


EDUCATIONAL INTERVENTION TO INCREASE THE SKILL OF INFORMAL CAREGIVERS: A QUASI-EXPERIMENTAL PILOT STUDY

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ABSTRACT

Objective: to compare the skill of informal caregivers to care for dependent people undergoing educational planning discharge intervention with and without follow-up at home.

Method: this is a quasi-experimental, randomized, simple pilot study, with pre and post-test, not blind, however, with blind assessment of the outcomes, with two follow-up interventions. It was carried out between October 2019 and January 2020 in Maringá, Brazil, with 21 informal caregivers of dependent people, randomized to Intervention Group I and Intervention Group II. Group I underwent an educational intervention consisting of guidance and training during the hospitalization period, with follow-up after hospital discharge by nurses at home, and participants in Group II received only guidance at the hospital. To assess the difference in the level of skill, the COPER 14 instrument was used, applied at times 0, week 1 and week 4, submitting the results to analysis of variance.

Results: group I had more than twice as much (mean score=8.94) of skill as Group II (mean score=3.90), with a significant increase in practically all the variables analyzed. A significant increase in the score ranks was detected between the variables cognitive and behavioral skill (1.19 - 3.00, $p=0.001$), psychomotor (1.13 - 3.00, $p=0.001$) and relational (1.75 - 2.75, $p=0.037$) in Group I.

Conclusion: the educational intervention given to the Intervention Group I (IG-I) was effective in increasing the skill of informal caregivers of dependent people. Brazilian Registry of Clinical Trials RBR-5rzmzf.

DESCRIPTORS: Caregivers. Nursing care. Health education. Transitional care. Comparative study.

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INTERVENÇÃO EDUCATIVA PARA AUMENTO DA COMPETÊNCIA DO CUIDADOR INFORMAL: ESTUDO PILOTO QUASE EXPERIMENTAL

RESUMO

Objetivo: comparar a competência de cuidadores informais para cuidar de pessoas dependentes submetidas à intervenção educativa de planejamento de alta com e sem acompanhamento no domicílio.

Método: estudo piloto quase experimental, aleatorizado, simples, com pré e pós-teste, não cego, porém, com avaliação cega dos desfechos, com dois seguimentos de intervenção. Realizado entre outubro de 2019 a janeiro de 2020, em Maringá, Brasil, com 21 cuidadores informais de pessoas dependentes, aleatorizados ao Grupo Intervenção I e Grupo Intervenção II. O Grupo I foi submetido à intervenção educativa composta por orientações e treinamentos durante o período de internação, com acompanhamento após a alta hospitalar por enfermeiros no domicílio, e os participantes do Grupo II receberam somente orientações no hospital. Para avaliar a diferença no nível de competência utilizou-se o instrumento COPER 14, aplicado nos momentos 0, semana 1 e semana 4, submetendo os resultados à análise de variância.

Resultados: o Grupo I apresentou mais do que o dobro (escore médio = 8,94) de competência que o Grupo II (escore médio = 3,90), com aumento significativo em praticamente todas as variáveis analisadas. Detectou-se significativo aumento nos *ranks* de pontuação entre as variáveis competência cognitiva e comportamental (1,19 – 3,00, $p=0,001$), psicomotora (1,13 – 3,00, $p=0,001$) e relacional (1,75 – 2,75, $p=0,037$) no Grupo I.

Conclusão: a intervenção educativa dispensada ao Grupo Intervenção I (GI-I) foi eficaz para aumentar a competência de cuidadores informais de pessoas dependentes. Registro Brasileiro de Ensaios Clínicos RBR-5rzmzf.

DESCRITORES: Cuidadores. Cuidados de enfermagem. Educação em saúde. Cuidado transicional. Estudo comparativo.

INTERVENCIÓN EDUCATIVA PARA AUMENTAR LA COMPETENCIA DEL CUIDADOR INFORMAL: UN ESTUDIO PILOTO CUASI-EXPERIMENTAL

RESUMEN

Objetivo: comparar la competencia de los cuidadores informales con el cuidado de personas dependientes que se someten a una intervención educativa de planificación del alta con y sin seguimiento en el hogar.

Método: estudio piloto cuasiexperimental, aleatorizado, simple, con pre y postest, no ciego, sin embargo, con evaluación ciega de resultados, con dos segmentos de intervención. Realizado entre octubre de 2019 y enero de 2020, en Maringá, Brasil, con 21 cuidadores informales de personas dependientes, aleatorizados al Grupo de Intervención I y Grupo de Intervención II. El grupo I se sometió a una intervención educativa consistente en orientación y formación durante el período de internación, con seguimiento tras el alta hospitalaria por enfermeras a domicilio, y los participantes del Grupo II recibieron únicamente orientación en el hospital. Para evaluar la diferencia en el nivel de competencia se utilizó el instrumento COPER 14, aplicado en los tiempos 0, semana 1 y semana 4, sometiendo los resultados a análisis de varianza.

Resultados: el Grupo I tenía más del doble (puntuación media=8,94) de competencia que el Grupo II (puntuación media=3,90), con un aumento significativo en prácticamente todas las variables analizadas. Hubo un aumento significativo en los rangos de puntuación entre las variables competencia cognitiva y conductual (1,19 - 3,00, $p=0,001$), psicomotora (1,13 - 3,00, $p=0,001$) y relacional (1,75 - 2,75, $p=0,037$) en el Grupo I.

Conclusión: la intervención educativa dada al Grupo Intervención I (GI-I) fue efectiva para incrementar la competencia de los cuidadores informales de personas dependientes. Registro Brasileño de Ensayos Clínicos (Registro Brasileiro de Ensaios Clínicos) RBR-5rzmzf.

DESCRIPTORES: Cuidadores. Cuidado de enfermería. Educación para la salud. Cuidado de transición. Estudio comparativo.

INTRODUCTION

Upon taking responsibility for caring for a dependent family member, subjects will undergo a process of transition to the role of caregiver¹. It is understood that this transition is a longitudinal, complex and multiphase event, which requires information and continuous training related to the understanding and implementation of tasks associated with care and self-care for a period that can extend for up to 12 weeks after hospital discharge². Frequently, the demands of these individuals go unnoticed by health professionals. A study carried out with informal caregivers of older adults identified that most participants had difficulty in exercising their role, which can negatively impact the health of all involved and the quality of care provided³.

However, it is known that the immediate phase after hospitalization, which occurs until the fourth week, consists of one of the most critical and distressing moments for caregivers and sick people, due to changes in daily life resulting from the care and instability of dependent people's clinical condition, exposing them to greater vulnerability⁴. Therefore, it is precisely during this period that it is necessary to develop tools that help caregivers to go through the transition in a healthy way, which are developed through information and training provided by health professionals⁵.

Numerous studies have been developed in order to implement interventions that optimize discharge, aiming at health education⁶⁻⁷. However, they did not address crucial issues for maintaining home care, such as managing unforeseen circumstances and skills necessary to develop safe and effective care outside the hospital environment, and also because they do not include family caregivers in care planning and implementation⁸⁻⁹. In this sense, a study found that more than 50% of patients reported difficulty in executing the hospital discharge plan, due to lack of subsidies, lack of post-discharge monitoring, inadequate training and lack of support from primary health care services².

Due to the scarcity of prospective studies that include family caregivers in discharge plans, associated with post-hospital discharge follow-up, aiming at continuity of care at home, a Pilot Study was necessary before conducting a Randomized Clinical Trial (RCT) at larger scale. Still, as the researcher Barbieri-Figueiredo defends¹⁰, due to the proximity of nurses in health services and the characteristics of their care, they can act as facilitators of the service approach to other professionals that make up the primary health care team, promoting the restoring health and individual and group autonomy.

In this perspective, the following question is asked in this study: which protocol has nursing interventions capable of increasing informal caregivers' skills and integrating the definitive study? This study aimed to compare informal caregivers' skills to care for dependent people who have undergone discharge planning educational intervention with and without home monitoring.

METHOD

This is a quasi-experimental pilot study, randomized, simple, with pre and post-test, not blind, but with blind assessment of the outcomes, with two intervention segments. CONSORT was used as a writing guide for non-pharmacological interventions¹¹. This study was carried out in order to identify which educational intervention protocol, conducted in a hospital environment, with or without follow-up at home, was effective, with the intention also to continue, later, with an RCT.

It was developed in the medical clinic of a public general hospital in Southern Brazil with informal caregivers of dependent people hospitalized in that institution. Caregivers aged 18 or over, being the main informal caregiver, residing in the municipality, literate, with no intention of changing the municipality during the research period and classified in the Mini Mental State Examination (MMSE) with scores between 22, 24 and 26, depending on education level¹² and with at least one phone contact and a cell phone with Android or IOS system, with the WhatsApp application and internet access were included.

For hospitalized dependent persons, those over the age of 18, hospitalized in the medical clinic of the referred hospital, with a minimum forecast of discharge, with an overall score on the Barthel Index between 10-30 points at the time of recruiting the survey were included¹³. Caregivers whose family members were transferred to a hospital or care institution other than home, who needed specialized health care, did not speak Portuguese, did not answer telephone contacts after three attempts on consecutive days were excluded. Discontinuity criteria were considered: a dependent person's death before the completion of educational interventions during hospitalization, changing the phone number and not informing the researcher.

For the sample calculation, the population hospitalized in the sector was used, estimated through retrospective data, obtained through a review of hospitalization control during 2018 and that met the inclusion criteria (n=192), adopting a confidence level of 95%; 20% of reserve units were raffled aiming at possible losses due to deaths, refusals and incomplete questionnaires (n= 22).

Data collection was carried out from October 2019 to January 2020. Recruitment was carried out for two months and follow-up for one month, totaling three months of follow-up. Of the 178 participants assessed, 26 were considered eligible for the study, which were randomly allocated using software, in two intervention segments: Intervention Group I (IG-I), submitted to the intervention in the hospital and at home, and Intervention Group II (IG-II), only in the hospital environment. At the end, of the 26 caregivers assessed for eligibility, 21 made up the sample; of these, 13 were randomized to IG-I, and eight to IG-II, and due to the discontinuity criterion, there was a sample loss rate of 50%.

The primary outcome was the performance regarding caregivers' skills to assist dependent people, measured using the COPER 14 instrument¹⁴, which allows the assessment of psychomotor (PS), emotional cognitive (ECS) and relational (RS) skills. It consists of 14 items: 1) *Identificar as limitações físicas da pessoa que você cuida* (Identify the physical limitations of the people you care for); 2) *Identificar os sinais e sintomas de piora da saúde da pessoa que você cuida* (Identify the signs and symptoms of worsening health of the people you care for); 3) *Identificar as necessidades de alimentação da pessoa que você cuida* (Identify the food needs of the people you care for); 4) *Identificar sinais e sintomas de desidratação da pessoa que você cuida* (Identify signs and symptoms of dehydration in the people you care for); 5) *Identificar os remédios que a pessoa que você cuida faz uso - horários, efeitos colaterais, indicações, contraindicação, alergias* (Identify the medicines that the people you care for use - schedules, side effects, indications, contraindications, allergies); 6) *Identificar expressões faciais (dor, raiva, felicidade) que a pessoa que você cuida pode apresentar* (Identify facial expressions (pain, anger, happiness) that the people you care for may present); 7) *Reconhecer sinais de alterações nas eliminações da pessoa que você cuida* (Recognize signs of changes in the eliminations of the people you care for); 8) *Quanto você se sente adaptado: com a rotina diária de cuidados* (How adapted do you feel: with the daily care routine); 9) *Quanto você se sente adaptado: em exercer o papel de cuidador* (How adapted you feel: to exercise the role of caregiver); 10) *Como você se sente em relação ao seu preparo para: administrar/ofertar os remédios* (How you feel about your preparation to: administer/offer the medications); 11) *Como você se sente em relação ao seu preparo para: avaliar a temperatura corporal da pessoa que você cuida* (How you feel about your preparation to: assess the body temperature of the people you care for); 12) *Como você se sente em relação ao seu preparo para: despir e vestir a pessoa que você cuida* (How you feel about your preparation to: undress and dress the people you care for); 13) *Como você se sente em relação ao seu preparo para: comunicar-se com a pessoa que você cuida* (How you feel about your preparedness to: communicate with the people you care for); 14) *Como você se sente em relação ao seu preparo para: estimular a autonomia da pessoa que você cuida* (How you feel about your preparation to: encourage the autonomy of the people you care for). The answers are of a Likert type, ranging from one to five, the results are grouped in quartiles, receiving the following classification:

up to 17 points, low skill, 18-35, little skill, 36-52, good skill and > 53, great skill. The general analysis of the items showed a Cronbach's alpha of 0.82¹⁴. The instrument was applied before randomization (point 0), in a hospital environment, to all caregivers who agreed to participate; after the first week of follow-up (at home), it was applied to IG-I participants; after 30 days of hospital discharge (4th week, at home), it was applied to all individuals who completed the intervention.

The instruments applied were the socioeconomic survey, proposed by the Brazilian Association of Research Companies¹⁵, Modified Barthel Index¹³, MMSE¹², and an instrument developed by the researchers, whose objective was to identify sociodemographic variables: sex, age, religion; and explanatory variables: experience in care, caregiver courses, leaving the job to dedicate to care, hours dedicated to care, comorbidities, use of continuous medications, presence of other caregivers; dependency time, use of devices, among others. These instruments were applied to all participants before randomization.

The interventions counted on the participation of nurses (doctors and doctoral students in progress) and statisticians, who were previously trained. The team responsible for applying the instruments, the hospital's health professionals and the statistician were blind. Participants were not blind. The interventions took place in two phases and were aimed only at informal caregivers, as described below.

Phase I, during hospitalization (IG-I and IG-II): Systematization of Nursing Care (SNC) was carried out, identifying the problems and the real needs of each dyad (caregiver-dependent person), the available resources, awareness, knowledge, expectations regarding this phase of health/disease transition (from an independent person to a dependent), and the situational transition, which is related to changing roles in the various contexts in which subjects are involved, especially when family members take over the role of caregiver¹⁵⁻¹⁶, which is the case of the subjects in this study. Preparation of discharge plan: based on participants' demands, identified in SNC, the main researcher (nurse) prepared, with caregivers, a discharge plan, from which health instructions (verbal) about the necessary care were given for follow-up at home - coping strategies and caregivers' self-care. Concomitantly with verbal guidelines, training in care techniques was carried out, which should be carried out at home. This care training was carried out with the dependent person, and, for this, a checklist with 13 items was adopted to verify the minimum aspects related to patient safety at home, provided by the Ministry of Health¹⁷. Allied to this, videos made available by the Youtube^{BR} channel, called the Innovation Portal - Innovation in SUS, Networks and PHC Management (*Portal da Inovação - Inovação na Gestão do SUS, Redes e APS, na playlist Atenção Domiciliar*), were used in the Home Care playlist, which contains 20 videos on care techniques for training caregivers, and participants could access them at any time. The topics covered were adapted to each case, and the general guidelines included doubts about the procedures, changes in roles and behaviors due to disability, expectations related to the performance of caregivers' roles, information on social assistance and request for available resources for the government. Specific interventions varied according to a dependent person's condition and involved guidance on enteral nutrition, handling of devices (nasogastric tube, gastrostomy, delayed vesical tube, tracheostomy and BIPAP - BI-level Positive Airway Pressure - BIPAP), orotracheal aspiration, use of oxygen at home and dressings.

For conducting educational interventions and training, a minimum of three meetings were held with each participant, with an average duration of 120 minutes each, in the hospital room itself. However, when there was a need, due to demand for care or caregivers' inexperience, more meetings took place. At the last meeting, the researches made available printed educational material for informal caregivers developed by the Ministry of Health¹⁸.

Phase II, at home, (IG-I): after hospital discharge, participants received two home visits, one until the seventh day of hospital discharge (1st week) and the other at the end of 30 days after hospital discharge (4th week). The follow-up time was determined based on the literature, whose systematic review supports that the immediate period after hospital discharge, considered to be up to 30 days, is the most critical for families returning home with a dependent person⁴, the first seven days being the most moment when there is a rapid transfer of responsibility for the health team's care to the family². Visits were previously scheduled with the participants as to the day and convenient time, and one day before the established date, the research team contacted to confirm the meeting. In addition to home visits, participants received phone calls and/or text messages sent via WhatsApp, in order to identify and manage possible problems that arose after discharge, including symptoms, doubts about medication administration, food and care, and detect possible hospital readmissions. These messages were sent on the 15th and 21st days after hospital discharge, as recommended by literature^{8,19-20}. It should be noted that the research team provided a telephone number for participants, who were able to contact her whenever necessary.

Data were double-tabulated in a Microsoft Office Excel, 2019 spreadsheet, and statistical analysis procedures were performed with the aid of the Statistical Package for Social Sciences (SPSS) software, version 20.0. Initially, data normality was identified by the Shapiro-Wilk test. For Group I, the Friedman test was used for analysis of variance, obtaining the median, standard deviation and confidence index, and also to verify possible difference or not between the three assessment points of that group. Subsequently, Friedman's analysis of multiple comparisons of related samples was used to detect which intervention differed from the others, assuming the adjusted value of $p < 0.05$, considering the intra-group comparisons for statistical significance. Group II was analyzed using the Wilcoxon test, as there are two assessment points in the study protocol.

This study was approved by a Research Ethics Committee and registered on the Brazilian Clinical Trials Registry (ReBEC - *Registro Brasileiro de Ensaios Clínicos*) platform. All ethical precepts contained in Resolution 466/2012 were respected, all participants were invited to read and sign the Informed Consent Form in two copies.

RESULTS

Twenty-one informal caregivers participated in this study, 13 in IG-I and eight in IG-II, as shown in Figure 1.

With regard to sociodemographic variables, no statistically significant differences were observed between groups IG-I and IG-II. Informal caregivers allocated to IG-I, 12 (93%) were female, with ages ranging from 25 to 74 years (mean=52 ± SD=12.84), being mostly daughters (n=6, 46%), followed by granddaughters and/or wives (n=4, 15%) who took care of a dependent person; eight (62%) were married, three (23%), divorced, and two (15%), single, and had an average of eight years of study (± SD=3.62). Of these, seven (54%) did not perform paid activities, eight (62%) belonging to class C1 and C2, and five (38%), to class B2.

As for IG-II, seven (88%) were female, aged between 50 and 69 years (mean=59 ± SD=12), all were married, half of whom were daughters and three (37%) were wives of the people who cared, had an average of eight years of study (± SD=3.73), six (75%) belonged to class C1 and C2, and two (25%), to class DE.

The time as an informal caregiver ranged from one month to 23 years, with the majority of participants, eight (62%) in IG-I and six (75%) in IG-II, performing the activity for less than a year and only four had previous experience in caring for someone with dependence (all from IG-I). Participants devoted more than 18 hours a day to caring for the family member (n=10, 77% IG-I and n=7, 87% IG-II).

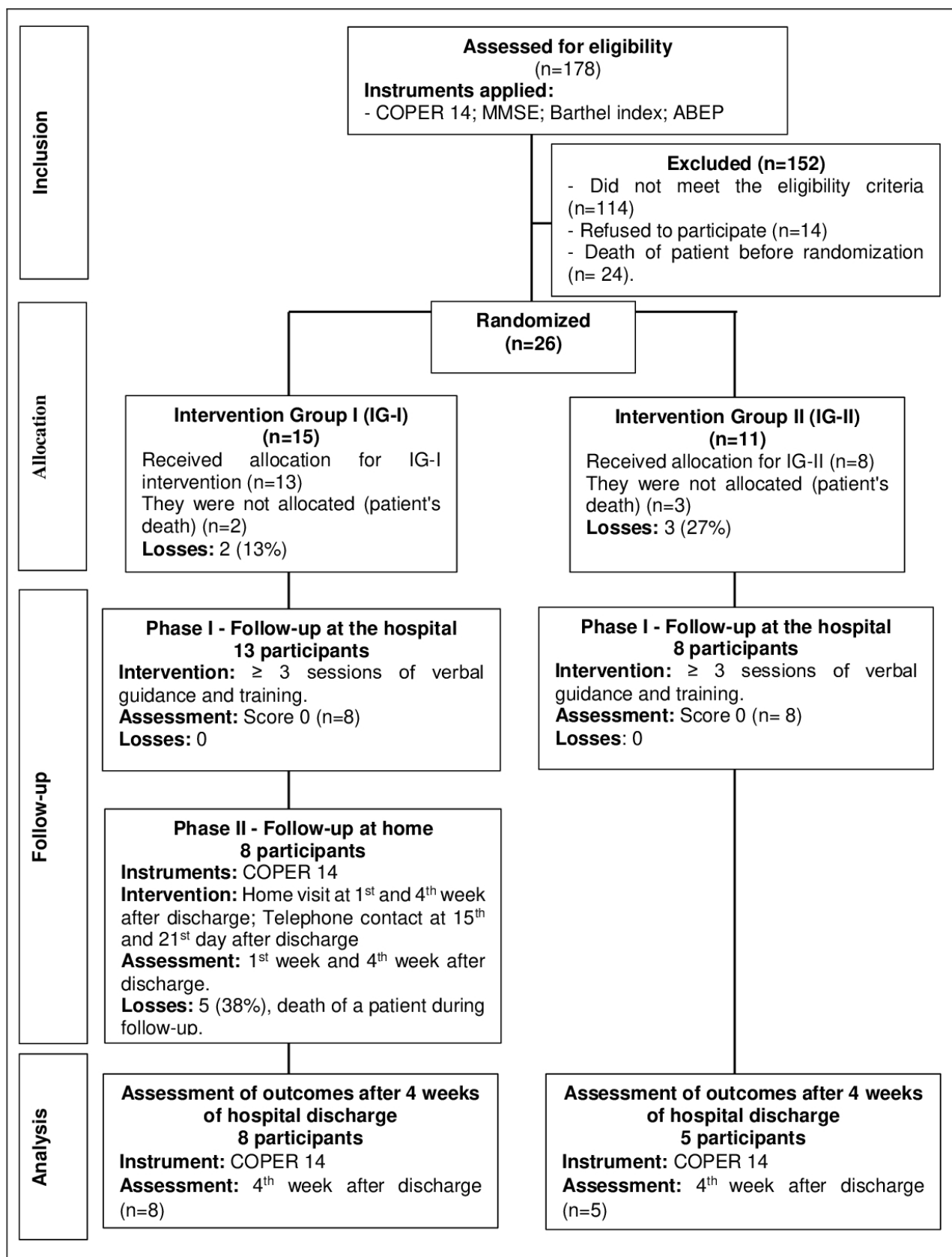


Figure 1 – Diagram of the flow of participants in each phase of this study according to CONSORT for non-pharmacological interventions. Maringá, PR, Brazil, 2020¹¹.

Also, five (38%) of IG-I caregivers and six (75%) of IG-II participants had to leave their professional and paid activities to dedicate themselves fully to care. It was noted that 10 (90%) of participants in IG-I had other people to help them in care; however, in IG-II only three (37%) could share such activities.

Regarding skill to care, in the zero assessment there was no significant difference, at the 95% confidence level, between IG-I and IG-II. However, in the 4th week of follow-up, the skill to care was significantly better in the participants of IG-I compared to the caregivers of IG-II ($p=0.0139$), Group I had an average score in COPER 14 higher than double (mean score=8.94) of the mean score obtained in Group II (mean score=3.90) (Table 1).

Table 2 shows the analysis of variance between the intervention groups IG-I and IG-II. In IG-I, almost all variables in the COPER 14 instrument showed a statistically significant difference between the assessment performed, except for variable 14, which comprises the encouragement of a dependent person's autonomy (2.50 ± 1.06 ; 3.00 ± 0.83 ; 3.50 ± 1.06 ; $p=0.142$). Variables related to dimensions and constructs also showed significance, with emphasis on the knowledge dimension (2.64 ± 0.46 ; 2.92 ± 0.41 ; 4.00 ± 0.44 , $p=0.000$) and cognitive skills and emotional (2.75 ± 0.51 ; 2.91 ± 0.39 ; 4.08 ± 0.36 , $p=0.001$) and psychomotor (2.70 ± 0.78 ; 3.20 ± 0.42 ; 4.00 ± 0.38 , $p=0.001$). IG-II did not present significant differences in any variable, according to Table 2.

In the analysis of intra-group comparison, the assessments performed at the zero point (allocation, in the hospital) and in the first week of follow-up (1st week, at home) IG-I did not show any significant difference regarding informal caregivers' skills. In the assessments between the zero point (allocation, in the hospital) and the fourth week of follow-up (at home), questions two (variables referring to the skill in identifying worsening in clinical conditions, $p=0.018$), three (feeding needs of dependent people, $p=0.037$) and overall average skills ($p=0.018$) were statistically relevant (Table 3).

As for ranks, increasing scores were detected between the zero point (allocation) and the fourth week of follow-up (at home), with the exception of variables one, eight and nine, which were slightly lower (1.38; 1.94; 1.44, respectively). This fact may point to the difficulty of maintaining care with quality and safety at home in the period immediately after discharge from a dependent person.

When analyzing the ranks of the instrument's dimensions, there was a significant increase in the variables knowledge and preparation compared to the assessment between point 0 (hospital) versus first week (home), and between the first and fourth week of follow-up. (home), whose scores increased almost three times (knowledge 1.06 - 3.00, $p=0.000$; preparation 1.25 - 3.00, $p=0.001$). The same was observed in cognitive and behavioral (1.19 - 3.00, $p=0.001$) and psychomotor (1.13 - 3.00, $p=0.001$) skills, with the relational skill also showing a significant increase in the score (1.75 - 2.75, $p=0.037$) (Table 3).

Table 1 – Wilcoxon test comparing skill between IG-I and IG-II caregivers for point 0 (hospital) and the 4th week of follow-up (home), Maringá, PR, Brazil, 2020. (n=21)

Assessment	N	Mean score	p-value
Point 0 (hospital)			
IG-I	13	11.23	0.4280
IG-II	8	10.62	
4th week (home)			
IG-I	8	8.94	0.0139*
IG-II	5	3.90	

*Significant at 95% confidence level ($p=0.05$).

Table 2 – Skill assessment of informal caregivers of dependent people in the hospital-home transition between IG-I and IG-II. Maringá, PR, Brazil, 2020. (n=13)

COPER 14 questions	Intervention Group I (IG - I)						Intervention Group II (IG - II)					
	Point 0 – Hospital		1st week -Home		4th week - Home		Point 0 – Hospital		4th week – Home		p †	
	Med±SD	95%CI	Med±SD	95%CI	Med±SD	95%CI	Med±SD	95%CI	Med±SD	95%CI		
1 – CES	3.00±0.70	2.65-3.85	3.00±0.75	2.37-3.63	4.00±0.64	3.59-4.66	0.002	2.50±1.21	1.39-3.93	3.00±0.63	2.33-3.66	0.317
2 – PS	3.00±0.70	2.15-3.34	3.00±0.53	2.55-3.63	4.00±0.46	3.86-4.64	0.002	3.00±0.51	2.12-3.20	2.50±1.21	1.39-3.93	1.000
3 – PS	2.50±0.88	1.50-2.99	2.00±0.91	1.61-3.14	4.00±0.70	3.16-4.34	0.003	2.00±0.51	1.12-2.20	2.50±1.04	1.39-3.60	0.102
4 – CES	2.00±0.51	1.19-2.05	2.00±0.70	1.66-2.84	4.00±0.53	3.55-4.45	0.001	2.00±0.75	1.04-2.62	2.00±0.75	1.37-2.95	0.317
5 – CES	3.00±0.75	1.86-3.13	3.50±0.53	3.05-3.95	4.00±0.64	3.59-4.66	0.002	2.50±0.54	1.92-3.07	3.00±0.75	2.73-3.59	0.102
6 – PS	3.00±1.16	1.77-3.72	3.00±0.46	2.86-3.64	4.00±0.64	3.34-4.41	0.012	3.50±0.54	2.92-4.07	3.00±0.40	1.24-3.41	0.317
7 – RS	2.00±1.03	1.38-3.11	3.00±0.83	2.34-3.41	4.00±0.64	3.34-4.41	0.010	2.00±0.40	1.40-2.26	2.00±1.03	1.80-3.86	0.414
8 – RS	3.50±1.12	2.18-4.06	3.00±0.51	1.86-3.39	4.00±0.75	3.37-4.63	0.011	2.00±1.03	1.58-3.75	2.50±0.98	1.43-4.22	0.655
9 – RS	4.00±1.06	2.48-4.26	3.00±0.64	2.34-3.41	4.00±0.53	3.55-4.45	0.030	3.00±0.89	2.06-3.93	2.00±1.32	2.33-3.66	0.785
10 – PS	3.00±1.18	1.63-3.61	3.50±0.74	2.75-4.00	4.00±0.35	3.58-4.17	0.006	3.00±0.40	2.40-3.26	3.00±0.63	2.33-3.66	0.655
11 – PS	3.00±1.16	1.77-3.72	4.00±0.51	3.19-4.06	4.00±0.53	3.55-4.45	0.006	2.50±0.81	1.80-3.52	3.00±0.51	2.79-3.87	0.102
12 - CES	3.00±0.75	2.36-3.63	3.00±0.53	2.55-3.45	4.00±0.70	3.16-4.34	0.006	3.00±0.40	2.73-3.59	3.00±0.40	2.73-3.59	1.000
13 - CES	3.00±0.70	2.65-3.84	3.50±0.53	3.05-3.95	4.00±0.51	3.94-4.81	0.002	3.00±0.40	2.73-3.59	3.00±0.83	2.62-4.37	0.317
14 - CES	2.50±1.06	1.73-3.51	3.00±0.83	2.18-3.57	3.50±1.06	2.74-4.51	0.142	3.00±0.63	2.33-3.66	2.50±1.16	1.60-4.06	0.705
General score	2.82±0.65	2.17-3.26	2.75±0.39	2.46-3.12	4.07±0.36	3.66-5.28	0.002	2.57±0.34	2.29-3.01	2.57±0.70	1.97-3.45	0.414
Dimensions												
Knowledge	2.64±0.46	2.09-2.87	2.92±0.41	2.54-3.24	4.00±0.44	3.62-5.27	0.000	2.42±0.26	2.10-2.66	2.50±0.70	1.97-3.45	0.285
Adaptation	3.50±1.03	2.38-4.11	3.00±0.75	2.11-3.88	4.00±0.59	3.50-4.49	0.009	2.50±0.93	1.85-3.81	2.25±1.12	1.65-4.01	0.655
Preparation	2.80±0.83	3.15-3.54	3.00±0.38	2.95-3.59	4.00±0.48	3.51-4.33	0.001	2.80±0.32	2.63-3.30	2.80±0.59	2.34-3.88	0.655
Construct												
CES	2.75±0.51	2.27-3.14	2.91±0.39	2.69-3.34	4.08±0.36	3.69-4.30	0.001	2.58±0.45	2.24-3.20	2.66±0.66	2.27-3.60	0.680
PS	2.70±0.78	1.97-3.27	3.20±0.42	2.76-3.27	4.00±0.38	3.63-4.26	0.001	2.70±0.16	2.49-2.83	2.70±0.64	2.26-3.60	0.461
RS	3.00±0.97	2.10-3.72	3.00±0.68	2.21-3.36	4.00±0.48	3.55-4.36	0.021	2.33±0.54	1.92-3.07	2.16±1.05	1.56-3.77	0.581

RS: relational skills; PS: psychomotor skills; CES: cognitive and emotional skills; Med: Median; SD: standard deviation; CI: confidence index; * Friedman's paired test; † Wilcoxon paired test

Table 3 – Multiple comparison between the interventions made to IG-I of informal caregivers of dependent people in the hospital-home transition. Maringá, PR, Brazil, 2020. (n= 13)

COPER 14 questions	Overall		Point 0 versus 1 st week		Point 0 versus 4 th week		1 st week versus 4 th week	
	X ²	DF	Ranks	p*	Ranks	p*	Ranks	p*
1 – CES	13.000	2	1.75	0.453	1.38	0.024	2.88	0.003
2 – PS	13.000	2	1.50	0.901	1.56	0.006	2.94	0.004
3 – PS	11.385	2	1.50	0.803	1.63	0.012	2.88	0.006
4 – CES	13.923	2	1.31	0.382	1.75	0.018	2.94	0.001
5 – CES	12.250	2	1.19	0.061	2.13	0.261	2.69	0.003
6 – PS	8.812	2	1.50	0.532	1.81	0.080	2.69	0.018
7 – RS	9.250	2	1.38	0.261	1.94	0.134	2.69	0.009
8 – RS	8.963	2	2.00	0.169	1.94	0.169	2.69	0.006
9 – RS	7.043	2	2.00	0.261	1.44	0.261	2.56	0.024
10 – PS	10.300	2	1.31	0.104	2.13	0.382	2.56	0.012
11 – PS	10.300	2	1.50	0.104	2.00	0.382	2.50	0.012
12 – CES	10.286	2	1.63	1.000	1.63	0.024	2.75	0.024
13 – CES	12.091	2	1.44	0.532	1.75	0.034	2.81	0.006
14 – CES†	3.909	2	1.63	-	1.94	-	2.44	-
General score	12.250	2	1.63	0.617	1.38	0.006	3.00	0.001
Dimensions								
Knowlwedge	15.548	2	1.06	0.080	1.94	0.034	3.00	0.000
Adaptation	9.500	2	1.94	0.211	1.31	0.104	2.75	0.004
Preparation	13.867	2	1.25	0.317	1.75	0.012	3.00	0.000
Construct								
Cognitive and behavioral skill	14.966	2	1.19	0.211	1.81	0.018	3.00	0.000
Psychomotor skill	15.200	2	1.13	0.134	1.88	0.024	3.00	0.000
Relational skill	7.7724	2	1.75	0.617	1.50	0.046	2.75	0.012

RS: relational skills; PS: psychomotor skills; CES: cognitive-emotional skills; X²: Chiman squared of the Friedman intergroup test; DF: degrees of freedom; *: robust significance; †adjusted significance, considering the levels of intra-group comparison; ‡multiple comparisons were not performed because the variable did not show any significant difference, maintaining the null hypothesis.

In this study, a limited number of participants was obtained associated with a high sample loss (50%), due to the fact that the unit has a reduced volume of participants that met the eligibility criteria, and part was due to the reduction in the number of beds available for admission at the time of recruitment. Also, as they are informal caregivers of individuals with total to severe dependence, in addition to patients' age (mean of 74 years), the clinical picture's instability led to a negative outcome - death. However, during the data collection period, it was observed that patients who progressed to palliative care had a higher lethality rate and were unable to complete the intervention. In this sense, patients' death has become the only reason for discontinuity in the intervention.

DISCUSSION

The results of this pilot study demonstrated that, despite the limited sample, there is a significant difference in cognitive, emotional, psychomotor and relational skill between informal caregivers submitted to the guidelines and training protocol during the hospitalization period, with follow-up after hospital discharge, by nurses at home. From this perspective, families that experience the transition process to exercise the role of caregiver, benefit from the implementation of programs to prepare for hospital discharge, because they have the potential to provide satisfactory answers to their needs in providing care to dependent people on their return to home²¹.

In addition, a randomized clinical trial conducted in Brazil, with people diagnosed with heart failure, who underwent a protocol similar to that adopted by this pilot study, showed greater therapeutic adherence ($p=0.0003$ relative risk=3.80), decreased readmissions ($p=0.0311$ relative risk=1.55) and deaths (5% relative risk=1.78) compared to participants in the control group⁶. Similarly, a randomized clinical trial conducted in Sweden, with informal caregivers of family members in palliative care, found that the psychopedagogical intervention resulted in a small but significant increase in preparation for care, both in the short and long term²².

Although the importance of adequate guidance during hospitalization is well documented by national and international literature^{2,5-6,23-24}, the results of this pilot study show that this alone is not sufficient to guarantee increased skill to informal caregivers' care.

The return home becomes an event in caregivers' lives, which, in general, is intertwined with dubious feelings, expressed by the desire and anxiety to return home, and this is understood as a safer place and that produces sensation comfort. However, the fatigue resulting from long periods of hospitalization, the loneliness to care, often experienced while still in hospital, when the other family members do not help with the relay of a companion, make the situation traumatic, generating stress, insecurity, impotence, and disorientation²³. In this sense, even though the guidelines during hospitalization are relevant to prepare caregivers to take over the role of care when returning home, the factors mentioned above can reduce their effectiveness.

The results of this pilot study indicated that there was no significant difference in the skill of caregivers allocated to IG-II, corroborating the understanding that, in addition to supporting strategies to return home, through health education, professionals' support after discharge, ensuring the identification of specific needs at regular intervals, in order to ensure the acquisition of skill and also its maintenance in the long term^{2,23}.

Similar findings were identified in a study developed with long-lived patients after admission to an Intensive Care Unit (ICU), whose patients and their families had doubts about the approach they should take in the face of emerging situations related to health conditions during the weeks or months that followed discharge. The scarcity of guidance in this critical period - return to home - can have serious consequences, such as the practice of harmful actions carried out inadvertently, consequently, the worsening of the health condition of people being cared for, which can generate feelings of guilt in caregivers⁵.

Regarding the results of IG-I, it was noted that the ranks for cognitive-behavioral and psychomotor skill had more than double the score between the assessments at zero point (at the time of randomization) and those carried out in the fourth week of follow-up. Such findings can be partly associated with the fact that, over time, informal caregivers incorporate care activities, disease management and the challenges that arise; however, in doing so, they experienced new demands for resources, information and support. Contrary to specific instructions, it is essential to develop tools to support them throughout the transition process, and the orientation strategies must be adapted to the changing needs that occur^{2,25}. Thus, it can be inferred that participants allocated to IG-I, when accompanied by a period considered critical for the transition process, had their new demands recognized by nurses, who inserted them into the care plan.

There was also a reduction in the score ranks in the first week after hospital discharge, compared to the assessment at the time of randomization. A study conducted in Italy, with caregivers of people with spinal cord injuries, identified that the willpower to face the situation collides with the decline in mental and physical health resulting from the routine of care and insecurity. The same study revealed that health and willingness to care can worsen with the return home, and in some cases, the decline occurs shortly after discharge²³. When relating the findings of this pilot study with the existing literature, it can be said that, to ensure the effectiveness of the intervention under the skill of informal caregivers and the consequent quality of the assistance provided, it is necessary to have a more present and constant monitoring, composed for more than one home visit and telephone contacts in the critical period following hospital discharge.

In this scenario, care routines are constantly established and reestablished, which requires greater attention from health professionals, especially nurses, as they are present in families' daily lives, identifying their difficulties and potentialities that influence the transition to care. caregiver role in a healthy way.¹⁶ Nursing therapies should focus on the assessment and the consequent implementation of individualized actions that meet the singularities of each family, promoting a more effective adaptation in the process of transition to the exercise of the required role of family members^{21,26}.

It is emphasized that the actions need to be concentrated, mainly, in the home environment, contemplating guidance on care, information on the family's health condition, in addition to adaptations in the physical environment, which can facilitate daily life and also accept caregivers' demands, promote a qualified listening of feelings and difficulties they face³.

In this context, the importance of a Home Care Service (HCS) stands out, which plays a strategic role to promote continuous post-hospitalization care for dependent individuals through a multidisciplinary team, contemplating the biopsychosocial aspects of both the sick and their families²⁷. A study carried out with families monitored by HCS identified the importance of these teams, but also highlighted the need to carry out a greater number of visits during the first month to the same patient; work in an integrated manner; build an individualized care plan, paying attention to the fact that informal caregivers are lay people, and that they demand attention from health professionals, so that they can have security and skill to care at home²⁵.

As a study limitation, the high rate of sample loss (50%) is cited, which resulted in a limited number of participants, which restricts the generalization of its effects. Another point was the absence of parameters to assess the effectiveness of the intervention during hospitalization, as COPER 14 was not applied at the end of the guidelines. It is recommended, therefore, its inclusion in the protocol of the definitive study. However, despite these limitations, the study consists of an initiative that, in addition to making it possible to fill the gap in literature, also contributed to the knowledge of barriers that can be adjusted in future replications.

In this sense, its conduction allowed the delimitation of parameters for the sample calculation of the definitive study, considering the high rate of sample loss. It is also possible to identify the need to adjust the eligibility criteria in relation to participants' ages and the episode of hospitalization, due to the high lethality rate, in addition to the exclusion of subjects who progress to palliative care. According to the results, it is recommended to continue the study, with a large and representative sample of patients, which will make it possible, in the future, to obtain categorical results, suggesting the use of only the intervention consisting of guidelines and training during hospitalization, with concomitant follow-up at home together with the control group.

CONCLUSION

The results of this pilot study demonstrated that the intervention consisting of guidance and training during the hospitalization period, with follow-up at home, through visits and telephone contacts after hospital discharge, was effective in increasing the skill of informal caregivers of dependent people, as proposed. From this perspective, the findings of this pilot study produced subsidies to understand the importance of nurses' actions for the successful transition of caregivers' role on the return from hospital to home, highlighting the singular assistance actions aligned with families' real needs. Although the intervention is complex, as it aggregates different components, its implementation is simple and requires only light technologies, enabling its replication in clinical practice, as it evidenced gains in health sensitive to nursing care.

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NOTES

ORIGIN OF THE ARTICLE

This study is a part of a dissertation - *Plano de alta qualificada para pessoas dependentes e seus cuidadores informais: ensaio clínico randomizado*, presented to the Graduate Program in Nursing of *Universidade Estadual de Maringá*, in 2021.

CONTRIBUTION OF AUTHORITY

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APPROVAL OF ETHICS COMMITTEE IN RESEARCH

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CONFLICT OF INTEREST

There is no conflict of interest.

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