ORIGINAL ARTICLE
Revista de Enfermagem do Centro-Oeste Mineiro
2022; 12/4538
DOI: http://doi.org/10.19175/recom.v12i0.4538
www.ufsj.edu.br/recom

Implications of informal health care of dependent people assisted at home after hospital discharge

Implicações do cuidado informal à saúde de pessoas dependentes assistidas no domicílio pós-alta hospitalar

Implicaciones de la atención informal para la salud de las personas dependientes atendidas en el domicilio tras el alta hospitalaria

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ABSTRACT

Objective: to identify the implications of informal health care for dependent people assisted at home after hospital discharge. **Method:** a cross-sectional study carried out with 41 dyads of informal caregivers-dependent people who were discharged home. Data were collected through questionnaires. Binomial Logistic Regression was performed. **Results:** leaving job activities increases the chances of caring for a person with a pressure injury by 55.79. The use of continuous medication was associated with the development of pressure injuries (OR=37.80), adverse events (OR=40.39) and death (OR=54.68). The time in hours dedicated to care reduces the chance of pressure injury (OR=0.81), the age of the caregiver decreases adverse events (OR=0.91) and death after discharge (OR=0.91). **Conclusion:** the implications were pressure injuries, adverse events and the death of the dependent person after hospital discharge, which were associated with the need to leave the job and the use of continuous medications.

Descriptors: Family Caregiver; Health of the Disabled Person; Comprehensive Health Assistance.

RESUMO

Objetivo: identificar as implicações do cuidado informal à saúde de pessoas dependentes assistidas no domicílio após a alta hospitalar. **Método:** estudo transversal realizado com 41 díades cuidadores informais-pessoas dependentes que receberam alta para o domicílio. Coletaram-se os dados por meio de questionários. Realizou-se Regressão Logística Binomial. **Resultados:** deixar as atividades laborais eleva em 55,79 as chances de cuidar de pessoa com lesão por pressão. O uso de medicamentos contínuos associou-se ao desenvolvimento de lesões por pressão (OR=37,80), eventos adversos (OR=40,39) e óbito (OR=54,68). O tempo em horas dedicado ao cuidado reduz a chance de lesão por pressão (OR=0,81), a idade do cuidador diminui os eventos adversos (OR=0,91) e o óbito após a desospitalização (OR=0,91). **Conclusão:** as implicações foram as lesões por pressão, eventos adversos e o falecimento da pessoa dependente após a alta hospitalar, as quais se associaram à necessidade de deixar o emprego e ao uso de medicações contínuas.

Descritores: Cuidador Familiar; Saúde da Pessoa com Incapacidade; Assistência Integral à Saúde.

RESUMEN

Objetivo: identificar las implicaciones del cuidado informal de la salud para las personas dependientes asistidas en el domicilio después del alta hospitalaria. **Método:** estudio transversal realizado con 41 díadas de personas dependientes-cuidadoras informales que fueron dadas de alta domiciliarias. Los datos fueron recolectados a través de cuestionarios. Se realizó Regresión Logística Binomial. **Resultados:** la salida de las actividades laborales aumenta en un 55,79 las posibilidades de cuidar a una persona con lesión por presión. El uso de medicación continua se asoció con el desarrollo de lesiones por presión (OR=37,80), eventos adversos (OR=40,39) y muerte (OR=54,68). El tiempo en horas dedicado al cuidado reduce la posibilidad de lesión por presión (OR=0,81), la edad del cuidador disminuye los eventos adversos (OR=0,91) y la muerte tras el alta (OR=0,91). **Conclusión:** las implicaciones fueron las lesiones por presión, los eventos adversos y la muerte de la persona dependiente después del alta hospitalaria, que se asociaron con la necesidad de dejar el trabajo y el uso continuo de medicamentos.

Descriptores: Cuidador Familiar; Personas con Discapacidad; Atención Integral de Salud.

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How to cite this article:

Rodrigues TFCS, Santos FGT, Silva ES, et al. Implications of informal health care of dependent people assisted at home after hospital discharge. Revista de Enfermagem do Centro-Oeste Mineiro. 2022;12:e4538. [Access_____]; Available in:_______. DOI: http://doi.org/10.19175/recom.v12i0.4538

INTRODUCTION

The world population is aging and the increase in life expectancy has been accompanied by chronic diseases and disabilities(1). Chronic conditions can result in dependence, staying for a short period, during rehabilitation, or indefinitely.

In Europe, the dependency rate of the senile population will practically double between 2016 and 2080, from 29.6% to 52.3%(2). In Colombia, 71.3% of people dependent on care were classified as having severe dependence(3). In Brazil, a study carried out with more than 1600 participants aged over 60 years found that 1200 had the frailty syndrome or pre-frailty, a biological syndrome that results in increased vulnerability of the individuals to the development of functional dependence(4).

From this perspective, informal caregivers play an important role, as they perform approximately 80% of the total hours of care for dependent people(5). An informal caregiver is defined as the person with or without family ties with the sick person who is responsible for helping the dependent person with in the basic and instrumental needs and who does not have professional training to carry out this task(1,6).

In Brazil, 82% of elderly people with dependency are assisted only by informal caregivers, and 62% are unpaid family members who live in the same household(7). Although informal care can reduce the financial burden of public health systems, by allowing dependent people to remain at home, avoiding hospitalization expenses(2), they can overload care providers, worsening their physical and mental health(8) , harming the offer of work or interrupting their leisure activities(6) and, consequently, affecting those who receive their care, object of investigation of this study.

Although aspects related to informal caregivers of dependent people that influence care are beginning to be explored(1,6), it is important to develop research in this context in order to support the planning of public policies and interventions focused on safety in care and support for caregivers. In this perspective, this research had the following question: what are the implications of informal health care for dependent people assisted at home after hospital discharge? And the objective was to identify the implications of informal health care for dependent people assisted at home after hospital discharge.

METHODS

This is a retrospective cross-sectional study in which data were collected from October 2019 to March 2020, as part of a larger project called “Preparation of informal caregivers of care-dependent patients during the hospital-to-home transition”, developed by a state university in the south of the country, described based on the STROBE initiative.

The target population consisted of the dyad of informal caregivers and dependent people who were hospitalized and discharged home. Participants were recruited during hospitalization at a general public hospital located in the Northwest region of the state of Paraná and data collection took place 30 days after hospital discharge, at home, through a visit carried out by prior appointment of a convenient date and time, applying the instruments selected for this study. Data collection was conducted by two previously trained nurses, who were studying to obtain their PhD degree.

The main outcome consisted of the implications of informal health care for dependent people, understood as the development of Pressure Injury (PI), adverse events, early readmission and the individual's death within 30 days after hospital discharge.

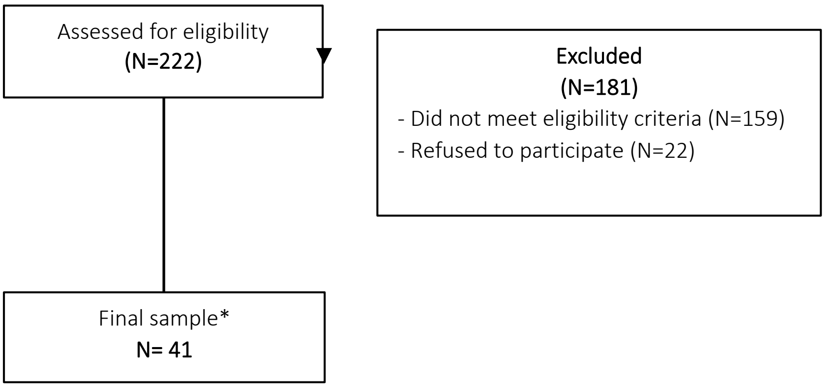
For the selection of participants, the following inclusion criteria were adopted: for the caregiver to be appointed as the main informal caregiver, aged 18 years or older, to be literate, classified in the Mini-Mental State Examination (MMSE), with scores between 22, 24 and 26, depending on the level of education(9), residing in the research municipality and not intending to change it during the study, and having at least one telephone contact; for the dependent person – undergoing hospitalization in the research hospital, in the medical clinic sector, classified as total to severe dependence, identified by the global score in the Barthel index of 10 to 30 points(10). Exclusion criteria: informal caregivers whose dependent person was transferred to another hospital or care institution, other than the home, and who did not respond to telephone contacts after three attempts on consecutive days.

Among the instruments used to detect the eligibility of dependent people, the Modified Barthel Index(10) was adopted and the MMSE(9) was used to select informal caregivers. For the socioeconomic stratification of the participants, the socioeconomic survey, proposed by the Brazilian Association of Research Companies(11) was adopted. These were applied only in the recruitment stage.

An instrument developed by the authors was used, containing the following variables: sex; marital status; age (in years, continuous variable); schooling (years of study); number of people per household; number of drugs used (polypharmacy ≥4); comorbidities (multimorbidity≥2 conditions); use of invasive devices (Indwelling Bladder Tube – IBT, Tracheostomy – TQT, Nasoenteral Tube – NET, Gastrostomy – GTT, Oxygen Catheter); dependency time (in months); time as an informal caregiver (in months); hours dedicated to care (≤12 hours, ≥12 hours – continuous variable); previous experience with care and the need to leave the job to dedicate themselves only to care; length of stay (in number of days); early readmission (one that occurs up to 30 days after hospital discharge); presence of PI; adverse events (infections, bronchoaspiration, diarrhea, vomiting, medication administration errors and falls); and death after discharge. These were applied to the participants, 30 days after hospital discharge, at home.

Sampling was by convenience. All eligible individuals hospitalized during the data collection period were invited to participate in the study. Among all 222 informal caregivers of hospitalized dependent people, 63 were considered eligible, however only 41 included the sample, as shown in Figure 1.

Figure 1 - Flowchart of entry of study participants. Paraná, 2020



*41 informal caregiver-dependent person dyads participated in the study.

Source: the authors.

Data were described using simple and crossed frequency tables for categorical variables. The information was double tabulated in a Microsoft Office Excel 2019 spreadsheet; inconsistencies were corrected and statistical analyses were performed using the R software version 4.1.1. The absolute frequency (n_i) was given by the number of times the variable assumed a certain value/category in question.

To estimate the association between the variables of informal care and the health implications of the dependent person (PI, AE, Early Rehospitalization and Death), the Binomial Logistic Regression model was used. The statistical model was adjusted using the Hosmer-Lemeshow test and residual analysis. As a measure of association between the variables of interest, odds ratios were calculated, as well as their respective 95% confidence intervals. Differences were considered significant when $p<0.05$.

The ethical precepts contained in resolution number 466/2012 were respected; all participants read and signed the Informed Consent Term, in two copies of equal content. Study was approved by the Ethics Committee for Research with Human Beings, under protocol number 2,698,239/2018.

RESULTS

The study included 41 informal caregivers-dependent people dyads. Among the informal caregivers, 33 (80%) were female, 32 (78%) were married, aged between 22 and 78 years (mean 52±15.30), 22 (54%) had more than 8 years of study (mean 8±3.77), 13 (32%) were unemployed, 28 (68%) were identified as consumption class C1-C2 and 5 (12%) DE.

Regarding the degree of kinship, it was identified that 15 (37%) caregivers are children, followed by 12 (29%) spouses. The number of people per household ranged from 2 to 18 (mean 5±3.37). Among the participants, 22 (54%) performed activities related to informal care for more than 6 months (mean 28.71±55.05). Only 9 (22%) caregivers had previous experience with care. These data did not demonstrate statistical significance in the model used.

As for the characterization of dependent people, the majority (22 - 54%) were female, aged between 19 and 93 years (mean 72.42±16.34), 20 (49%) were married and 17 (41%) illiterate (mean 4±3.77). According to the Modified Barthel Index classification, 26 (63%) were total dependents and 15 (37%) were severely dependent, and they had dependence for more than 6 months (minimum one month and maximum 23 years). Almost half of the dependent people (49%) had polypharmacy and 71% used invasive devices, such as IBT, TQT, NET, GTT, among others.

There were 12 (29%) readmissions within 30 days after hospital discharge, the length of stay ranged from 1 to 28 days (mean 9.16±9.14). It is noteworthy that half of the readmissions occurred within 7 days after dehospitalization. Readmission did not show statistical significance in the adopted model.

Table 1 – Binomial logistic regression between the variables of informal caregivers and the implications of care for the dependent person (PI, Adverse Event and Death). Maringá-Paraná, 2020

Variables	Pressure Injury			
	N(%)	OR	95% CI	*p*-value
Left the job				
No	28(68.30)		Reference	
Yes	13(31.70)	55.79	7.21 – 1301.45	0.001
Continuous medication use				
No	27(65.86)		Reference	
Yes	14(34.14)	37.80	3.49 – 1239.96	0.011
Hours of care per day*		0.81	0.63 – 0.96	0.038
	Adverse Event			
	N(%)	OR	CI 95%	*p*-value
Continuous medication use				
No	28(68.30)		Reference	
Yes	13(31.70)	40.39	4.35 – 801.63	0.004
Age (in years)†		0.91	0.83 – 0.97	0.009
	Death			
	N(%)	OR	CI 95%	*p*-value
Continuous medication use				
No	30(73.17)		Reference	
Yes	11(26.83)	54.68	4.69 – 1886.63	0.006
Age (in years)		0.91	0.83 – 0.97	0.017

*Continuous variable: for every 1 hour dedicated to care, the chance of the dependent person developing PI is minimized. †Continuous variable: every 1 year that the caregiver's age is increased, the chance of the dependent person having adverse events and dying 30 days after hospital discharge is minimized.

Source: the authors.

From the logistic regression model, it was identified that caregivers who left their work activities showed 55.79 more chances of assisting individuals with PI (*p*= 0.001). Also that dependent people whose caregivers used continuous medication were 37.80 times more likely to develop PI (p=0.011), 40.39 chances of experiencing an adverse event (p=0.004) and 54.68 chances of dying in up to 30 days after hospital discharge (p=0.006) (Table 1).

Receive cared of the older informal caregivers was a protective factor, in which, with each addition of 1 year to the caregiver's age, the probability of the dependent person developing an adverse event was reduced by 9% (*p*=0.009) e/or dying within 30 days after hospital discharge (*p*=0.017) (Table 1).

Thirty-five (85%) informal caregivers dedicated more than 12 hours a day to care (mean 15±5.15 hours). It was also noted that, for every 1 hour applied to care, the chance of the dependent person developing PI was reduced by 19% (Table 1).

DISCUSSION

The results of this study showed that the implications of informal health care for dependent people assisted at home after hospital discharge were the development of PI, adverse events at home and death, which were associated with the need for the caregiver to leave work activities and the use of continuous medication.

Similarly, research conducted in Italy identified that 94% of dependent people assisted by informal caregivers suffered urological complications, 45% pressure injuries, 38% spasticity, 24% chronic pain, 22% respiratory, 18% psychological and 11% nutritional problems(12). Nevertheless, the literature has shown that at least 22% of individuals who were discharged from the hospital experienced an avoidable adverse event during the first month at home, related to medication errors, infections or falls(13).

Returning from the hospital to the home is a complex and risky event, if there is no proper planning and monitoring of the people involved. Thus, the individual undergoing dehospitalization may become susceptible to functional decline and, consequently, suffer from unnecessary readmissions or premature death. Just transferring the responsibility for care to families, without adequate professional support, is undesirable and dangerous(14).

Although readmissions do not fit the statistical model, their relevance is emphasized. The 30-day readmission rate observed in this study was higher than that found in a study carried out with people with coronary syndrome in Brazil(15). Research developed in the USA observed that hospital readmission rates within 30 days can vary significantly according to chronic diseases, with 20.2% (cystic fibrosis), 19.8% (inflammatory bowel disease), 20.4% (spina bifida), 22.5% (type I diabetes) and 34.6% (sickle cell anemia)(16). It is also known that the difficulties experienced by caregivers in daily life can contribute negatively to the occurrence of readmissions(1); conversely, the guidelines provided by health professionals can avoid them, highlighting the role of nurses in the transition of care(17).

Regarding the time dedicated to care, it was observed that 85% of informal caregivers spent more than 12 hours daily on the related tasks. Similar results were observed in other studies(18-19). The time spent in care is configured as a protective factor for the development of PI, therefore, it is necessary for the caregiver to abstain from any other activity, which can be seen when it is verified that the participants who left the job had a nearly 56% chance of assisting a person with PI.

Thus, when caring for people with dependence, multidimensional implications can be developed, related to physical, psychological and emotional health, impacting the entire family system. The responsibilities imposed by care can interrupt social life and work activities(2), causing them to face particularly dangerous financial conditions. This scarcity of resources limits access to timely health care, making them vulnerable(6). This negatively impacts the person-dependent caregiver dyad, so that 68% of caregivers in this study had comorbidities and 66% used continuous medication. The latter was associated with the emergence of PI, adverse events and even the death of the assisted person. It is imperative to develop practical solutions to meet the needs of caregivers.

The findings of this study also suggest that the age of caregivers can act as a protective factor for the implications of care, being associated with a reduced chance of PI, adverse events at home and death after discharge. Such data differ from those found in a study carried out in Portugal, whose authors pointed out that as caregivers aged, they perceived themselves to be less capable of performing tasks related to care, such as food, mobility, medication and symptom management(1). However, this characteristic can be partly explained by the understanding that older individuals are more likely to have previous experiences with care and have more time to dedicate to these tasks.

It should be noted that the dependent people participating in this study were classified as having severe and total dependence, resulting in a high burden of complex care, which requires the handling of devices, administration of medication and enteral diet, manual dexterity for transfers, hygiene and mobilization, as well as the dedication of countless hours of the day to meet the basic and instrumental needs.

However, it is noteworthy that the time dedicated to care alone is not enough to guarantee the quality of care provided. It is known that, in order to perform all these tasks after hospital discharge, it is necessary for health professionals to guide and train informal caregivers, providing support for the construction and reconstruction of the routine, roles and management of the demands that may arise in this period(13-14).

Research developed in Portugal identified that the information received by caregivers was not sufficient to enable them to perform this task, with approximately 33% not being instructed on bathing, 27% on how to dress the patient, 26% on how to assist in using the bathroom or eliminations, 40% on financial support and 28% on auxiliary care equipment(1). In another study conducted in Italy, it was identified that caregivers wanted to receive more information about prevention and nutrition and, at the time of hospital discharge, they wanted guidance associated with home care and the side effects of the implemented therapy(20).

A study carried out in Mexico, with informal caregivers of patients with chronic diseases, identified a negative and statistically significant correlation between burden and care skills, with greater burden among caregivers with a lower level of competence(18). By observing the literature data and the findings of this study, it is inferred that the low competence of informal caregivers may be due, in part, to the fact that they do not receive adequate guidance from health professionals who provide them with instruments to perform care after hospital discharge.

From this perspective, monitoring and continuity of care should be carried out in the home environment, thus facilitating personal, family, social and professional integration(21). The continuity of care ensures the improvement of the quality of care provided, considering the demands of the patients and their families(22). It is important to emphasize the importance of covering the care plan and the demands not only of patients, but also of caregivers, since such non-compliance can compromise the caregivers' quality of life and harm (directly or indirectly) the health of the dependent person, the which was identified in this study as the development of adverse events and the death of the assisted person after hospital discharge.

Nurses are the main professionals responsible for health education actions and, consequently, for training informal caregivers(1), being considered strategic professionals, due to their proximity to the service and the community, so that they can act as facilitators in the articulation among the devices, the other members that make up the team and the families, promoting the reestablishment of health and individual and group autonomy(14).

As a limitation of the study, the small sample is pointed out, as a result of the COVID-19 pandemic, and it was necessary to interrupt data collection also because the participants were caregivers of people with a high degree of dependence, which restricted generalizations, from so that such findings may not reflect the reality of other populations. However, these findings can provide subsidies to health professionals, especially nurses, for the construction of a care plan appropriate to the educational and financial level, experience, knowledge, time and reality of informal caregivers, in order to promote home care with safe and quality, avoiding the decline in the health of the dependent person. From this perspective, the importance of teams training informal caregivers is highlighted, as they are active participants in care, and keep monitoring the dyads at home after hospital discharge.

CONCLUSION

Based on the results of this study, it can be identified that the implications of informal health care for dependent people assisted at home were the development of PI, the emergence of adverse events at home and the death of the individuals 30 days after hospital discharge. These implications were associated with the need for the caregiver to leave work activities and use medications of continuous use. On the contrary, the age of the caregiver and the longer the time in hours spent in care were configured as protective factors for adverse events and the death of the dependent person.

There is a need for health services to implement interventions that equip informal caregivers to assist dependent people at home, encouraging continuity of care, filling an important gap observed in the results. They should also be included in public policy discussion agendas in order to offer them better conditions to provide care after dehospitalization.

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Responsible editors:
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Note:
This study was financed in part by the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES) – Finance Code 001. Contemplated by CP 11/2020 - Programa Pesquisa para o SUS: Gestão Compartilhada em Saúde - PPSUS Edição 2020/2021 - 11/2020, funded by the Fundação Araucária.

This study is a part of a dissertation - Educational intervention to increase the competence of informal caregivers in the dehospitalization process: Randomized Clinical Trial. presented to the Graduate Program in Nursing of Universidade Estadual de Maringá, thesis defended in 2022.

Received in: 17/11/2021
Approved in: 14/06/2022