

## DIFFICULTIES OF THE INFORMAL CAREGIVER IN THE CONTEXT OF HOME HOSPITALIZATION IN PORTUGAL

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**Abstract:** In Portugal, there has been an increase in the number of informal caregivers (ICs), whose importance has grown in the partnership of nursing care in the context of home hospitalization (HD). For this reason, a study was carried out with the following objectives: to characterize the sociodemographic profile of the ICs of people hospitalized in HD; to identify the ICs' difficulties; and to implement improvement strategies. This study was carried out in two stages: The first involved a descriptive study for situational diagnosis and the second the creation and implementation of a leaflet aimed at socio-financial support needs. A questionnaire was administered with sociodemographic data and the Index for assessing caregiver difficulties. Data was analyzed using SPSS® and ethical standards were met. 10 IC participated (7 female), with an average age of  $62.60 \pm 17.64$  [32;82] years. Of these, 60% had not been to school or had only completed the 1st cycle of schooling. 50% were unemployed/retired and 40% earned less than the national minimum wage. The main technical difficulty was handling the infusion pumps/syringes. But it was in the socio-financial context that the greatest difficulties were identified. From this study, it emerges that IC of people admitted to HD need support to mitigate their needs, requiring a multidisciplinary approach.

**Keywords:** Caregiver, home care services, nursing, person-centered care.

## INTRODUCTION

Sociodemographic changes in recent years have contributed to the growing number of people who are dependent on others (Instituto Nacional de Estatística [INE], 2020; PORDATA, 2021). Associated with this phenomenon, there has also been an attempt to respect the wishes of DPs to remain in their own homes for as long as possible, and to try to

reduce periods of hospitalization in healthcare institutions. It is known that by ensuring that the DP remains at home, it is possible to reduce healthcare costs and hospital infection rates, thus increasing the DP's quality of life and well-being. However, in order to ensure that the PD remains at home, for example through Home Hospitalization (HD), it is essential to have informal caregivers (IC) to ensure continuity of care, which would otherwise have to be provided in care settings and units.

Caring is inherent to the human condition and the role of the family, which is a source of emotional, physical and financial support (Schulz et al., 2020). However, caring for a PD at home is challenging for ICs who experience significant changes to their daily routine, impairing its quality and imposing high levels of physical, emotional and economic burden (Carvalho et al., 2023). In addition to these challenges, the unpreparedness to provide healthcare (Sousa et al., 2022), the lack of support and information, the failure to appropriate facilitating strategies and mechanisms (physical; technical; financial and time management), further aggravate their difficulties in caring for PD. This is because ICs find it difficult to reconcile their time caring for their family member with other personal and professional demands (Matos, 2019; Sousa et al., 2022).

Given these facts, the guiding objectives of this study were: to characterize the sociodemographic profile of the ICs of people admitted to the HD unit of a healthcare institution in the Central region of Portugal; to identify the ICs' main difficulties and to implement strategies for improvement.

## MATERIALS AND METHODS

### TYPE OF STUDY

A two-part study was carried out in an HD unit of a public hospital in the central region of Portugal.

The HD nursing team consisted of four *full-time* and five *part-time* nurses. Home visits were made from Monday to Friday by the multidisciplinary team (nurses and doctors) to all the PDs who were being monitored in the HD. At the weekend, the visits continued to be carried out only by the nursing team. The HD unit provided a telephone contact for IC support 24 hours a day, and the internal medicine doctor on duty that day was responsible for responding to this need.

The first stage of the study took place during the months of March-May 2023, when diagnostic data was collected. The second phase of the study took place between June and December 2023 and involved the creation and provision of an information leaflet for ICs. In addition, teaching and training were also carried out in relation to the difficulties perceived by ICs in terms of the technical dimension of care.

Data collection and the implementation of these strategies were carried out by the care nurses, in a home environment, without the presence of the DP.

### DATA COLLECTION INSTRUMENT

A questionnaire was administered at time 1, constructed by the researchers with data on the sociodemographic characterization of the IC and the care context, consisting of 18 questions (17 closed and 1 open). The following data was collected: gender (female/male); age (years); marital status (single/married/marital partnership); educational qualifications (able to read and write, but without attending formal education/ 1st cycle of basic education/ 2nd cycle of basic

education/ 3rd cycle of basic education/ secondary education).secondary education); employment status (employed / unemployed / retired without incapacity for work); monthly income (less than the national minimum wage / between 1 and 2 national minimum wages / between 2 and 3 national minimum wages / more than three national minimum wages); degree of kinship with the person being cared for (mother or father/spouse or partner/child/sister); living with the DP (yes/no); existence of secondary caregiver(s) in caring for the DP (yes/no); existence of other DPs under the responsibility of the IC (yes/no); existence of support from third parties in the act of caring (yes/no); ease of obtaining help from others (yes/no); lack of support from others in the IC's situation (yes/no); time spent caring for the DP in months; average daily hours spent caring; existence of financial support from the Portuguese state (yes/no); technical difficulties experienced (handling infusion pumps/syringes/ intravenous feeding/ nasogastric tube feeding/ bladder catheter care/ peripheral catheter care/ and others) and an open question about the difficulties experienced by the IC in providing care.

The questionnaire also asked people to fill in the Caregiver Difficulties Assessment Index (CADI), adapted and validated for the Portuguese population by Guimarães et al. (2020). This index consists of thirty statements made by caregivers regarding the difficulties they face (Brito, 2000). The CADI includes 30 items representing potential difficulties, subdivided into seven factors: problems related to the person being cared for (items 5, 11, 12, 14, 22, 25 and 26); restrictions on social life (items 8, 18 and 20); physical demands of providing care (items 6, 10, 13, 15, 23 and 24); reactions to providing care (items 1, 2, 3, 9, 17, 19, 29 and 30); lack of family support (items 16 and 28); lack of professional support (items 7 and 27); and financial problems (items 4 and

21). For each item on the scale, the IC has four response options: it doesn't happen in my case (0); it happens, but it doesn't disturb me (1); it happens and it causes me some disturbance (2); it happens and it disturbs me a lot (3).

## SAMPLE

The study sample was non-probabilistic for convenience and consisted of the ICs of the PDs admitted to the HD unit during the period in which the data was collected.

## STATISTICAL TREATMENT

The data was analyzed using the *Statistical Package for the Social Sciences* version 26 (SPSS®). A descriptive analysis of the data was carried out using absolute (n) and relative (%) frequencies, measures of location (minimum (min) and maximum (max)), measures of central tendency (mean (M) and median (Md)) and measures of dispersion (standard deviation (s)).

## FORMAL AND ETHICAL ISSUES

All the ethical requirements inherent to the study were met, namely, informed consent was obtained from each participant and a favorable opinion was given by the Ethics Committee of the institution where the study was carried out (CiC2Fs: 07.OBS.23). Authorization was also obtained from the author of CADI for its application, guaranteeing recognition of intellectual property.

## RESULTS

Ten ICs from 10 PDs hospitalized in HD participated in the study. The ICs were mostly female (n=7) and had a mean age of  $62.60 \pm 10.74$ ; [32;82] years. Eight IC were married or in a de facto relationship. Two had not attended any school and four were unemployed. With regard to monthly income and considering the national minimum wage (OMN), four CI reported earning less than the OMN and the majority (n=9) said they had no financial support from the Portuguese state. The majority said they were the child of the DP (n=6) and lived with her (n=8). Eight confessed to having more than one DP in their care. Of the 10 ICs who took part in the study, only four answered the question about how long they had been caring for the DP. On average, they had been caring for the DP for around 24.50 months and spent around 18.75 [3;24] hours a day on care. When asked about technical difficulties, the ICs identified handling infusion pumps/syringes (n=7); administering intravenous and nasogastric feeding (n=2); and caring for people with urinary catheters (n=1). There were no responses to the open question about the difficulties experienced as a CI (**Table 1**).

## IC DIFFICULTIES

Using the CADI scale, it was possible to find out about the difficulties identified by the ICs. **Table 2** shows the results for the thirty items on the CADI scale. The difficulties most perceived by the ICs are identified in the items: 20 "I don't get enough rest time for myself" ( $M=3.10 \pm .99$ ); 24 "the person I care for suffers from incontinence" ( $M=3.10 \pm 1.10$ ) and 25 "the behavior of the person I care for causes me problems" ( $M=3.20 \pm 1.14$ ), which had a higher average value. This was followed by items 1 "I don't have enough time for myself" ( $M=2.70 \pm .82$ ), 14 "the person I care for doesn't always help as much as they could"

Variables	Average	s	Md	Min	Max	No. of answers
Age	62,60	17,64	69,00	32	82	10
Time of PD care (months)	24,50	32,02	12,00	2	72	4
Daily care time (hours)	18,75	10,50	24,00	3	24	4
Variables						n (%)
Sex	Female					7 (70)
	Male					3 (30)
Marital status	Single					2 (20)
	Married					8 (80)
Academic qualifications	Can read and write					2 (20)
	1st Cycle of Education					4 (40)
	Basic					2 (20)
	2nd Cycle of Education					1 (10)
	Basic					1 (10)
	3rd Cycle of Education					
Professional status	Employee					5 (50)
	Unemployed					4 (40)
	Retired					1 (10)
Monthly income	Less than OMN					4 (40)
	Between 1 OMN					3 (30)
	Between 2 OMN					2 (20)
	More than 3 OMN					1 (10)
Degree of relationship with the DP	Mother or Father					6 (60)
	Spouse /Partner					2 (20)
	Child					1 (10)
	Sister					1 (10)
Living with the DP	Yes					8 (80)
	No					2 (10)
It has the support of caregiver secondary?	Yes					5 (50)
	No					5 (50)
You have more than one PD at your care?	Yes					8 (80)
	No					2 (20)
What technical difficulties do you feel about PD care?	Bpumps/syringes					7 (70)
	infusers					2 (20)
	ASNG feeding					1 (10)
	Parenteral nutrition					1 (10)
	Curinary ateter					
Financial support from the state Portuguese?	Yes					1 (10)
	No					9 (90)

**Table 1.** Sociodemographic, professional and financial characterization of Informal Caregivers.

**Legend:** M - mean; s - standard deviation; Md - median; Min - minimum; Max - maximum; n - sample size; % - percentage; OMN - Ordained Minimum National; SNG - nasogastric tube.

Item	n	Min	Max	M	s
1. I don't have enough time for myself	10	1	4	2,70	,82
2. Sometimes I feel like my hands are tied/there's nothing I can do to control the situation	10	1	3	2,10	,88
3. I can't devote enough time to other people in the family	10	1	3	1,50	,71
4. It brings me money problems	10	1	4	2,10	1,19
5. The person I'm looking after even puts me out of my mind	10	1	4	2,60	1,08
6. The person I'm looking after depends on me to get around	10	1	3	1,70	,68
7. It seems to me that health professionals (doctors, nurses, social workers, etc.) have little idea of the problems faced by caregivers	10	1	4	1,70	1,06
8. It takes me away from other people and other things I like	10	1	4	2,40	1,08

Item	n	Min	Max	M	s
9. It even upsets my family relationships	10	1	4	2,60	,97
10. Makes me physically very tired	10	1	3	1,90	,99
11. Sometimes the person I'm looking after demands too much of me	10	1	4	2,60	1,17
12. There's no longer the feeling that there was in my relationship with the person I'm looking after	10	1	4	2,20	,79
13. The person I care for needs a lot of help with their personal care	10	1	4	1,90	1,10
14. The person I'm looking after doesn't always help as much as they could	10	1	4	2,90	1,10
15. I'm sleeping worse because of this situation	10	1	4	2,60	,97
16. People in the family don't pay as much attention as I'd like	10	1	4	2,50	1,43
17. This situation makes me feel angry	10	1	4	2,30	1,06
18. I'm not with my friends as much as I'd like	10	1	4	2,20	1,14
19. This situation is getting on my nerves	10	1	4	2,80	,92
20. I can't take time off, I can't take a few days' vacation	10	1	4	3,10	,99
21. The quality of my life has deteriorated	10	1	4	2,20	,92
22. The person I look after doesn't always appreciate what I do	10	1	3	2,70	,68
23. My health was shaken	10	1	4	2,50	1,18
24. The person I care for suffers from incontinence (can't control their needs)	10	1	4	3,10	1,10
25. The behavior of the person I care for causes me problems	10	1	4	3,20	1.1 4
26. Taking care of this person doesn't give me any satisfaction	10	1	3	2,40	,69
27. I don't get enough support from health and social services	10	1	4	2,80	1,14
28. Some family members don't help as much as they could	10	1	4	2,70	1,25
29. I can't rest because I'm worried about care	10	1	4	2,30	,95
30. This situation makes me feel guilty	10	1	2	1,70	,48

**Table 2:** Results for the CADI scale items.

**Legend:** n - absolute frequency; Min - minimum; Max - maximum; M - mean; s - standard deviation.

Factor/Item	n	Min.	Max.	M	s
Problems related to the person being cared for (5, 11, 12, 14, 22, 25 and 26)	10	8,00	21,00	18,60	4,38
Restrictions on social life (8, 18 and 20)	10	3,000	9,000	7,70	2,26
Physical demands of providing care (6, 10, 13, 15, 23 and 24)	10	8,00	18,00	13,70	3,92
Reactions to the provision of care (1, 2, 3, 9, 17, 19, 29 and 30)	10	11,00	23,00	18,00	3,77
Lack of family support (16 and 28)	10	2,00	6,00	5,20	2,67
Lack of professional support (7 and 27)	10	3,00	6,00	4,50	1,08
Financial problems (4 and 21)	10	2,00	6,00	4,30	1,57

**Table 3:** Results for the CADI scale factors.

**Legend:** n - absolute frequency; Min - minimum; Max - maximum; M - mean; s - standard deviation.



( $M=2.90\pm 1.10$ ), 19 “this situation is upsetting my nerves” ( $M=2.80\pm .91$ ), 22 “the person I care for doesn’t always appreciate what I do” ( $M=2.70\pm .68$ ), 27 “I don’t get enough support from the health services” ( $M= 2.80\pm 1.14$ ). The items that were least difficult for the ICs to perceive were: 3 “I can’t devote enough time to the other people in the family” ( $M=1.50\pm .71$ ); 6 “the person I care for is dependent on me to get around” ( $M=1.70\pm .68$ ); 7 “it seems to me that the caregivers don’t have a good idea of the problems the caregivers face” ( $M=1.70\pm 1.08$ ); and 30 “this situation makes me feel very guilty” ( $M=1.70\pm .48$ ).

The results shown in **Table 3** show that the ICs express difficulty in all the factors, the most significant of which are “Problems related to the person being cared for” ( $M=18.60\pm 4.378$ ), “Restrictions on social life” ( $M=7.70\pm 2.263$ ) and “Reactions to the provision of care” ( $M=18.00\pm 3.771$ ). Despite averages higher than the central point, the factors expressing the least difficulty were “Lack of professional support” ( $M=4.50\pm 1.080$ ) and the factor related to “Financial problems” ( $M= 4.50\pm 1.567$ ).

## DISCUSSION

History has always attributed the role of family care to women (Renk et al., 2022), and this may explain the results found, which show that 7 out of 10 of the ICs who took part were female. According to other studies (Dixe et al., 2020; Pérez-Cruz et al., 2017), the IC profile is described by people who are mostly married or in a de facto union, with the degree of kinship of children of the DPs being cared for, with a low level of qualifications and living with the dependent person, which is in line with the results found in this study.

Social and financial support seems to be important for the ICs who took part in the study. In addition to the fact that 40% say they are unemployed and earn less than the OMN,

90% say they have no financial or social support from the Portuguese state, despite this finding. When the CADI was applied, the ICs did not identify financial problems as the most difficult factor ( $M= 4.50\pm 1.567$ ). However, low financial resources can be considered a barrier to the quality of care provided, aggravating the difficulties faced by ICs and putting the quality of care at risk. ICs’ lack of knowledge about their rights and the financial support available to them could be one reason for this response obtained by CADI, or on the other hand, the difficulty in assuming this need, which is typical of Portuguese culture. Wages and pensions in Portugal are among the lowest in Europe, in a country where the cost of living is rising (Patrício, 2024).

The lack of financial support is an aspect listed in another study (Lima et al., 2022). In this study, the authors found that only 25% of ICs received financial support, and this was considered insufficient for the daily needs of PD care. Strategies such as interviews or planned home visits were identified as fundamental in order to ensure that ICs are properly informed about the different types of support they can receive in accordance with Law 100/2019, of September 6, with an impact on the preservation of their health and the quality of care they provide to PD. Home visits should be more than just a place to provide care, they can be a form of intervention with ICs (Chan, 2022; Stanhope & Lancaster, 2011), as it is often in the home that the doubts and difficulties inherent in the care process arise. HD is recognized as a more cost-effective strategy than traditional hospitalization and is a solution to the problems of hospital overcrowding (Chan, 2022; Melo et al., 2023).

The number of hours per day ( $M=18.75$  hours) devoted to caring for the DP shows that the ICs devote a large number of hours per day to caring, hours that were previously allocated to the ICs’ personal time, thus suggesting

changes to their daily routines and activities. Added to this is the length of time these ICs have already been subjected to this change, and it was found that on average they had been caring for the DP for more than 2 years ( $M=24.50$  months). This data may justify the results found for the items “I can’t take time off or go on vacation” ( $M=3.10\pm 0.99$ ) and “I don’t have enough time for myself” ( $M=2.70\pm 0.82$ ).

As a measure to support ICs in this regard, a decree (Decree no. 335-A/2023, 2023) provides for the possibility of each IC being able to take up to 30 days, consecutive or interpolated, per calendar year, through an internment in social support units, to allow ICs to recover. The aim of caregiver rest is to reduce physical and emotional overload, prevent burnout and promote physical and/or mental health (Ordinance no. 335-A/2023, 2023). What we see in practice is that ICs are unaware of this support and the conditions in which it can be provided.

Other difficulties that stand out in the ICs’ perception are the relational problems with the DP, specifically: the “DP doesn’t always help as much as they could”; the “DP doesn’t value the IC’s work”; and the “DP’s behavior tends to trigger problems”. These results are similar to those obtained by Amaral et al. (2020) in their study, in which the difficulties most perceived by ICs were related to the dimensions “Reactions to the provision of care” and “Relational problems with the dependent person”. Kuluski et al. (2018) also identified in their study that caregivers did not feel valued and recognized by the DP. These results suggest that the emotional and mental health of ICs are vulnerable dimensions and should therefore be considered when planning HD by the health team during home visits.

With regard to the physical demands of providing care, the majority of ICs showed no difficulties, with the exception of the

question related to incontinence of the DP. On the other hand, the technical difficulty most frequently expressed by ICs was handling syringes/infusion pumps. It is important to note that ICs have limitations and difficulties in their daily care, and it is important for them to know where they can get information and support (Kuluski et al., 2018). This need must be taken into account in nursing interventions, and visits resulting from HD are important moments for early diagnosis and intervention.

It should also be noted that none of the ICs answered the open question about the difficulties they experience as ICs. This may be related to cultural issues, as ICs’ complaints are not well understood by society, which means that many continue to perpetuate their suffering for fear of being recriminated by their community. The IC are an isolated population with little support, which is why it is important to continue developing psychoeducational support interventions for them (Palma, 2024). As such, strategies for improvement included the creation and availability of an information leaflet on socio-financial support and reinforcing teaching and training related to the difficulties perceived by ICs in terms of the technical dimension of care.

### **PROPOSALS FOR PRACTICAL INTERVENTION AND LIMITATIONS OF THE STUDY**

As future suggestions, in the field of training, we suggest developing in-service training so that the health team, specifically nurses, properly integrate the IC as a fundamental part of care and are able to intervene in their training, not only in the technical and knowledge domains, but also in the mental and emotional domains. As far as clinical practice is concerned, it is suggested that the IC’s difficulties be identified early on, specifically in the technical area of care and in the financial and social areas, so that early



intervention can be made and the negative effects associated with the wear and tear caused by caring for the DP can be minimized. It is also suggested that an adequate assessment of the family be carried out, not limited to the DP and the IC, so that potential resources and support for the IC can be identified, as well as other points of fragility. In the field of research, it is suggested that the study be replicated with a larger sample, as this aspect is identified as the biggest limitation in this research and its results cannot be generalized to other contexts. Also, the fact that the effect of the implemented improvement interventions was not evaluated did not allow for a comparison of the results that would identify the ICs' difficulties after implementing the strategy, and thus reassess the need to rectify the continuous quality improvement project.

## FINAL CONSIDERATIONS

The role of the IC develops in various and complex dimensions, which brings up difficulties and needs that cannot be overlooked. The difficulties encountered and most identified by ICs center on financial and social support, reactions to the provision of care, the relationship with the PD and restrictions on social life, which can negatively affect their physical, mental and emotional health. Active support for the IC should be a priority for health professionals, specifically nurses, respecting their stories, expectations and needs. It is also important to emphasize the importance of investing in and improving IC support policies, which, despite already being a reality in Portugal, are still inadequate in terms of effective responses to the needs of PDs in the context of home care and to ICs who are confronted every day with difficulties that generate stress and suffering.

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