REVISTA PORTUGUESA DE
ENFERMAGEM DE
REABILITAÇÃO

VOL. 6, Nº 2

Original article reporting clinical or basic research
DOI - 10.33194/rper.2023.339 | Electronic identifier – e339
Submission date: 09-06-2023; Acceptance date: 09-11-2023; Publication date: 13-11-2023

A INTERVENÇÃO DO ENFERMEIRO DE REABILITAÇÃO NA CAPACITAÇÃO DO CUIDADOR INFORMAL DO IDOSO DEPENDENTE POR AVC: UM ESTUDO QUASE-EXPERIMENTAL

THE INTERVENTION OF THE REHABILITATION NURSE IN THE TRAINING OF THE INFORMAL CAREGIVER OF THE DEPENDENT ELDERLY PERSON DUE TO STROKE: A QUASI-EXPERIMENTAL STUDY

LA INTERVENCIÓN DE LA ENFERMERA REHABILITADORA EN LA FORMACIÓN DEL CUIDADOR INFORMAL DEL ANCIANO DEPENDIENTE POR ICTUS: UN ESTUDIO CUASIEXPERIMENTAL

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How to cite: Maciel dos Santos AS, Fonseca MJ, Gomes J, Soares S, Ribeiro C. A Intervenção do Enfermeiro de Reabilitação na Capacitação do Cuidador Informal do Idoso Dependente por AVC: um estudo quase-experimental. Rev Port Enf Reab [Internet]. 13 de Novembro de 2023 [citado 23 de Novembro de 2023];6(2):e339. Available in: https://rper.aper.pt/index.php/rper/article/view/339

TECHNICAL FILE

eISSN: 2184-3023 pISSN: 2184-965X
www.rper.pt

INTELLECTUAL PROPERTY

Associação Portuguesa dos Enfermeiros de Reabilitação
www.aper.pt

The journal's editorial team can be consulted on https://rper.aper.pt/index.php/rper/about/editorialTeam
The journal's review team can be consulted on https://rper.aper.pt/index.php/rper/revisores

RESUMO

Introdução: Os cuidadores informais da pessoa com acidente vascular cerebral deparam-se com dificuldades no regresso ao domicílio, nomeadamente na aquisição de competências para o seu desempenho. Este estudo objetiva: avaliar os efeitos de um programa de enfermagem de reabilitação na capacitação dos cuidadores informais no autocuidado do idoso dependente por acidente vascular cerebral, no domicílio.

Metodologia: Estudo quase-experimental. Amostra constituída por cuidadores informais (n=15) de uma Unidade de Cuidados na Comunidade do norte de Portugal (amostragem não probabilística por conveniência). A capacidade do cuidador para os autocuidados: cuidar da higiene pessoal, transferir, posicionar, providenciar ajudas técnicas, usar o sanitário, alimentar/hidratar e vestir/despir foram as variáveis avaliadas antes e após a implementação do programa, que contemplou seis contactos baseados no ensino, instrução e treino de competências. Instrumentos de recolha de dados utilizados: Formulário de Caraterização do Cuidador Informal e Escala de Capacidades do Prestador Informal de Cuidados a Idosos Dependentes por Acidente Vascular Cerebral.

Resultados: A maioria dos cuidadores da amostra são mulheres e têm em média 59,9 anos (± 8,86). Em todas as áreas de autocuidado houve melhoria da sua capacidade após a intervenção, sendo mais significativa naquelas que inicialmente apresentaram maior dificuldade: vestir/despir, transferir, posicionar. Existiram diferenças estatisticamente significativas entre os dois momentos.

Conclusão: O programa de enfermagem de reabilitação influenciou favoravelmente a capacitação dos cuidadores informais para o autocuidado do idoso dependente por acidente vascular cerebral, no domicílio. Esta investigação oferece suporte às equipas de saúde para uma prática clínica significativa para as populações, corroborando o papel fundamental da intervenção individualizada do enfermeiro de reabilitação.

Descritores: Cuidadores; Acidente Vascular Cerebral; Idoso; Autocuidado; Enfermagem em Reabilitação.

ABSTRACT

Introduction: Informal caregivers of people with stroke face difficulties in returning home, such as in acquiring skills for their performance. This study aims to: evaluate the effects of a rehabilitation nursing program on the empowerment of informal caregivers for the self-care of dependent elderly persons due to stroke at home.

Methodology: Quasi-experimental study. Sample made up of informal caregivers (n=15) from a Community Care Unit in the Northern Portugal (non-probability convenience sampling). The caregiver's capacity for self-care: taking care of personal hygiene, transferring, positioning, providing technical aids, using the toilet, feeding/hydrating and dressing/undressing were the variables evaluated before and after the implementation of the intervention program, which included six contacts based on teaching, instruction and skills training. Data collection instruments used: Informal Caregiver Characterization Form and Skills Scale of Informal Caregivers of Dependent Older People Post-stroke.

Results: Most of the caregivers in the sample are women with an average age of 59.9 years old (± 8.86). In all areas of self-care, there was an improvement in their capacity after the intervention, being more significant in those that initially presented greater difficulty: dressing/undressing, transferring and positioning. There were statistically significant differences between the two moments.

Conclusion: The rehabilitation nursing program favorably influenced the empowerment of informal caregivers for the self-care of dependent elderly people due to stroke at home. This research supports health teams in meaningful clinical practice for populations, corroborating the fundamental role of the rehabilitation nurse's individualized intervention.

Descriptors: Caregivers; Stroke; Elderly; Self-Care; Rehabilitation Nursing.

RESUMEN

Introducción: Los cuidadores informales de personas con ictus enfrentan dificultades en el regreso a casa, principalmente en la adquisición de habilidades para su desempeño. Objetivo del estudio: evaluar los efectos de un programa de enfermería de rehabilitación en el empoderamiento de cuidadores informales para el autocuidado de ancianos dependientes por ictus en casa.

Metodología: Estudio cuasiexperimental. Muestra: cuidadores informales (n=15) de una Unidad Comunitaria del norte de Portugal (muestro no probabilístico por conveniencia). La capacidad de autocuidado del cuidador: cuidar el aseo personal, trasladarse, posicionarse, brindar ayudas técnicas, usar el baño, alimentarse/hidratarse, vestirse/desvestirse fueron las variables evaluadas antes y después de la implementación de la intervención, que incluyó seis contactos, basados en la enseñanza, instrucción y formación de habilidades. Instrumentos de recolección de datos: Ficha de Caracterización del Cuidador Informal y Escala de Capacidades de los Cuidadores Informales de Ancianos Dependientes por Ictus.

Resultados: La mayoría de los cuidadores de la muestra son mujeres con edad media de 59,9 años (± 8,86). En todas las áreas del autocuidado hubo una mejora en su capacidad tras la intervención, siendo más significativa en aquellas que inicialmente presentaban mayor dificultad: vestirse/desvestirse, trasladarse, posicionarse. Hubo diferencias estadísticamente significativas entre los dos momentos.

Conclusión: El programa de enfermería de rehabilitación influyó favorablemente el empoderamiento de cuidadores informales para el autocuidado de ancianos dependientes por ictus en casa. Esta investigación apoya a los equipos de salud en una práctica clínica significativa para las poblaciones, corroborando la importancia de la intervención individualizada de las enfermeras de rehabilitación.

Descriptores: Cuidadores; Accidente Cerebrovascular; Anciano; Autocuidado; Enfermería en Rehabilitación.

INTRODUCTION

The aging and increase of the population, associated with the progress of science and technology, has led to greater chronicity of illness and disability in health[1]. The number of people aged 60 or over will increase from 900 million to 2 billion between 2015 and 2050[2]. This growing trend towards longevity is not accompanied by living these years in good health[1].

Worldwide, stroke is one of the pathologies that most contributes to years of healthy life lost[1]. Stroke mainly affects the elderly population[2] and it is one of the main causes of death and disability in Portugal[3], with 40% of survivors who have moderate to severe disability, and who require specific monitoring[4].

In Europe, 80% of long-term care is provided by informal caregivers (IC), and their role can influence several dimensions of health: individual and social[5]. In Portugal, the value of the work carried out by ICs reaches almost 4 billion euros/year[5]. They face difficulties in the return to home, having the need of knowledge and support in skills acquisition that enables them to perform[6-8]. Family participation and social and community reintegration becomes a priority[9], especially from the perspective of IC training: "a person who provides unpaid care to someone with a chronic illness, disability or other health or long-term care need duration, outside a professional or formal framework"[5].

Training can be defined as a multidimensional process that involves knowledge, decision and action, being a sensitive indicator for rehabilitation nursing care[10]. Within the scope of the intervention with the IC, along with emotional support, teaching and training skills on basic self-care and support devices are fundamental educational areas, as well as guidance on health services and of the disease[6-7,11 -16]. Santos et al.[13] built and validated an educational nursing protocol for IC of elderly people after stroke, with guidance on: nutrition; airway; medication; hygiene; skin care; elimination; dressing/undressing; positioning and transfer; fall prevention; emotional support. An educational program aimed at the IC of stroke survivors, developed by Day et al.[15], lasting 1 month (3 home visits), included: guidance on health services; teaching about self-care, medication and other devices; guidance on causes/consequences of stroke; emotional support; provision of educational material, recommending that professionals should consider previous knowledge, experience and financial resources of ICs. Sequeira[8], in line with previous studies, also suggests the development of formal programs to provide IC with prioritizing information (illness, dependency, type of care) in the first phase; in a second phase, instrumental support (guiding, instructing, training on the provision of care) and in a third phase, the provision of support in terms of emotional and psychological support. Krieger, Feron and Dorant[16] also developed a program to support IC of stroke survivors, highlighting the importance of content being adapted to individual needs, long-term support and the program being carried out by a specialized professional trained in the area, which brings us to the importance of the Rehabilitation Nurses. Martins and Santos[17] point out that the main needs of IC are those related to the domains of self-care: personal hygiene, dressing/undressing, feeding, elimination and mobility.

Evidence has also demonstrated that educational programs based on the acquisition of IC skills for dependent elderly people due to stroke contribute to the reduction of cognitive impairment, anxiety and depression in stroke survivors[18], reduction of health costs[6,15],

the functional improvement of the survivor[6], the reduction of IC overload[12,15,18-20], satisfaction in the IC role[15,19], the improvement of the IC's practical capabilities[20] and also the improvement of their quality of life[15,21]. The IC's needs and their training depend on the time factor, being more effective the sooner it starts, not neglecting their follow-up over time[12,16]. The home environment, good communication and the implementation of adaptive strategies at home positively influence rehabilitation[6,12]. Telecare has also proven to be an added value in this area[12].

In Portugal, there are few studies that demonstrate the relevance and contents of these programs, particularly those that evaluate the IC's capabilities/training to assist in self-care using specific measurement instruments[11,20,22]. Araújo [et al.][20] evaluated the effectiveness of the InCare program in training the IC of dependent elderly people due to stroke, the results of which highlight the relevance of early and structured intervention in this context. The same authors developed the Capacity Scale of the Informal Care Provider for Dependent Elderly People due to Stroke (*Escala de Capacidades do Prestador Informal de Cuidados a Idosos Dependentes por AVC* - ECPICID-AVC)[23], revealing to be a reliable and innovative tool to support the assessment of the needs and capabilities of ICs for the self-care of dependent elderly people affected by stroke. This scale gained international dimensions and was adapted and validated for the Brazilian population and served as an assessment instrument in a study carried out in that country on 190 ICs, the results of which revealed that transfer and positioning were the activities that ICs presented the most difficulty due to the lack of guidance, regarding the appropriate posture to perform these tasks[11]. The relevance of these results rise due to the fact that the body mechanics principles by IC is barely used, when the majority of IC, associated with emotional exhaustion, presents osteoarticular pain, with the lumbar spine being the most affected body segment[24-25].

There is a lack of consensual and implemented practice of these programs[7,11], with emphasis on the role of rehabilitation nursing. The implementation of training programs for caregivers of people with stroke is a goal to achieve excellent practice and a line of action for policies that promote health gains. Within the scope of their competencies, the Rehabilitation Nurses have a preponderant role within the multidisciplinary team, as they intervene in the education of people and their families, evaluating and diagnosing limitations of the activity, in all aspects and phases of the life cycle and in all contexts of care practice, from acute to reintegration into the community, aiming at quality of life, reintegration and participation of the person/family in society[26].

Therefore, a study was developed with the aim of: evaluating the effects of a rehabilitation nursing program on IC training for the self-care of elderly people dependent on stroke at home, with regard to taking care of personal hygiene, transferring, positioning, provide technical aids, use the toilet, feed/hydrate and dress/undress.

METHODOLOGY

This is a quasi-experimental study of a single group[27].

The study took place in a Community Care Unit (CCU) in the northern region of Portugal, from December 2021 to January 2022. The study population corresponds to ICs that take care of dependent elderly people due to stroke, at home. Sampling was carried using the

non-probabilistic convenience sampling method[28], consisting of 15 participants (n=15). The inclusion criteria were: being an IC of a person aged 65 years old or over, dependent on at least one self-care activity after the first stroke event that must have occurred in the last 3 years; being over 18 years old; and do not present cognitive deficits.

The following statistical hypotheses (H) were formulated: The rehabilitation nursing program influences the IC's training to: H1 – assist with the personal hygiene of dependent elderly people due to stroke at home; H2 – assist in the transfer of dependent elderly people due to stroke at home; H3 – assist in the positioning of dependent elderly people due to stroke at home; H4 – provide technical assistance to dependent elderly people due to stroke at home; H5 – assist dependent elderly people due to stroke at home using the toilet; H6 – feed/hydrate dependent elderly people due to stroke at home; H7 – provide technical assistance for dressing/undressing dependent elderly people due to stroke at home. Thus, the IC's capacity for self-care: taking care of personal hygiene, transferring, positioning, providing technical aids, using the toilet, feeding/hydrating and dressing/undressing were the variables assessed before and after the implemention of the program.

The following data collection instruments were used: the IC Characterization Form and the Informal Care Provider Capabilities Scale for Dependent Elderly People with Stroke (ECPICID-AVC)[23]. The IC Characterization Form was created for the study, with the purpose of collecting sociodemographic and clinical data from the participants. The ECPICID-AVC is the first scale existing in Portugal to evaluate the different capabilities of ICs to assist the self-care of dependent elderly people due to stroke [11,23]. It presents 32 items rated from 1 to 4 points (1=not at all well prepared; 2=reasonably well prepared; 3=prepared; 4=very well prepared) and presents 8 factors: [1] ability to feed/hydrate through a tube; [2] ability to assist with personal hygiene; [3] ability to assist in transfer; [4] ability to assist with positioning, [5] ability to provide technical assistance; [6] ability to assist in using the restroom; [7] ability to feed/hydrate; [8] ability to provide technical aids for dressing/undressing[23]. It is important to note that the area of self-care feeding/hydration through a tube was not addressed in this study as the sample did not include IC of elderly people whose feeding/hydration was carried out through a tube.

Study participants were recruited by obtaining a list of all people affected by CCU, diagnosed with stroke in the last 3 years, in a computerized clinical record. Then the ranking began by evaluating the inclusion criteria. They only participated in the study after voluntary agreement, with validation through signing the declaration of free and informed consent. In addition to informed consent, other principles were also considered, namely the principle of beneficence, non-maleficence and autonomy, with subjects being able to leave the study at any time. The data was coded and processed in such a way that it was impossible to identify the participants. This study obtained a favorable opinion from the Health Ethics Committee (HEC) representing the place where the study was carried out: Opinion nº 71/2021. Furthermore, authorization to use ECPICID-AVC in the present study was requested from the authors, which received a favorable opinion.

During the first home visit, the IC Characterization Form was applied, as well as the ECPICID-AVC, through questioning and observation of the care provided. Over the following six weeks (between December 2021 and January 2022), the intervention program was implemented, which included six contacts (five in person and one via telephone), through individual

sessions held at the IC's homes, with the exception of the fifth session, which was carried out in a group, at CCU. Thus, the temporal difference between the first and last contact with each IC was 6 weeks.

An action plan was drawn up for the different sessions and the program was implemented by a single researcher (Rehabilitation Nurse), which minimized the possibility of bias. It was based on a literature review, that included teaching about stroke and the rehabilitation process; IC teaching, instruction and training on self-care (eating, personal hygiene, using toilet, dressing/undressing, transferring, positioning) according to: the degree of commitment and the potential for improvement IC knowledge and capacity on the use of self-care adaptation techniques and support devices; encouraging the share of difficulties and feelings; orientation to resources in the community; and a group training session at CCU, on the topic: Body Mechanics in the Mobilization of Dependent Persons. In the sixth session, the final assessment was carried out at home, using ECPICID-AVC.

Statistical analysis (descriptive/inferential) was performed using the Statistical Package for Social Sciences (SPSS), version 28.0. The internal validity of the ECPICID-AVC in this study was measured using Cronbach's alpha (0.918), indicating high reliability[28]. The level of significance (sig. or p-value) admitted in all situations was $p<0.05$, which means a confidence interval of 95%. To identify the type of test to be used in the treatment of the hypotheses, the data distribution was evaluated: when comparing population means of paired samples in relation to ordinal variables, the Student's t-test or Wilcoxon test was used, depending on whether or not the distribution is normal. In areas where distribution normality is verified, the parametric test was applied, as long as all assumptions for it were ensured[28]: interval or ratio variable (which is verified) and homogeneity of variance. The test statistic used to test homogeneity of variance was the student's t-test.

RESULTS

SAMPLE CHARACTERIZATION

The ICs in this study's sample are on average 59.9 years old (± 8.86) and the majority are female (73.3%), married (73.3%), retired (46.7%), have the elementary school as academic qualification (53.3%), with a monthly income between €500 and €1000 (53.3%), live with their dependent family member (73.3%) or their children (46, 7%). These IC spend, on average, 4.9 hours/day caring for their dependent family member and have been caring for them, on average, for 3.5 years (±5.01). Although the stroke of the elderly person being cared for occurred no more than 3 years ago, in some cases the ICs had already been caring for the elderly person for a longer time period due to the existence of other previous pathologies. The majority have the help of another caregiver (66.7%), and of these, the most frequent parental relationship (half of the cases) is also being the child of the dependent elderly person. The majority of ICs in this study did not have IC status (80%); only cares for one person informally (73.3%); and they were taught before being discharged home (53.3%), with the Integrated Continuing Care Unit being the most frequently mentioned location (62.5%). Regarding clinical aspects, the majority (66.7%) do not consider that their health status has worsened since caring for the elders, even though they experience musculoskeletal pain

associated with providing care, with a higher incidence in the lumbar region: 73, 3% claim to have pain in this region, with an average value on the numeric pain scale (END) of 5.3 (±3.92); followed by the wrists/hands region (60% of cases, with an average value of 4.5 (±4.02) in the END); neck (equally 60% and mean value of 3.8 (±3.74) in END); shoulders (53.3% of cases and mean value of 3.7 (±4.03) in END); hips/thighs (40% and mean value of 2.7 (±3.42) in END); knees (reported by 33.3% of IC and mean value of 1.8 (±2.68) in END); ankles/feet (26.7% of cases and mean value of 1.7 (±3.18) in END); elbows (with 20% and a mean value of 1.7 (±3.46) in END); and finally the thoracic region (13.3% of cases and with a mean value of 0.8 (±2.15) in the END). Thus, the lumbar region is the most affected region, either due to the frequency of complaints or their intensity.

IC'S CAPACITY FOR SELF-CARE OF ELDERLY DEPENDENT BY STROKE

With regard to the IC's capacity for self-care of dependent elderly people due to stroke, according to the ECPICID-AVC items (table 1), the data reveal that, in the initial assessment, the lowest scored items were "adopts principles of body mechanics during the positioning technique" (1.33±0.71) and "adopts principles of body mechanics during the transfer technique" (1.60±0.83). It appears that "provides necessary technical assistance to facilitate personal hygiene" was the lowest scored item (3.33±0.72) in the IC's ability to assist with personal hygiene (factor 2 of ECPICID-AVC); "provides necessary technical aids to facilitate dressing" was the lowest scored (3.0±1.00) in the IC's ability to provide technical aids (factor 5); as for assisting in the use of the toilet (factor 6), it was found that in the initial assessment the ICs already presented maximum capacity values and that they were maintained in the final assessment; "monitors swallowing" was the lowest scored item (3.53±0.74) regarding the IC's capacity to feed/hydrate (factor 7); in the IC's ability to provide technical assistance with dressing/undressing (factor 8), it appears that, in the initial assessment, the items present, on average, some of the lowest scoring values (2.79±0.89). After the intervention there was an improvement in all ECPICID-AVC items.

Table 1. Capacity of the IC for self-care of dependent elderly people due to stroke before and after application of the intervention program according to the ECPICID-AVC items (n=15). CCU of Northern Portugal, 2021-2022.

FACTOR	Item of ECPICID-AVC	Initial Assessment *Score*		Final Assessment *Score*	
		x (σ)	Min.-Max.	(σ)	Min.-Max.
7	Prepares the meal according to the prescribed diet	3.60 (±0.74)	2 - 4	3.93 (±0.26)	3 - 4
5	Places food on the plate on the side on which the elderly person is least dependent	3.75 (±0.62)	2 - 4	3.92 (±0.29)	3 - 4
7	Monitors food intake	4.0 (±0.0)	4 - 4	4.0 (±0.0)	4 - 4

FACTOR	Item of ECPICID-AVC	Initial Assessment *Score*		Final Assessment *Score*	
		x (σ)	Min.-Max.	(σ)	Min.-Max.
5	Provides necessary technical assistance to facilitate feeding	3.42 (±0.99)	1 - 4	3.92 (±0.29)	3 - 4
7	Monitors swallowing	3.53 (±0.74)	2 - 4	3.93 (±0.26)	3 - 4
2	Provides hygiene material	4.0 (±0.0)	4 - 4	4.0 (±0.0)	4 - 4
2	Assists in the bath	3.87 (±0.35)	3 - 4	4.0 (±0.0)	4 - 4
2	Assists with oral hygiene	3.85 (±0.56)	2 - 4	3.92 (±0.28)	3 - 4
2	Maintains a well-groomed appearance	4.0 (±0.0)	4 - 4	4.0 (±0.0)	4 - 4
2	Provides necessary technical aids to facilitate personal hygiene	3.33 (±0.72)	2 - 4	4.0 (±0.0)	4 - 4
6	Provides privacy when using the bathroom	4.0 (±0.0)	4 - 4	4.0 (±0.0)	4 - 4
6	Assists with intimate hygiene after using the toilet	4.0 (±0.0)	4 - 4	4.0 (±0.0)	4 - 4
6	Provides technical assistance necessary for using the toilet	4.0 (±0.0)	4 - 4	4.0 (±0.0)	4 - 4
5	Provides necessary technical aids to make dressing easier	3.0 (±1.00)	1 - 4	3.73 (±0.47)	3 - 4
5	Provides necessary technical aids to facilitate undressing	3.09 (±1.04)	1 - 4	3.73 (±0.47)	3 - 4
8	Watches the person get dressed	2.79 (±0.89)	2 - 4	3.93 (±0.27)	3 - 4
8	Watches the person undress	2.79 (±0.89)	2 - 4	3.93 (±0.27)	3 - 4
3	Assesses the person's ability to transfer	3.60 (±0.51)	3 - 4	4.0 (±0.0)	4 - 4
3	Adopts body mechanics principles during transfer technique	1.60 (±0.83)	1 - 3	3.40 (±0.51)	3 - 4
3	Explains to the person the transfer technique	2.60 (±1.12)	1 - 4	3.87 (±0.35)	3 - 4
3	Provides technical transfer assistance	3.58 (±0.52)	3 - 4	3.75 (±0.45)	3 - 4
3	Assist with transfer	3.67 (±0.62)	2 - 4	3.93 (±0.26)	3 - 4

FACTOR	Item of ECPICID-AVC	Initial Assessment *Score*		Final Assessment *Score*	
		x (σ)	Min.-Max.	(σ)	Min.-Max.
4	Adopts body mechanics principles during positioning technique	1.33 (±0.71)	1 - 3	3.22 (±0.44)	3 - 4
4	Positions in all positions	2.56 (±1.24)	1 - 4	3.56 (±0.53)	3 - 4
4	Provides technical positioning aids	2.33 (±1.12)	1 - 4	3.56 (±0.73)	2 - 4
4	Assesses the need to alternate positioning	3.47 (±0.83)	2 - 4	3.87 (±0.35)	3 - 4

x = average; †σ = standard deviation; ‡Min. = minimum; § Max. = maximum

If the items are grouped by self-care areas/ECPICID-AVC factors (table 2), the data reveal that the lowest initial mean IC capacity score concerns assisting with dressing/undressing (2.79±0.89), followed by transferring (2.97±0.56), positioning (3.00±0.97) and providing technical aid (3.27±0.71); on the other hand, the areas of self-care with higher mean initial values of IC capacity were assisting in the use of the toilet (4.0±0.0), taking care of personal hygiene (3.80±0.24) and feeding/hydrating (3.71±0.47). After the intervention, there was an improvement in the average score in all areas of self-care on the scale, with the exception of those who already obtained a maximum score in the first assessment, and there was a greater average increase in capacity in those who initially presented a lower score.

Table 2. Capacity of the IC for self-care of elderly people dependent on stroke before and after application of the intervention program according to the ECPICID-AVC factors (n=15). CCU of Northern Portugal, 2021-2022.

Factor of ECPICID-AVC	Initial Assessment *Score*		Final Assessment *Score*	
	x (σ)	Min.-Max.	(σ)	Min.-Max.
Ability to assist with personal hygiene	3.80 (±0.24)	3.2 - 4	3.93 (±0.26)	3.8 - 4
Ability to assist in transfer	2.97 (±0.56)	1.8 - 3,8	3.79 (±0.19)	3.4 - 4
Ability to assist with positioning	3.00 (±0.97)	1.5 - 4	3.71 (±0.31)	3 - 4
Ability to provide technical assistance	3.27 (±0.71)	2 - 4	3.79 (±0.33)	3 - 4
Ability to assist in using the restroom	4.00 (±0.00)	4 - 4	4.00 (±0.00)	4 - 4
Ability to feed/hydrate	3.71 (±0.47)	2.7 - 4	3.95 (±0.17)	3.3 - 4
Ability to provide technical assistance with dressing/undressing	2.79 (±0.89)	2 - 4	3.93 (±0.27)	3 - 4

x = average; †σ = standard deviation; ‡Min. = minimum; § Max. = maximum

HYPOTHESIS TEST

The IC's ability to assist in the toilet use was not part of the hypothesis test, as in the initial assessment all ICs obtained the maximum score on the ECPICID-AVC, which they maintained in the final assessment. Also, as already mentioned, the ability of the IC to feed/hydrate through a tube was not addressed in this study due to the characteristics of the sample. Despite the ECPICID-AVC being made up of 32 items and 8 factors, in this study, after the first assessment moment, only 26 items and 7 factors were operationalized.

Given the study sample size (n<30), the Shapiro-Wilk test[28] was applied to test whether or not the distribution was normal (table 3).

Table 3. Shapiro-Wilk test for the normality of distribution of the ECPICID-AVC items according to the factors that compose it (n=15). UCC of Northern Portugal, 2021-2022.

Factor of ECPICID-AVC	Statistic		Degrees of freedom		Sig.	
	Pre-test	Post-test	Pre-test	Post-test	Pre-test	Post-test
Ability to assist with personal hygiene	0.812	0.284	15	15	0.005	<0.001
Ability to assist in transfer	0.954	0.879	15	15	0.583	0.045
Ability to assist with positioning	0.851	0.845	15	15	0.018	0.015
Ability to provide technical assistance	0.885	0.674	12	12	0.100	<0.001
Ability to feed/hydrate	0.670	0.284	15	15	<0.001	<0.001
Ability to provide technical assistance with dressing/undressing	0.750	0.297	14	14	0.001	<0.001

*sig. = significance

There was no normal distribution of the sample with regard to the IC's ability to assist with personal hygiene (p<0.001), assist with positioning (p=0.015), provide technical aids (p<0.001), feed/hydrate (p< 0.001) and provide technical assistance with dressing/undressing (p<0.001), meaning the use of the non-parametric test is assumed: the Wilcoxon test.

After applying this test (table 4), statistically significant differences were found (p<0.05), allowing us to confirm that the rehabilitation program influenced the IC's training in self-care for elderly people dependent on stroke, at home, with regard to personal hygiene, positioning, providing technical aids, feeding/hydrating and dressing/undressing.

Table 4. Wilcoxon test for the IC Training variable for self-care of elderly people dependent on stroke (n=15). CCU of Northern Portugal, 2021-2022.

Factor of ECPICID-AVC	*t*	Sig.
Ability to assist with personal hygiene	-2.536	0.011
Ability to assist with positioning	-2.677	0.007
Ability to provide technical assistance	-2.678	0.007
Ability to feed/hydrate	-2.041	0.041
Ability to provide technical assistance with dressing/undressing	-2.889	0.004

**t* = test; †Sig. = significance

Regarding the IC's ability to assist in the transfer, after assuming normality of distribution (p=0.45), it was decided to apply a parametric test, taking into account that in the homogeneity of variance test for paired samples it was found there is a significant correlation (-7.229) (0.002) between the two moments. Thus, when carrying out the student t-parametric test for paired samples it was found that, in relation to the IC's ability to assist in the transfer, the p value (<0.001) is less than 0.05, meaning that there is a statistically significant difference between the two moments. Thus, it is possible to confirm that the rehabilitation program influenced the IC's training in self-care for elderly people dependent on stroke, at home, with regard to transfer.

The research hypotheses were therefore confirmed: H1, H2, H3, H4, H6 and H7. As for H5, given that the initial and final values remained at the same level (maximum value), there was no change with the intervention.

DISCUSSION

Regarding the characterization of ICs, most of the sociodemographic data are in line with data from several national and international studies: the majority of ICs are women, with an average age of around 50 years old and married[7,11-12,14 ,20-21,24,29], have low educational qualifications[11,20,24], have a monthly income between €500 and €1000 (or close to the national minimum wage) and live with a dependent family member[11,14,20,24]. Regarding the kinship relationship with the person being cared for, while in some studies, the majority of ICs are their children[11,20,24], in others the most frequent situation is being the spouses[7,12,14]. Also in relation to professional status, the data is disparate: in line with this study, the situation of retirement is the most frequent[21,24], but there are cases in which the ICs are in the situation of being employed[29] and still there are others in which they are unemployed[20]. The data also indicate that this characteristic varies depending on age – if the ICs are older, the retired status predominates, if they are younger or middle-aged, the employed status predominates.

Regarding the care provided by ICs, also in the study by Araújo et al.[20] and Da Silva et al.[14] the majority provided care for less than 6 hours/day, while Predebon et al.[11] speak about superior time of care: approximately 143 hours/week. With regard to time as IC, the results of this study are in line with the situation found by Matos and Araújo[24], differing

from other national and international studies[11,20] which speak of shorter times. This aspect may be influenced by the IC's eligibility criteria for the respective studies. Regarding the existence of another caregiver, the studies are consistent with the fact that the majority of ICs have the help of another caregiver, this being, in general, also a family member[11,20,24]. Regarding the application for IC status and the number of people cared for, the data from this study corroborate those from the national survey of the "Caring Movement for Informal Caregivers"[29], as the majority of CIs had not yet applied for the aforementioned status and provide care of a person in an informal way. The fact that the majority of ICs in the sample had received education before being discharged home but maintained the need for specific training in some aspect of care was also demonstrated in the aforementioned national survey[29] and corroborated by several authors[6-7,20].

In relation to clinical aspects, the majority of ICs do not consider that their health status has worsened, contrary to what was admitted in the study by Matos and Araújo[24], even though they manifest musculoskeletal pain associated with the provision of care, with a higher incidence and intensity of pain in the lumbar region, this time in accordance with data revealed by Matos and Araújo[24] and Saikai et al.[25].

Regarding the training of ICs of dependent elderly people due to stroke, particularly by area of self-care, it was found that, in relation to the ability to assist with personal hygiene, this was one of the areas in which ICs presented higher average scores, as early as the initial assessment. This well preparation of ICs in the area of personal hygiene is corroborated by the study by Predebon et al.[11], carried out on 190 ICs of dependent elderly people due to stroke in Brazil, as well as by Wu[30] who states that 60 to 75% CI demonstrates practical skills in this field, correctly carrying out self-care activities. However, in this context, it is one of the areas of self-care most frequently highlighted as central in IC education, as other studies point out[6-7,14,17,22,30]. In the present study, providing support products to facilitate personal hygiene and encouraging the elderly's autonomy are the most frequent interventions in this self-care, corroborating previous studies[11,17,22,30].

With regard to the IC's ability to assist with transfer and positioning, these were aspects of care with lower initial average scores on the ECPICID-AVC, including the items "adopts principles of body mechanics during the positioning technique" and "adopts principles of body mechanics during the transfer technique" the lowest scoring on the scale. These data are again in line with previous studies[11,17,22,24,25]. Predebon et al.[11] demonstrated that transfer and positioning were the activities that IC presented the greatest difficulty, due to the inadequate posture to perform these activities. This aspect reinforces the conviction that this evaluation and intervention by the Rehabilitation Nurse is fundamental, with individual and group intervention on this topic being an added value in this study. In the same way, the results of the study by Matos and Araújo[24] and Saikai et al.[25] point to transfer and positioning as areas that lack instruction and training given by health professionals and on which ICs demonstrates difficulties. From the point of view of alternating positioning, contrary to what is mentioned by Araújo[22] and Predebon et al.[11], it was necessary to reinforce this importance in order to prevent complications associated with immobility.

In relation to providing technical aids/support products, it was found that it was necessary to work with the IC, whose elderly people needed this support, to encourage their autonomy through their use. Examples were: cutlery thickener using a sponge; cutlery more suited

to the elderly's difficulties (thick handle); long-handled shoehorns or wooden box to make it easier to put on/take off shoes, as well as replacing clothes with buttons. The fact that Rehabilitation Nurses frequently use support products resulting from the adaptation of household materials, as well as the relevance of encouraging the autonomy of the elderly, instead of replacing their action, is also pointed out by Oliveira et al.[9]. The IC may tend to replace the elderly person so as not to expose their difficulties, despite their potential. Araújo[22], Wu[30] and Ribeiro et al.[31] also allude to this aspect.

Regarding food/hydration self-care, in addition to the interventions related to the previous factor, interventions related to monitoring signs of dysphagia, the correct use of the thickener and the consistency of the diet were fundamental. Although in the present study the average score values presented through the ECPICID-AVC in relation to this area of self-care are among the highest, it was essential to intervene with those who presented difficulties in this area, due to the high risk of important complications, such as breath infections by aspiration. These data are corroborated by those presented by Araújo[22], Martins Santos[17] and Pereira et al.[32]. Pereira et al.[32] demonstrate the importance that the Rehabilitation Nurses can have in the diagnosis and treatment of people with impaired swallowing after a stroke, as well as in the education of their caregivers, proving to be fundamental for the person's survival and safety. In the study by Predebon et al.[11], this was an area in which ICs did not presented relevant difficulties.

Regarding the IC's ability to provide technical assistance with dressing/undressing, an area with the lowest initial score, it was necessary to address the lack of knowledge on which side of the body should start dressing and undressing respectively. After teaching, instruction and training, there was a clear improvement on this ability. Again, the issue of not replacing the elderly people in what they are capable of doing, even if it takes longer, had to be encouraged. These are aspects that are in line with what was mentioned by Araújo[22], Wu[30] and Ribeiro et al.[31]. In the study by Predebon et al.[11], despite the existence of difficulties in approaching from the correct side, the IC's ability to dress/undress presented a high score.

Regarding IC training, the professional must know the real difficulties and needs, through an instrument that rigorously allows this assessment, as warned by Dixe et al.[33]. The ECPICID-AVC in the present study proved to be a reliable tool to support the assessment of IC needs and capabilities for the self-care of dependent elderly people after a stroke, and can be used in intervention programs structured by health teams. Rehabilitation Nurses have a preponderant role here given the scope of its specific skills, whether through basic self-care, the use of body mechanics principles or guidance in terms of technical aids/support products.

By carrying out this work, it is clear that programs based on education and training positively influence IC training for the self-care of dependent elderly people due to stroke, particularly in the home context and according to identified individual needs. These are fundamental from the point of view of excellent health care, which is in line with several studies[6,11-17,20,22], adding to the role of enabler that Rehabilitation Nurses have in this area within the scope of their competencies. We are left with the concern that, being a topic already widely studied and its importance being recognized, the lack of preparation for the role of IC remains evident, particularly upon return home, which is why there is an urgent need for a concrete and systematized implementation for the populations these types of programs.

CONCLUSION

This study allowed us to conclude that the rehabilitation program influenced the IC's training in self-care for elderly people dependent on stroke, at home, in terms of: taking care of personal hygiene, transferring, positioning, providing technical aids, feeding/hydrating and dressing/undressing. In all areas of self-care, there was an improvement in the IC's capacity to care for elderly people dependent on stroke at home, which was more significant in those areas that initially presented greater difficulty: assisting with dressing/undressing, followed by transferring and positioning. On the other hand, the self-care areas with higher average IC capacity values, before the intervention, were: assisting the use of the toilet and taking care of personal hygiene. The intervention in the area of assisting with feeding/hydration was of particular relevance for preventing serious complications associated with dysphagia. The literature is consistent when it comes to assisting in transferring and positioning, particularly in the use of body mechanics principles during these activities, but slightly more divergent in other areas of self-care, which brings us to the individuality of each person/IC/family.

Intervention in the area of IC training for the self-care of elderly people dependent on stroke must be in accordance with the specific needs of each individual, and this work contributed to the identification of these needs, adequacy of interventions and assessment of acquired capacity. The concrete and systematized implementation of this type of education and training programs in the role of CI, based on information and training, is reiterated. We highlight the significant role of Rehabilitation Nurses, whose intervention stands out for maximizing functional capacity and reintegrating the person/family into the community, using adaptive strategies and support products and identifying obstacles.

We point out as limitations of this study the small sample size and the program's time horizon. These were influenced by the temporal limitation of the study, which took place in an academic context: the extension of data collection and intervention would provide a more robust and consistent sample in its characteristics, as well as long-term monitoring of ICs with these needs. Another limitation is the fact that the vast majority of studies found on this topic do not refer to the assessment of the IC's capabilities for its role using instruments to measure this capability, which made the discussion of results difficult. Furthermore, we identified as a limitation the fact that the program was not subject to evaluation by experts.

More research is suggested in this area through the creation of instruments that assess the capabilities of ICs for self-care that is not restricted only to the population of ICs who care for elderly people dependent on stroke, as well as the impact in terms of health gains and reduction of the social costs of these training programs, through the Rehabilitation Nurses.

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ETHICAL DISCLOSURES

Contribution of the author(s):

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Data curation: A.S.; M.J.F.; J.G.; S.S.; C.R.

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All authors read and agreed to the published version of the manuscript.

Financing:

This work did not receive any financial contribution or grant.

Ethics Committee:

This study authorized by the Health Ethics Committee of the Local Health Unit of Alto Minho (Opinion nº 71/2021).

Declaration of informed consent:

Written informed consent to publish this work was obtained from participants.

Interest conflicts:

The authors declare no conflict of interest.

Provenance and peer review:

Externally peer reviewed.