

RESEARCH ARTICLE (ORIGINAL) 

How documentation reflects nursing care design for caregivers

A conceção de cuidados de enfermagem dirigida aos prestadores de cuidados espelhada na documentação

La concepción de los cuidados de enfermería dirigida a los prestadores de cuidados se refleja en la documentación

Daniela Clara Silva França ^{1,2}

 <https://orcid.org/0000-0002-3687-8312>

António Joaquim Rocha Festa ^{3,4}

 <https://orcid.org/0000-0002-9163-5305>

Patrícia Maria Silva Santos ⁵

 <https://orcid.org/0000-0001-7284-864X>

Maria José Peixoto ³

 <https://orcid.org/0000-0003-4131-4279>

Maria de Fátima de Araújo ³

 <http://orcid.org/0000-0001-5254-530X>

¹ ICBAS - School of Health and Life Sciences, Porto, Portugal

² Portuguese Oncology Institute of Porto, Adult Day Hospital, Porto, Portugal

³ Nursing School of Porto, Porto, Portugal

⁴ Regional Health Administration of the North, *Faria Guimarães* Family Health Unit, Porto, Portugal

⁵ Regional Health Administration of the North, *Covelo* Family Health Unit, Porto, Portugal

Corresponding author

Daniela Clara Silva França

E-mail: danielat.franca@gmail.com

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Abstract

Background: Caregivers must acquire knowledge and develop skills that ensure the safety of the care delivered and guarantee their own self-care. Nurses take on the role of facilitators in this transition process, with nursing information systems being used as tools to safeguard the continuity and quality of care.

Objective: To understand nursing care design for caregivers.

Methodology: This is a mixed method study with a descriptive exploratory research design, analyzing 163 files of caregiver documentation and using a questionnaire ($N = 72$).

Results: It was possible to identify the underreporting of caregivers. Caregivers were predominantly elderly women with moderate burden who reported difficulties in instrumental activities and needed support from an additional caregiver or a formal support network.

Conclusion: Identifying the needs and difficulties of caregivers combined with the observed under-reporting strengthens the need for bringing the models in use closer to the models presented, thus translating this process into an improvement of quality standards in nursing care for caregivers.

Keywords: caregivers, nursing, primary health care, documentation

Resumo

Enquadramento: A assunção do papel de cuidador exige a aquisição de conhecimentos e habilidades, garantindo a segurança dos cuidados à pessoa cuidada e assegurar o seu próprio autocuidado. O enfermeiro assume o papel de facilitador neste processo de transição, sendo os sistemas de informação em enfermagem uma ferramenta que garante a continuidade e qualidade dos cuidados.

Objetivo: Compreender a conceção de cuidados de enfermagem relativa ao prestador de cuidados.

Metodologia: Estudo descritivo exploratório com abordagem mista, através da análise da documentação do prestador de cuidados em 163 processos e aplicação de um questionário ($N = 72$).

Resultados: Identificou-se subnotificação no prestador de cuidados. Estes eram predominantemente mulheres, com idade avançada e sobrecarga moderada. Expressaram dificuldades nas atividades instrumentais e necessidade de apoio de outro cuidador/redes formais.

Conclusão: A identificação das necessidades e dificuldades do prestador de cuidados em confronto com a subnotificação observada reforça a necessidade de uma aproximação dos modelos em uso aos modelos expostos, traduzindo este processo numa melhoria dos padrões de qualidade em enfermagem dirigida aos prestadores de cuidados.

Palavras-chave: familiar cuidador; enfermagem; cuidados de saúde primários; documentação

Resumen

Marco contextual: La asunción del papel de cuidador requiere la adquisición de conocimientos y habilidades, lo que garantiza la seguridad de los cuidados a la persona cuidada y asegura su propio autocuidado. El enfermero asume el papel de facilitador en este proceso de transición, y los sistemas de información de enfermería son una herramienta que garantiza la continuidad y la calidad de los cuidados.

Objetivo: Comprender la concepción de los cuidados de enfermería en relación con el cuidador.

Metodología: Estudio descriptivo exploratorio con un enfoque mixto, para el cual se analizó la documentación del proveedor de cuidados en 163 procesos y se aplicó un cuestionario ($N = 72$).

Resultados: Se identificó un subregistro en el cuidador. Eran predominantemente mujeres, con una edad avanzada y una sobrecarga moderada. Manifestaron dificultades en las actividades instrumentales y necesidad de apoyo de otro cuidador/redes formales.

Conclusión: La identificación de las necesidades y dificultades del cuidador frente al subregistro observado refuerza la necesidad de una aproximación de los modelos en uso a los modelos expuestos, lo que traduce este proceso en una mejora de los estándares de calidad en enfermería dirigida a los cuidadores.

Palabras clave: cuidador familiar; enfermería; atención primaria de salud; documentación



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Introduction

The present study focuses on nursing care delivery to the caregiver (CG) of a dependent person (DP) in primary health care settings. The relevance of this topic arises from the growing number of families who are part of and ensure the continuity of home care to family members. Since the end of the last century, this challenge posed to families has received increasing attention from the scientific community, which seeks to obtain evidence to help health professionals, particularly nurses, in supporting CGs using an integrated approach. This approach is based on a partnership and empowerment model that provides CGs with the knowledge and skills necessary to perform their role.

This study aims to understand nursing care design for CGs.

Background

The sociodemographic and epidemiological changes in current societies have led to the emergence of health conditions often associated with functional impairments that require support from others to ensure self-care. Faced with this situation, some family members must assume the responsibility of taking care of the DP. This transition process to the CG's role demands acquiring knowledge and skills (Ploeg et al., 2020). In the healthcare team, nurses are in a privileged position to support the CG in this complex process. Working closely with informal CGs to identify and respond early to emerging needs allows for promptly preventing and diagnosing CG burden. Thus, nursing professionals need their decision-making to be based on a solid conceptual framework (Ribeiro et al., 2018). This process should be supported by nursing information systems (NIS), and electronic records should mirror daily practice. The information gathered through the documentation process is crucial for health care management, allowing the understanding of nurses' experiences and implemented strategies, leading to health gains (Ribeiro et al., 2019). Nurses' awareness of the importance of documentation is vital, as it allows for recording autonomous and collaborative work while contributing to the self-affirmation of the nursing profession (Reis et al., 2016; Vieira, 2018).

In Portugal, the NIS has evolved from an initial system called *Sistema de Apoio à Prática de Enfermagem* (SAPE - Support Systems for Nursing Practice) based on the International Classification for Nursing Practice β 2 to a more current version called *SClínico*. This system allows for standardizing information in different areas, helping health professionals perform more efficiently and effectively (Serviços Partilhados do Ministério da Saúde, 2018), using the International Classification for Nursing Practice version 1. The *SClínico* provides two *foci* for CG-associated records: the Caregiver's Role (CGR) and Caregiver's Stress (CGS).

Research question

Does the documentation reflect nursing care design for CGs?

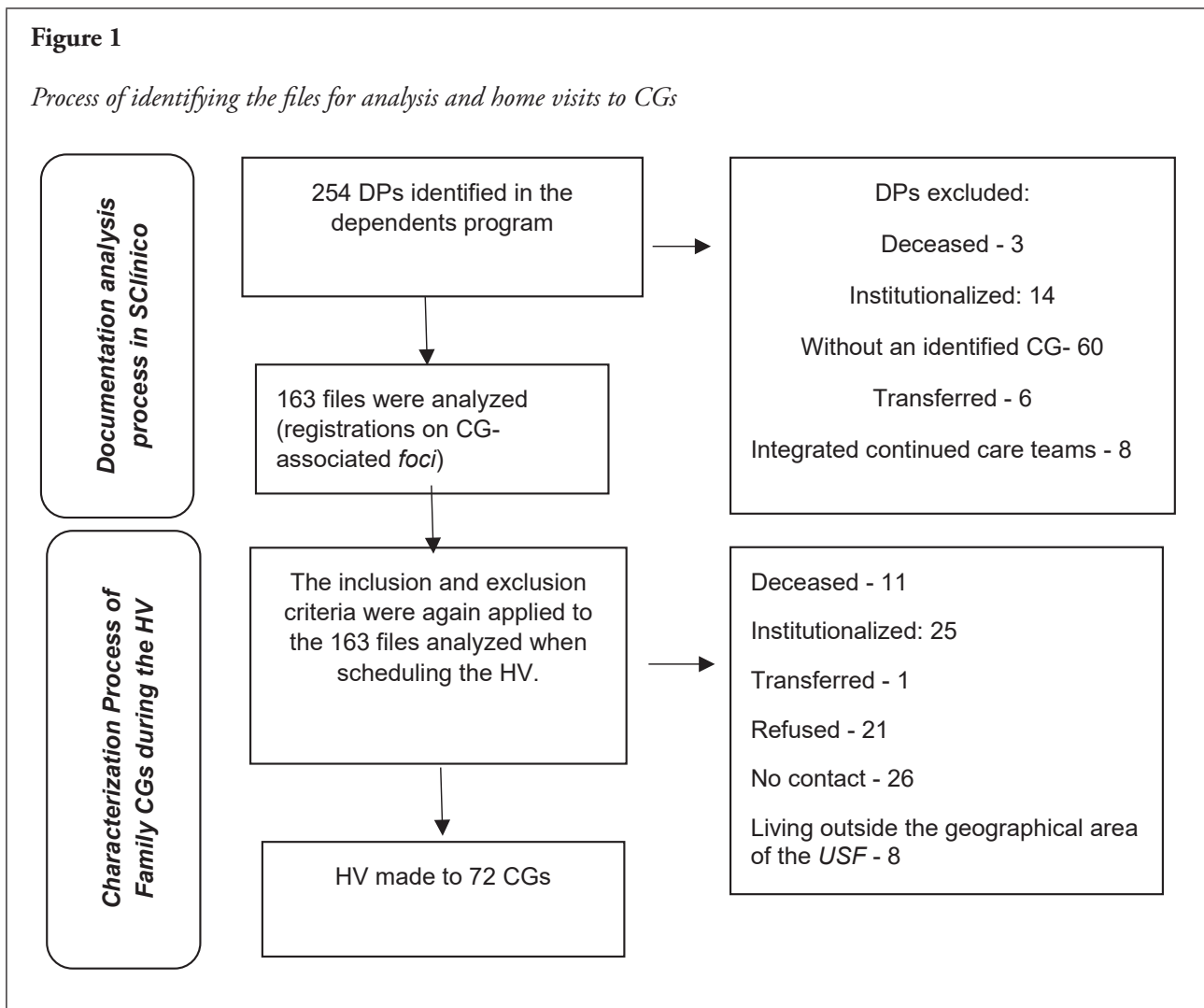
Methodology

This is a mixed method study with a descriptive exploratory research design based on the analysis of nursing documentation on CGs in the NIS over 6 months (from 1 August 2016 to 1 February 2017) and the characterization of the CGs of dependent/elderly adults who were part of a convenience sample. The data were collected during two sequential moments: the first corresponded to the retrospective search in the NIS (*SClínico*) for the *foci* CG diagnoses and CG interventions, and the second was dedicated to characterizing the CGs. The inclusion criteria for participating in this study were to be a DP enrolled in one of the dependents' lists of two *Unidades de Saúde Familiar* (USFs - family health units) of the metropolitan region of Porto in the past six months, with self-care dependency, and an identified CG. Institutionalized individuals, individuals referred to an integrated continued care team, or transferred from the USFs involved in this study were excluded.

Searching the lists of the DPs' health program (March 2017) allowed for identifying 254 DPs. In the first data collection phase, 163 DPs were selected, and their clinical files were analyzed. In the second data collection phase, a home visit (HV) was made to 72 CGs (Figure 1).

Figure 1

Process of identifying the files for analysis and home visits to CGs



The nurse interlocutor in each USF collected the data from the clinical files in the NIS, using the DP's file number, consulting the nursing documentation, and sending it to the principal investigator while ensuring the DP's anonymity. After this stage was completed, a high level of underreporting of the *foci* CGR and CGS was identified. In a meeting with the nurse interlocutors from the two USFs, it was decided to extend data collection to other DP-related care *foci*, where it was clear that there was CG-associated information. It was possible to identify files where the *foci* CGR and CGS were active but without records in the period under analysis. While data was being searched in the NIS, the family nurse of the selected DP contacted the CG explaining the purpose of the study and providing information on the investigator. After the CG's consent, the investigator telephoned to schedule the HV, which would allow for a more accurate understanding of the reality of the context of care. For data collection, the CGs completed a self-administered questionnaire including variables for their characterization using closed-ended questions. Two open-ended questions were included to allow CGs to explain their needs and difficulties in performing the role of CG. Two other questions were used to assess CGs' perceptions of their

health and quality of life. These were answered through a Likert-type format with the options "very good," "good," "reasonable," "bad," and "very bad." The data collection instrument also included the *Questionário de Avaliação da Sobrecarga do Cuidador Informal* (QASCI – Informal Caregiver Burden Assessment Questionnaire), an instrument designed for the Portuguese population by Martins et al. (2003) aimed at assessing the CGs' physical, emotional, and social strain. It consists of 32 items, assessed by an ordinal scale ranging from 1 to 5, with the categories *no/never, rarely, sometimes, almost always, and always*. The questionnaire includes seven dimensions, namely: *Implications on the CG's personal life; Satisfaction with the CG role and the family member; Reactions to demands; Emotional burden; Family support; Financial burden; and Perception of efficacy and control mechanisms*. The score for each subscale ranges from 0 to 100, with lower scores indicating less burden in the first four subscales. In comparison, higher scores in the last three subscales indicate more significant support, satisfaction, or self-efficacy. Considering this study's authors and the score range from 0 to 100, the analysis was performed considering the 25th, 50th, and 75th percentiles. Thus, scores below 25 revealed light burden, between 25 and 50 moderate burden, between 51 and 75 severe burden, and above

this value an extreme burden.

In this study ($N = 72$), Cronbach's alpha coefficient ($\alpha = 0.79$) demonstrated that the total scale had good internal consistency.

The IBM SPSS Statistics software, version 24.0, was used for descriptive statistics (measures of central tendency and dispersion) and bivariate analysis. All variables were presented as absolute and relative frequencies.

The t -test was used to assess the correlations between the QASCI, the scale's dimensions, and the dichotomous variables (gender, age, years of education, whether the CG lived with the DP, whether there was an additional CG, whether the CG had health problems, and whether the CG quit an activity they enjoyed). A significance level of 0.005 was assumed for analyzing the results. Two groups were created for the variables "age" [Adult CGs (< 65 years) and Elderly CGs (≥ 65 years)] and "years of education" [years of education (< 5 years), and years of education (≥ 5 years)]. When presenting the data in the tables, the total number of participants can differ due to the existence or not of missing values.

Considering the open-ended questions, content analysis was performed according to Bardin's model (2013). An initial reading was done to systematize ideas. First, the answers were read several times, the data to include in the analysis were selected, and the analysis *corpus* was coded. Second, the data were coded, broken down, and listed. In the third and final phase, the data were categorized to become more explicit.

This study began after receiving the favorable opinions of the CNPD - Portuguese Data Protection Authority (authorization 10744/2016), the Health Ethics Commit-

tee (authorization 105/2016) of the Portuguese Regional Health Administration of the North, and the Executive Director of the Portuguese *Agrupamento de Centros de Saúde* (Health Center Cluster) where the study was conducted. Each participant was informed about the objectives and purpose of this study and signed the informed consent form. Authorization was also obtained from the author of the instrument used.

Results

The results were organized into two domains: Characterization of CGs and Documentation of CG-related *foci*.

Caregiver

Sixty-two of the 72 CGs (86.1%) were women with a mean age of 61.9 ± 13.6 years (23-89) with high education levels (8 ± 4.5 years; 0-18). Forty-four (61.1%) of CGs were married or in a *de facto* union, 32 (44.9%) were retired, and 62 (86.1%) lived with the DP. Thirty-six (50%) of the CGs were the DP's daughters/sons, and 36 (50%) reported the existence of an additional CG. On average, the CGs had been taking care of the DP for 8.10 ± 7.0 years (1-39), approximately 11.8 ± 8.8 hours per day (24 hours), and 60 (83.3%) said they had no other DP in their care. Fifty-five (76.4%) of the DPs suffered from health problems, the most frequent being hypertension, which was observed in 33 (60%) DPs. Forty-one (56.9%) CGs perceived their health status as reasonable, and 46 (63.9%) considered they had a reasonable quality of life (Table 2).

Table 1

Absolute and relative frequencies of the CGs' sociodemographic variables

Variables		N (72)	%
Gender	Female	62	86.1
	Male	10	13.9
Marital status	Married/ <i>de facto</i> union	44	61.1
	Single	16	22.2
	Divorced/Separated	10	13.9
	Widow/er	2	2.8
	Employed	24	33.3
Current employment status	Unemployed	16	22.2
	Retired	32	44.4
	Yes	62	86.1
Living with the DP	No	10	13.9
	Husband/ Wife	24	33.3
Relationship with the DP	Son/ Daughter	36	50.0
	Daughter-in-law/ Son-in-law	1	1.4
	Other	11	15.3
	Yes	36	50.0
Is there another CG?	No	36	50.0
	Yes	12	16.7
Do you have another DP in your charge?	No	60	83.3
	Very good	3	4.2
How do you perceive your health status?	Good	13	18.1
	Reasonable	41	56.9
	Poor	13	18.1
	Very poor	2	2.8
	Very good	0	0.0
How do you perceive your quality of life?	Good	12	16.7
	Reasonable	46	63.9
	Poor	8	11.1
	Very poor	6	8.3

Forty-six (63.9%) CGs answered the question, “What are your main difficulties as a CG?”. The data gathered revealed 49 mainly physical difficulties, totaling 33 (67.3%) answers.

Thirty-five (48.6%) CGs answered the question, “What are your main needs as a CG?” and 37 needs were listed, with the most mentioned, with a total of 26 answers (70.3%), being the support from an additional CG or a formal support network.

Forty-eight (66.7%) CGs (the majority) reported receiving some support. The most mentioned with 29 (60.4%) answers was home support (hygiene, food, ...). Forty-seven (65.3%) participants received support from the USF nursing team. About 32 (44.4%) CGs reported that to take care of their family member, they stopped doing some activity, and 30 (93.8%) specifically mentioned they quit some leisure activity.

The QASCI's results showed a mean score of 32.8 ± 21.4 , corresponding to a moderate burden. Thirteen (18.1%) CGs reached burden levels higher than 51.0, indicating severe and extreme burden. The highest perception of burden was identified in the dimension Implications on the CG's personal life (46.7 ± 29.9), despite corresponding to a moderate level of burden. In contrast, the highest satisfaction level was achieved in the dimension Perception of efficacy and control mechanisms (75.8 ± 25.5). Statistically significant differences were found between male and female CGs in the dimension Family support ($t(70) = 2.923; p = 0.008$), with male CGs having higher values of Family support (87.5 ± 18.6).

When comparing Adult CGs (< 65 years) and Elderly CGs (≥ 65 years), it was possible to observe statistically significant differences in burden in the dimensions Implications on the CG's personal life ($t(70) = 2.073; p =$

0.042), Family support ($t(70) = 2.664; p = 0.010$) and Satisfaction with the CG role and the family member ($t(70) = 2.189; p = 0.032$). Elderly CGs had greater Implications on [their] personal life (55.2 ± 27.4) and perceived greater Family support (80.8 ± 29.3), and Adult CGs expressed greater Satisfaction with the CG role and the family member (77.6 ± 23.8). There were statistically significant differences between CGs with < 5 years of education and CGs with ≥ 5 years of education in the dimension Family support ($t(70) = 2.047; p = 0.044$), i.e., CGs with fewer years of education had higher levels of Family support (79.8 ± 31.0).

It was also possible to observe statistically significant differences in the dimension Financial burden ($t(70) = 18.356; p = 0.014$). CGs living with the DP presented higher values (40.1 ± 40.3).

The existence of an additional CG, compared to a CG without another CG's support, also revealed statistically significant differences in the dimensions Emotional burden ($t(70) = 2.457; p = 0.016$), Reaction to demands ($t(70) = 2.699; p = 0.009$), Family support ($t(70) =$

$2.615; p = 0.011$), and in the QASCI's total score ($t(70) = 2.857; p = 0.006$). Those without the support of another CG demonstrated a higher Emotional burden (45.7 ± 30.5), a higher burden on Reaction to demands (32.5 ± 27.7), and a higher burden on the scale's total score (39.7 ± 24.3). On the other hand, an additional CG was associated with greater Family support (79.8 ± 29.4). The results also demonstrated that CGs with health problems presented a significantly worse burden ($t(70) = 2.216; p = 0.032$) in the dimension Perception of efficacy and control mechanisms (72.9 ± 27.0). When compared with CGs who did not stop doing an activity they enjoyed, those who had to quit doing a significant activity also presented statistically significant values in the dimensions Emotional burden ($t(70) = 2.590; p = 0.012$), Reaction to demands ($t(70) = 2.828; p = 0.007$) and the QASCI's total score ($t(70) = 2.621; p = 0.011$). CGs who quit doing an activity they enjoyed showed a higher Emotional burden (47.5 ± 33.9), higher Reaction to demands (34.1 ± 27.5), and higher total burden (40.0 ± 22.4 ; Table 2).

Table 2

Correlations between the QASCI, the scale's dimensions, and the dichotomous variables (gender, age, years of education, whether the CG lived with the DP, whether there was an additional CG, whether the CG had health problems, and whether the CG quit doing an activity they enjoyed)

		EB	ICGL	FB	RD	ECM	FS	SRF	Total QASCI
		<i>M(SD)</i>	<i>M(SD)</i>	<i>M(SD)</i>	<i>M(SD)</i>	<i>M(SD)</i>	<i>M(SD)</i>	<i>M(SD)</i>	<i>M(SD)</i>
Gender	Male	23.8 ± 23.3	35.7 ± 29.0	36.3 ± 36.1	14.5 ± 15.2	85.0 ± 20.3	87.5 ± 18.6	77.5 ± 23.0	22.9 ± 15.0
	Female	39.5 ± 30.3	48.5 ± 29.8	36.7 ± 40.1	27.0 ± 24.4	74.3 ± 26.1	65.3 ± 37.6	71.0 ± 27.3	34.4 ± 21.9
	<i>P</i>	0.121	0.210	0.974	0.122	0.222	0.008	0.482	0.114
Age	CG ≥ 65 years	38.8 ± 29.7	55.2 ± 27.4	40.0 ± 42.7	25.8 ± 25.5	68.9 ± 29.1	80.8 ± 29.3	64.0 ± 28.9	35.1 ± 22.3
	CG <65 years	36.3 ± 30.1	40.7 ± 30.4	34.2 ± 37.0	24.9 ± 22.6	80.8 ± 21.7	59.5 ± 38.5	77.6 ± 23.8	31.2 ± 20.8
	<i>P</i>	0.734	0.042	0.543	0.868	0.051	0.010	0.032	0.441
Years of education	≥ 5 years	36.0 ± 31.2	42.5 ± 30.5	35.6 ± 39.7	25.8 ± 25.0	77.4 ± 24.9	62.0 ± 37.8	71.3 ± 27.0	32.8 ± 21.7
	< 5 years	39.7 ± 27.6	54.1 ± 27.6	38.5 ± 39.4	24.4 ± 21.6	73.1 ± 26.8	79.8 ± 31.0	73.1 ± 27.0	32.8 ± 21.7
	<i>P</i>	0.620	0.115	0.769	0.820	0.498	0.044	0.789	0.970
CG living with the DP	Yes	39.4 ± 28.7	49.5 ± 29.0	40.1 ± 40.3	25.9 ± 24.2	74.5 ± 26.6	68.8 ± 37.0	70.2 ± 27.4	34.5 ± 21.6
	No	24.4 ± 34.8	29.8 ± 31.2	15.0 ± 24.2	21.5 ± 21.0	84.2 ± 16.4	66.3 ± 33.9	83.0 ± 20.0	22.5 ± 17.6
	<i>P</i>	0.139	0.052	0.014	0.590	0.268	0.842	0.160	0.099
Additional CG	Yes	29.0 ± 26.9	44.1 ± 29.7	28.1 ± 36.8	18.1 ± 16.2	81.3 ± 18.9	79.2 ± 29.4	77.1 ± 23.9	26.0 ± 15.6
	No	45.7 ± 30.5	49.4 ± 30.2	45.1 ± 40.5	32.5 ± 27.7	70.4 ± 30.0	57.6 ± 39.7	66.8 ± 28.7	39.7 ± 24.3
	<i>P</i>	0.016	0.455	0.066	0.009	0.071	0.011	0.103	0.006
CG with health problems	Yes	39.7 ± 30.2	50.5 ± 30.0	40.9 ± 40.9	25.3 ± 25.1	72.9 ± 27.0	69.8 ± 36.8	72.4 ± 26.6	34.5 ± 22.3
	No	29.8 ± 27.8	34.4 ± 26.5	22.8 ± 30.7	25.3 ± 19.2	85.3 ± 17.6	64.0 ± 35.6	70.6 ± 27.9	27.5 ± 17.6
	<i>P</i>	0.234	0.050	0.059	0.997	0.032	0.569	0.813	0.241
CG quit doing an activity they enjoyed	Yes	47.5 ± 33.9	53.4 ± 28.7	45.3 ± 42.0	34.1 ± 27.5	71.6 ± 28.5	61.3 ± 38.5	67.8 ± 29.0	39.9 ± 22.4
	No	29.2 ± 23.5	41.4 ± 30.0	29.7 ± 36.1	18.3 ± 17.6	79.2 ± 22.6	74.1 ± 33.9	75.3 ± 24.6	27.1 ± 19.0
	<i>P</i>	0.012	0.089	0.094	0.007	0.215	0.141	0.243	0.011

Note. DP = Dependent Person; CG = Caregiver; ICGL= Implications on the caregiver's personal life; SRF = Satisfaction with the CG role and the family member; RD = Reactions to demands; EB = Emotional burden; FS = Family support; FB = Financial burden; ECM = Efficacy and control mechanisms; QASCI = Questionário de Avaliação da Sobrecarga do Cuidador Informal (*Informal Caregiver Burden Assessment Questionnaire*).

Documentation

This study analyzed 163 files of documentation. However, it was only possible to characterize the 72 CGs after data collection during the HV. Of the 163 clinical files, only one (0.6%) had the CG's identification in the admission form. The CGR focus was

observed in five cases (3.1%), and the CGS in six (3.7%). This study also identified CG-associated records in DP-related *foci*, namely: "Therapeutic Regime Management" [13(8.0%)], "Fall" [5(3.1%)], "Feeding" [4(2.5%)], "Pressure Ulcer" [3(1.8%)], "Aspiration" [2(1.2%)], "Maceration" [2(1.2%)], "Self-Care" [1(0.6%)], "Orientation"

[1(0.6%)], “Walking” [1(0, 6%)], “Energy metabolism” [1(0.6%)], “Medication self-administration” [1(0.6%)], “Self-monitoring” [1(0.6%)], “Dyspnea” [1(0.6%)], “Sleep” [1(0.6%)], “Self-hygiene” [1(0.6%)], “Confusion” [1(0.6%)] and “Dehydration”[1(0.6%)].

Considering the diagnoses recorded by nurses, 33 distinct diagnoses were identified, covering potential, knowledge, and ability. The most documented diagnosis (with nine records; 5.5%) was about the CG’s knowledge of the therapeutic regime.

Seventy-eight interventions were identified in association with these diagnoses, mainly related to “Assessing,” “Teaching,” “Instructing,” “Encouraging,” “Training,” “Guiding,” and “Supporting.” The most documented intervention was: “To assess the CG’s knowledge of the therapeutic regime.” The most documented interventions related to identified needs were “Teaching” with 53 records and “Assessing” with 51 records. The interventions under “Guiding” and “Supporting” were recorded only once (Table 3).

Table 3

Types of interventions documented in the SClínico regarding CGs

Types of interventions	Number of times documented	Number of distinct interventions
Teaching	53	27
Assessing	51	25
Instructing	24	14
Training	8	5
Encouraging	5	5
Guiding	1	1
Supporting	1	1

Discussion

This study is limited by the timeframe defined for data collection, as more comprehensive retrospective research could have enriched the documentation data.

This study observed that CGs were mostly elderly women, which is consistent with other studies (Cunha, 2018; Day et al., 2021; Duarte et al., 2017; Park et al., 2015; Peixoto, 2016; Pereira & Petronilho, 2018), with a high mean of education level, as mentioned by Day et al. (2021). Most CGs were married, retired, and lived with the DP, a profile described in Portuguese and foreign literature (Park et al., 2015; Peixoto, 2016; Pereira & Petronilho, 2018). As also observed in other studies, in terms of kinship, most CGs were sons and daughters of the DP (Pereira & Petronilho, 2018).

This study observed that the mean time performing the role of CG was 8.10 ± 7.0 years, similar to that demonstrated by Cunha (2018) and higher than that determined by Park et al. (2015). This prolonged period can be associated with worse quality of life (Duarte et al., 2017). The answers to the question on the difficulties/needs perceived by CGs primarily pointed to physical difficulties. As for CGs’ primary needs, the respondents expressed their need for another CG or a formal support network so that they could rest. These data obtained through the open-ended questions indicate that the questionnaire may not have been a suitable collection method and that these associations can also be made during the HV. As Pereira (2018) pointed out, an interview would probably have yielded different results. The literature currently points out that, in the care process, the existence of resources for CGs is essential for maintaining their well-being and preventing and decreasing CG burden, as described by

Araújo and Martins (2016). Pereira (2018) also corroborates the importance of support from an additional CG or a formal support network.

The almost non-existence of the CG’s identification in the initial assessment form of the clinical file and the significant underreporting of the *foci* CGR and CGS demonstrate that the nursing records on CGs do not reveal an integrative and directed approach to their needs. Nevertheless, this study observed that nurses documented some CG-associated diagnostic activities and interventions in DP-related *foci*. These results may indicate nurses’ weak adherence to the documentation process. The scientific literature has reported some of the obstacles perceived by professionals in care documentation, including the lack of knowledge and preparation (Huitzi-Egilegoret et al., 2018; Silva et al., 2016; Vieira, 2018), the lack of material and human resources (Huitzi-Egilegoret et al., 2018; Vieira, 2018), the lack of time and overwork (Reis et al., 2016), the need for continuous training, the lack of technical support (Silva et al., 2016), and also the resistance to change (Huitzi-Egilegoret et al., 2018).

Vieira (2018) conducted a study aimed at understanding how much importance nurses assigned to nursing care documentation considering the NIS reformulation and comparing the main changes between the SClínico and the SAPE. Vieira’s results showed that, despite the importance nurses assigned to records, they considered that the change was not easy. They also identified as main limitations the deficit of institutional leadership, inadequate training, lack of human resources, and motivational issues.

Identifying CG-associated information in DP-related *foci* demonstrates nurses’ perceptions of the importance of documenting their activities. Nonetheless, it also reflects some difficulties in the registration process. Some studies

identify the lack of time, overwork, and even resistance to change as factors conditioning nurses' documentation (Huitzi-Egilegoret et al., 2018; Reis et al., 2016).

Vieira (2018) considers that nurses' unfavorable perceptions of the recent NIS change to the *SCLínico* can be explained by the teams' lack of monitoring during the change process, resulting in each service creating its strategies and hindering a documentation standard. "Teaching" interventions are the most representative. Nevertheless, "Instructing" and "Training" interventions are also documented, corresponding to the acquisition of skills for the new role. These types of interventions can reflect an approach focused on "knowing how to do" and CGs' need to acquire knowledge to meet the necessities of their dependent relatives.

Assessing CG burden, the QASCI's total score demonstrated a moderate level of burden (32.8 ± 21.4), which corroborates the data observed by Cunha (2018). In this study, the dimension Implications on the CG's personal life revealed higher values of burden, and the highest satisfaction was found in the dimension Perception of efficacy and control mechanisms, which is similar to the study conducted by Peixoto (2016).

Male CGs had more significant Family support, possibly due to the association of CG's role with women.

Elderly CGs had more considerable Implications on their personal life due to being a CG, as well as Family support. At the same time, adult CGs revealed greater "Satisfaction with the CG role and the family member." CGs with fewer years of education also had more substantial Family support, which can be associated with the variable Elderly CGs. Duarte et al. (2017) also associated these data with elderly CGs and demonstrated an association between a higher burden and CGs' health problems, also observed in this study.

The support from an additional CG proved to be positive for maintaining CGs' well-being, as CGs without support demonstrated higher levels of Emotional burden, Reaction to demands, and overall burden, and lower Family support. It is worth noting that these values cannot be generalized. Nevertheless, they point to the importance the literature gives to family CGs due to the positive impact they can have on the performance of the CG's role and the prevention/decrease of CG burden (Araújo & Martins, 2016). CGs who quit doing activities they enjoyed for taking care of their DPs revealed higher values of burden (Emotional burden, "Reaction to demands, and overall), justifying the relevance of the support of an additional CG or a formal support network (Peixoto & Machado, 2016).

Analyzing the documentation demonstrated that only six (3.7%) clinical files had records on the focus CGs. This underreporting reflects a limiting approach, considering nurses' privileged role in leading the multidisciplinary team in empowering CGs to maintain self-care and promote their well-being by implementing nursing interventions that prevent/reduce CG burden.

This study's CGs had been delivering care for 8.10 ± 7.0 years, and 18.1% revealed a severe and extreme burden. Thus, it is relevant to implement a more comprehensive

approach that includes assessing the stress levels of CGs (CG's knowledge of stress management and CGS). This approach must allow for the acquisition of data supporting the diagnosis and identification of interventions to maintain CGs' well-being and prevent/decrease CG burden (Peixoto, 2016; Peixoto & Machado, 2016).

Conclusion

The documentation found on CG-related *foci* in the period under analysis was limited. Nevertheless, there were records on DP-related *foci* that concerned CGs. This documentation revealed interventions very focused on instrumental care, with "Teaching" interventions being the most frequently recorded.

Analyzing the documentation revealed the lack of anticipatory care to promote CGs' well-being, which is still not a focus of nurses' attention.

Identifying CGs' needs and difficulties and comparing them with the observed underreporting strengthens the need for an approximation between the models in use and the models presented, thus translating into an improvement of the quality standards of nursing care for CGs.

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Author contributions

Conceptualization: França, D. C., Peixoto, M. J., Araújo, M. F., Festa, A. J.

Data Curation: França, D. C., Peixoto, M. J., Araújo, M. F.

Formal analysis: França, D. C., Peixoto, M. J., Araújo, M. F.

Investigation: França, D. C., Peixoto, M. J., Araújo, M. F., Festa, A. J., Santos, P. M.

Methodology: França, D. C., Peixoto, M. J., Araújo, M. F.

Visualization: França, D. C., Peixoto, M. J., Araújo, M. F.

Writing - original draft: França, D. C.

Writing - review & editing: França, D. C., Peixoto, M. J., Araújo, M. F., Festa, A. J., Santos, P. M.

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