respectively). However, it is noteworthy that it is among the informal caregivers that the highest percentages for depression and hypertension are shown (31% and 29%, respectively).

Caregivers were asked how often they felt isolated from family members or close friends during the pandemic. Both informal and formal caregivers had a predominance of the "often" response, 57.2% and 52.0% respectively (Table 4).

Table 1 – Caregivers profile by time of work in the occupation

Time	Informal Caregivers		Formal Caregivers	
	N°	%	N°	%
Less than 3 months	5	2,8	8	2,6
3 to 6 months	8	4,5	5	1,6
7 to 12 months	22	12,4	5	1,6
1 to 3 years	48	27,1	38	12,4
More than 3 years	94	53,1	250	81,7
Total respondents	177	100,0	306	100,0
I prefer not to answer	8		3	
Did not answer	50		72	
TOTAL	412		381	

Table 2 - Caregivers' profile according to the activities performed

	Ca	Caregivers	
	Informal	Formal	
Activities	N°	N°	
Bath time assistance	108	159	
Food aid	102	176	
Tours	85	93	
Medication management and/or administration	126	158	
Food preparation	105	86	
Cleaning of the home or institution	94	83	
Washing and/or ironing clothes	88	52	
Purchase of food or other products	130	51	
Conversation/Entertainment/Games	114	129	
Other (do not specify)	68	150	

Table 3 - Caregivers profile by health self-assessment

	Informa	Informal Caregivers		Caregivers
Health status	N°	%	N°	%
Excellent	8	4,8	28	9,8
Good	51	30,7	138	48,1
Moderate	95	57,2	103	35,9
Bad/Bad	12	7,2	10	3,5
I prefer not to answer	0	0,0	8	2,8
TOTAL	166	100,0	287	100,0

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The feeling of sadness was often perceived by both informal (56.9%) and formal (56.2%) caregivers. It is worth noting that social distancing measures were still in effect during this period.

Profile of Formal Caregivers

The formal caregivers with complete higher education level were asked about their area of training, and the areas of social service, nursing, pedagogy/teaching, psychology and other were listed for answers, besides the option "do not want to answer". The areas of social work (36.7%), nursing (24.5%), psychology (8.4), and other (26.6%) were the most predominant.

As for the type of employment relationship they had as caregivers, the vast majority, 237 people (62%) were employed, followed by 16 self-employed answers, nine sole proprietorships, five were employed as domestic workers, 46 chose the item "other" without specifying, and four chose not to answer. It is worth noting that only 65 people did not answer this question. Regarding the salary range received as a caregiver, 39% were in the 651-1,000 euro range. It is noted that 73 people did not answer this question (Table 5).

In the question about who is the contractor of these caregivers, 85.5% of the respondents said that it was an institution, agency or company that was responsible for the contract. The category "civil servant" accounted for 6.5% of the contracts. The "elderly person cared for" and the "family of the elderly person cared for" accounted for 2.9% and 2.6% of the contracts, respectively. Note that 72 people chose not to answer this question.

Regarding the average number of days of the week worked, 68.1% of the respondents answered that they worked in care from 3 to 6 days a week.

On a typical day of work as a caregiver, just over half of the respondents (50.8%) said they worked an average of 7 to 8 hours per day.

Regarding the number of different locations they provided care, 78.3% of the respondents said they worked in only one location.

Profile of Informal Caregivers

When asked who provides the care, the majority of respondents, out of 185 (73.2%) stated that care was provided to a family member or relative. With regard to responsibility for care, 73 respondents (31.1%) stated that they were the sole caregiver and another 74 (31.5%) noted that they share this care with a relative, neighbor or friend. The help of a hired caregiver was pointed out by 27 respondents (11.5%).

DISCUSSION

The results found in the research confirm that the activity of caring, in both the institutional/formal and family/informal dimensions, is essentially female ^{5,9-12} In the family sphere, women have historically been focused on domestic activities and the care of their children, and in this context, the woman assuming the role of caregiver would be a defining characteristic of her identity and work.¹³

The predominance of higher education among informal caregivers was found in another study. However, attention is drawn to the fact that, in our study, this predominance was also present among formal caregivers. The initial objective of the investigation was to characterize, in this specific item of the questionnaire, the basic and secondary level professional categories. However, no filter was instituted for the exclusion of higher level formal caregivers in the data collection instrument. Thus, it is verified that more than 60% of the respondents in this category have completed higher education, with a predominance of training in social work (36.7%) and in nursing (24.5%). The questionnaire

Table 4 – Profile of caregivers by the frequency with which they felt isolated from family members or close friends during the pandemic

	Inform	al Caregivers	Forma	al Caregivers
Frequency	N°	%	N°	%
Never	8	4,8	22	8,2
Infrequently	51	30,7	56	20,8
Often	95	57,2	140	52,0
Always	12	7,2	51	19,0
TOTAL	166	100,0	269	100,0

Table 5 - Profile of Formal Caregivers by Salary Range (Monthly in Euros)

Salary Range (€)	N°	%
Less than 650	62	16,2
Between 651 and 1000	149	39,0
Between 1001 and 1500	68	17,8
Between 1501 and 2000	16	4,2
More than 2000	4	1,0
l don't know	1	0,3
I prefer not to answer	9	2,4
Did not answer	73	19,1
TOTAL	382	100,0

does not allow us to reach a definitive explanation, but only to raise some hypotheses that could justify the predominance of the college level category among formal caregivers. The first hypothesis is the bias derived from the people from the institutions who were asked to disclose the questionnaire. A second possibility regarding more specifically the higher percentage found in the category of social service professionals is that they, despite having a degree, are exercising the role of caregiver. We can also add the fact that the questionnaire was applied in the middle of the pandemic that caused, among the health professional categories, absence from work due to the SarsCov2 virus contagion. In this situation, other professionals ended up taking over the tasks necessary for the well-being of the elderly people in the institutions.

It is also noteworthy that more than 80% of the formal caregivers stated that it was an institution, agency, or company that was responsible for their contract, with most having a work schedule of up to 9 hours and acting in only one workplace.

However, when we analyze the salary range among the formal caregivers, it is observed that 55.2% claimed to receive salaries up to 1000€. According to a study on the workers in long-term care facilities, these usually receive wages well below those practiced in hospital care, ¹⁵ and there is a significant part that works with temporary contracts ¹⁵ and for having training above the required for the position. ¹¹ Among the informal caregivers, in turn, 73.2% claimed to provide care to a family member or relative, a fact also aligned with other studies. ¹⁶⁻¹⁷

The age range of most formal caregivers is younger (below 45 years) when compared to the informal caregivers, which is coherent with similar studies. 12,18

There was a majority participation of Portuguese respondents for both formal and informal caregivers. Among the formal caregivers, given the extensive and little valued nature of the work in long-term care institutions⁷ and also the strong gender bias, it would be expected to have a more significant presence of other nationalities, especially those that in recent years have had a substantive growth such as the Brazilian nationality which, in 2020, represented 27.8% of the total foreign community in Portugal.¹⁹

There was greater participation of caregivers, both informal and formal, in the Lisbon and Tagus Valley, Center, and North regions. Perhaps because these regions have greater access to the internet network and digital literacy, we have more representation in these three regions. It was expected that the Alentejo and Center regions would have a higher representation of respondents than the one presented in this research, as these two regions are the oldest in the continent.²⁰

It has been verified that the activities of caring for a person with functional dependence imply certain movements and postures in the aid to perform some activities of daily living, which can cause chronic pain, especially in the spinal region. These situations tend to worsen when the caregiver is female and older. The findings regarding the formal and informal caregivers' reference to the presence of spinal pain are consistent with those found in other studies in this area. 21-23

It was evidenced in this study that the pandemic of COVID 19 may have contributed to the worsening of caregivers' mental health, especially the feelings of sadness and depression that affected more than half of the informal and formal respondents in our survey. It is noteworthy, however, that depression could have been present even before the pandemic. ²⁴⁻²⁵ However, other studies of the kind support the thesis that the pandemic had a negative impact on the mental health of formal and informal caregivers. ²⁶⁻²⁸

CONCLUSION

The present study aimed to analyze the sociodemographic profile of formal and informal caregivers and assess the impact of the Covid 19 pandemic on their work and health.

The caregiving activity is predominantly female with strong components of wage devaluation and social invisibility. Family caregivers had worse self-rated health compared to formal caregivers. The pandemic had relevance for the musculoskeletal health of caregivers in their care work and in helping with activities of daily living.

Equally important impact was observed on caregivers' mental health in the pandemic period, especially feelings of sadness, isolation, and depression.

Follow-up measures for caregivers' health should be taken in order to mitigate the post-pandemic effects and to provide more institutional support to the care provided by this important social segment.

The results of this study can subsidize the social movements that fight for the valorization of women's work in the act of caring, given the relevance that these women caregivers assumed during the most dramatic period of the pandemic for the elderly people they care for.

LIMITATIONS

Despite the wide dissemination by the partner institutions and organizations, there was low participation of both formal and informal caregivers. Some factors may have contributed to this situation: a) there were no face-to-face contacts for the dissemination of the research; b) the data of the institutions providing services to the elderly population available in the Social Charter may not be updated; c) difficulty in accessing informal caregivers; d) greater participation of those people with better digital literacy.

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