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THE BURDEN OF INFORMAL CAREGIVERS OF PEOPLE WITH PRESSURE INJURIES IN-HOME CARE

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ABSTRACT

Objective: To identify the overload of informal caregivers of people with pressure injuries in home care. **Method:** This is a descriptive and cross-sectional study carried out with 29 patients with pressure injuries and 29 informal caregivers, in March 2019, in the interior of São Paulo state, Brazil. An instrument was used to assess the sociodemographic and clinical profile of patients and caregivers, in addition to the Caregiver Burden Scale. **Results:** People with pressure ulcers were mostly men, elderly and with neurological problems. There was a predominance of female caregivers, with a mean age of 56 years. In the analysis of care overload, the most affected domains were isolation ($\bar{x}$ = 2.38), followed by general tension ($\bar{x}$= 2.31) and disappointment ($\bar{x}$ = 2.06). The mean total burden was 2.02. As factors contributing to the burden, age, duration of injury, time dedicated to care, degree of kinship between the caregiver and the person with pressure injury and the presence of health problems self-reported by caregivers stood out. **Conclusion:** Informal caregivers of people with pressure injury have subjective impacts measured by the burden scale, mainly in the domains of isolation, general tension and disappointment, as a result of the involvement of a family member. Understanding the overload experience of care overload can contribute to the development of care strategies for family members/informal caregivers, to reduce the risk of exhaustion and illness.

DESCRIPTORS: Pressure ulcer. Caregivers. Caregiver burden. Enterostomal therapy.

SOBRECARGA DE CUIDADORES INFORMAIS DE PESSOAS COM LESÃO POR PRESSÃO EM ASSISTÊNCIA DOMICILIAR

RESUMO

Objetivo: Identificar a sobrecarga de cuidadores informais de pessoas com lesão por pressão em assistência domiciliar. **Método:** Trata-se de um estudo descritivo e transversal realizado com 29 pacientes com lesão por pressão e 29 cuidadores informais, no mês de março de 2019, no interior de São Paulo. Utilizou-se um instrumento de avaliação do perfil sociodemográfico e clínico dos pacientes e cuidadores, além de escala de sobrecarga do cuidado (Caregiver Burden Scale). **Resultados:** As pessoas com lesão por pressão eram majoritariamente homens, idosos e com problemas neurológicos. Houve predomínio de cuidadoras mulheres, com média de 56 anos de idade. Na análise da sobrecarga do cuidado, os domínios mais afetados foram o isolamento ($\bar{x}$ = 2,38), seguido de tensão geral ($\bar{x}$ = 2,31) e decepção ($\bar{x}$ = 2,06). A média de sobrecarga total foi de 2,02. Como fatores contribuintes para a sobrecarga, destacaram-se idade, tempo de lesão, tempo dedicado ao cuidado, grau de parentesco entre o cuidador e a pessoa com lesão por pressão e presença de problemas de saúde autorrelatados pelos cuidadores.

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Conclusão: Os cuidadores informais de pessoas com lesão por pressão apresentam impactos subjetivos aferidos pela escala de sobrecarga, principalmente nos domínios isolamento, tensão geral e decepção, como consequência do envolvimento com o paciente por este ser um membro da família. A compreensão da sobrecarga experiência da sobrecarga do cuidado pode contribuir com a elaboração de estratégias de cuidados aos familiares/cuidadores informais, para reduzir o risco de desgaste e adoecimento.

DESCRITORES: Lesão por pressão. Cuidadores. Fardo do cuidador. Estomaterapia.

CARGA DE CUIDADORES INFORMALES DE PERSONAS CON LESIONES POR PRESIÓN EN ATENCIÓN DOMICILIARIA

RESUMEN

Objetivo: Identificar la sobrecarga de cuidadores informales de personas con lesiones por presión en la atención domiciliaria. **Método:** Este es un estudio descriptivo y transversal, realizado con 29 pacientes con lesiones por presión y 29 cuidadores informales, en marzo de 2019, en el interior de São Paulo. Se utilizó un instrumento para evaluar el perfil sociodemográfico y clínico de pacientes y cuidadores, además de la Escala de Sobrecarga del Cuidador. **Resultados:** Las personas con úlceras por presión fueron en su mayoría hombres, ancianos y con problemas neurológicos. Predominó el sexo femenino, con una media de edad de 56 años. En el análisis de la sobrecarga de cuidados, los dominios más afectados fueron Aislamiento ($\bar{x}$ = 2,38), seguido de Tensión General ($\bar{x}$ = 2,31) y Decepción ($\bar{x}$ = 2,06). La carga total media fue de 2,02. Como factores contribuyentes a la sobrecarga, se destacaron la edad, la duración de la lesión, el tiempo dedicado al cuidado, el grado de parentesco entre el cuidador y la persona con lesión por presión y la presencia de problemas de salud autoreferidos por los cuidadores. **Conclusión:** Los cuidadores informales de personas con IP tienen impactos subjetivos medidos por la escala de sobrecarga, principalmente en los dominios de aislamiento, tensión general y desilusión, como consecuencia del involucramiento de un familiar. Comprender la experiencia de sobrecarga del cuidado puede contribuir al desarrollo de estrategias de cuidado para familiares/cuidadores informales, para reducir el riesgo de agotamiento y enfermedad.

DESCRIPTORES: Úlcera por presión. Cuidadores. Carga del cuidador. Estomaterapia.

INTRODUCTION

Pressure injury (PI) is a worrying adverse event and a factor capable of aggravating the clinical status of patients. PIs form when pressure, friction, and/or shear cause localized damage to the skin and underlying soft tissues[1]. They tend to occur more frequently in people with reduced mobility, with changes in sensory perception, in the level of consciousness and peripheral circulation, with less nutrition than the body needs or immunosuppressed and exposed to constant pressure for an extended period of time.[2].

PIs also tend to occur more frequently in hospitalized patients2. In hospital units, the incidence rate of this adverse event varies widely, depending on the hospitalization sector[3–5]. However, previous studies indicate an increase in the prevalence rates of PI in patients at home at the international (9–12%)[6] and national (22.3–30.3%) levels[6,7].

It is noteworthy that caring for a person with PI in a home environment requires essential adaptations, which affect the caregiver's personal, emotional, social and professional life, especially if they are an informal caregiver[8]. Informal caregivers are usually family members, neighbors or close friends who provide informal and unpaid care support to people with chronic illnesses, disabilities or partial or total dependence[9].

The informal caregiver, when assuming the responsibility of offering care to a patient who needs attention in the home environment, often faces difficulties in performing this task due to the lack of ability regarding the necessary care, as well as in achieving the role of intercessor between the patients, families and health professionals. Due to a lack of care skills, most informal caregivers perform care intuitively, which can later generate high levels of burden[10].

Thus, health professionals, specifically nurses, should monitor the caregiver's preparation process and periodically assess the care burden provided to people with PI at home to minimize the care burden and preserve the quality of life of patients and caregivers[11]. In addition, little is known about the determinants of caregiver burden, especially in caregivers of people with wounds that are difficult to heal, such as PI, since most studies are carried out in hospitals.

Studies that assess the overload of informal caregivers are relevant for the construction of data that can support the implementation of educational programs, aiming to guide, assist, plan and implement improvements in the living and health conditions of informal caregivers who provide care at home, given that there is an increasing number of referrals of people at risk of developing PI from hospital units to home care[12,13].

This study aimed to identify the overload of informal caregivers of people with PI in-home care.

METHOD

The present is a descriptive and cross-sectional study carried out in a medical work cooperative of a private network in the state of São Paulo that provides home care services in 11 municipalities.

People with PI and receiving care at home, assisted by nurses who are team members responsible for treating skin lesions at the cooperative mentioned above, and their respective informal caregivers, were invited to participate in the study.

The inclusion criteria were: having PI at any stage, being at least 18 years old and being under the care of an informal caregiver. Regarding the caregiver, the following inclusion criteria were considered: being the primary caregiver, being over 18 years of age and being able to answer questions relevant to the study. Exclusion criteria were: not found at home (patient or caregiver) after the second interview appointment.

In the first stage of data collection, the identification of people with PI assisted by the cooperative was carried out through the analysis of the attendance reports for March 2019, obtained through the Incoway electronic medical record. Through this analysis, 30 people being monitored by the dressing team were identified. In the second stage, a face-to-face invitation was made to 30 people with PI and their caregivers through scheduled home visits, respecting their availability. There was one refusal to participate in the research, and thus, the final sample consisted of 29 people with PI and 29 caregivers.

Then, the interviews were carried out at home. The average duration of each interview was 30 minutes. The interviews were conducted in March 2019 by nurses specialized in the treatment of skin lesions, duly trained before the beginning of the research, for the application of the three data collection instruments.

Initially, a specific instrument was used to assess the sociodemographic profile (gender, date of birth, education, occupation, religion, marital status and income) and injuries of the person with PI according to the criteria of the National Pressure Injury Advisory Panel[14] (number of lesions, stage, tissue characteristics, presence of exudate, duration of lesion and anatomical location).

The second instrument[15] evaluated the sociodemographic profile of the caregiver (gender, date of birth, education, occupation, marital status, degree of kinship with the patient, time devoted to the care, remuneration and/or assistance for care activities, difficulties in care, absence from work employment to care for the patient, improvements in-home care with professional home care, self-reported illness and health treatment).

The third instrument consists of the care burden scale, known as CBScale, translated and validated for the Brazilian scenario16, composed of 22 questions, divided into five domains: general tension, isolation, disappointment, emotional involvement and environment. For each of the 22 questions, answers from 1 to 4 can be assigned; 1 = not at all; 2 = rarely; 3 = sometimes; 4 = often. The higher the value obtained by applying the instrument, the greater the impact/burden resulting from care. In addition, an overall care burden score or an individual score for each domain can be obtained. The global score is obtained by calculating the arithmetic mean of the 22 items and the score for each domain by the arithmetic mean of the values of each item that make up that domain.

The variables were presented according to the distribution of frequencies (absolute and relative), values (minimum, maximum and mean) and standard deviation. The care burden index was evaluated in its total score and dimensions:

general tension, isolation, disappointment, involvement and environment. For data analysis, the Prisma program was used, in which Pearson's correlation coefficient was performed for the variables classified as quantitative, and Kruskal-Wallis was applied to compare burden scores in groups of caregivers. Pearson's correlation intensity was classified as: null ($r = 0$), weak ($0 < r < 0.3$), moderate ($0.3 \leq r < 0.6$), strong ($0.6 \leq r < 0.9$), very strong ($0.9 \leq r < 1$) and perfect ($r = 1$).

The present study followed all the regulations of the National Health Council, in line with Resolution nº 466/2012, and was ethically approved by the Research Ethics Committee of the School of Nursing of Ribeirão Preto, University of São Paulo (opinion nº 3.204. 494). All patients and their respective caregivers agreed to participate in the study through written consent.

RESULTS

Of the 29 people with PI, 17 (58.6%) were men, 16 (55.2%) were between 60 and 79 years old, and 20 (69%) were married. Of the investigated patients, 11 had a neurological problem resulting from stroke, spinal cord trauma or myelomeningocele (37.9%). It was identified that 10 patients had dementia, such as senile dementia, Alzheimer's and other unspecified dementias (34.5%), in addition to three cases of orthopedic problems (10.3%).

As for the occurrence of PI, there was a variation of one to five PIs per person, making a total of 54 injuries, and 17 (58.6%) had only one PI. The time since PI onset ranged from two months to seven years, with a mean of 1.6 years (± 1.8 years).

Concerning the location of the PI, lesions were predominant in the sacral region (n = 20; 37%), trochanter (n = 14; 25.9%) and calcaneus (n = 10; 18.5%). Of the 54 PIs identified, 37 (68.5%) were stage 4, and 10 (18.5%) were classified as stage 3. Regarding the type of tissue in the PI bed, 37 (68.5%) had a tissue of granulation; six (24.1%) had sludge and granulation tissue; and five (9.3%) had necrosis and granulation tissue.

In the evaluation of the characteristics of the exudate, there was a predominance of serous exudate (n =38; 70.4%), and only two cases (3.7%) showed signs of infection. Despite the predominance of stage 4 LP, it is noteworthy that the majority had granulation tissue. Furthermore, the LP classification does not change during healing.

Of the informal caregivers, 26 (89.7%) were female and married, aged 56 years (± 13.6). Regarding schooling, 19 (65.5%) had eight or more years of study, including higher education; 11 (37.9%) were housewives; and eight (27.6%) retired. Only two caregivers had to leave their employment to dedicate themselves to care. As for the kinship of the caregiver with the person with PI, the presence of the daughter (n = 14; 48.3%) was observed more frequently, followed by the spouse (n = 12; 41.4%), and 23 (79.3%) of them lived in the same residence.

In the analysis of the care performance, 19 (65.5%) informal caregivers said they had no difficulties, and 10 (34.5%) mentioned having some difficulty in the correct care performance. Caregivers referred to the importance of support from health professionals who make up the home care team as facilitators of the process. Of the self-reported health problems among caregivers, 12 (41.4%) reported having some health problem, highlighting cases of diabetes mellitus, arterial hypertension, hypothyroidism and arthrosis.

When investigating care burden, it was observed that the highest mean CBScale scores were for the isolation ($\bar{x} = 2.38$), general tension ($\bar{x} = 2.31$) and disappointment ($\bar{x} = 2.06$) domains. There was a mean total burden score (2.02) (Table 1).

In analyzing the correlation between the person's age with PI and the scores of the CBScale domains, a negative correlation was identified in all domains except for the isolation domain ($r = 0.08$). Thus, it can be seen that, even with a weak correlation, advancing age follows a decrease in caregiver burden in almost all domains (Table 2). When evaluating the duration of the injury, a positive correlation was identified in general tension ($r = 0.22$), isolation ($r = 0.27$) and emotional involvement ($r = 0.05$). These results reveal that the longer the PI appears, the greater the caregiver burden. Particularly in the disappointment domain, a strong and statistically significant correlation was identified ($r = 0.41$; $p < 0.05$).

Table 1. Distribution of domain scores on the care burden scale (CBScale) applied to informal caregivers. Campinas (SP), Brasil, 2019.

CBScale domain	Minimum	Maximum	Mean	SD
Overall tension	1.13	4.00	2.31	0.90
Isolation	1.00	4.00	2.38	0.96
Disappointment	1.00	3.80	2.06	0.75
Emotional involvement	1.00	3.00	1.36	0.64
Environment	1.00	3.00	1.46	0.60
Total overload	1.14	3.14	2.02	0.63

SD: standard deviation

Table 2. Distribution of the correlation of overload scores (domain and total) and the variables age of the person with a pressure ulcer, time and number of injuries. Campinas (SP), Brasil, 2019.

CBScale domain	Age *R*	Injury time *R*	Number of injuries *R*
Overall tension	-0.09	0.22	-0.03
Isolation	0.08	0.27	0.21
Disappointment	-0.29	0.41*	-0.05
Emotional involvement	-0.16	0.05	-0.12
Environment	-0.09	-0.16	-0.13
Total overload	-0.14	0.27	-0.01

r: Pearson correlation coefficient; $*p < 0.05$; CBScale: care burden scale.

Negative correlations were also observed in the analysis of lesions in all domains except for the isolation domain. In this domain, in particular, there was a positive correlation ($r = 0.21$). Thus, the greater the number of PIs in the patient, the greater the caregiver burden.

Concerning the average scores inherent to the overload when performing care, in terms of the health problem of the patient with injury, a greater total burden was identified for caregivers of patients with dementia ($\bar{x} = 2.25$), orthopedic problems ($\bar{x} = 2.02$) and neurological ($\bar{x} = 1.91$). However, such differences were not statistically significant. There was a negative correlation between the age of informal caregivers and the care burden scores in all domains, except for the isolation domain ($r = 0.14$).

As for the self-reported presence of health problems by caregivers, there was overload in all domains of the scale and total overload (Fig. 1). A statistically significant difference was identified in the isolation domain ($p < 0.05$).

Figure 2 compares the care burden scores and the time the informal caregiver dedicates to care in hours per day. When evaluating the time devoted by informal caregivers to provide care to patients, 23 (79.3%) of caregivers reported that they were available for about 12 hours or more. This group's average care burden scores were higher in the overall tension domains, followed by isolation and disappointment.

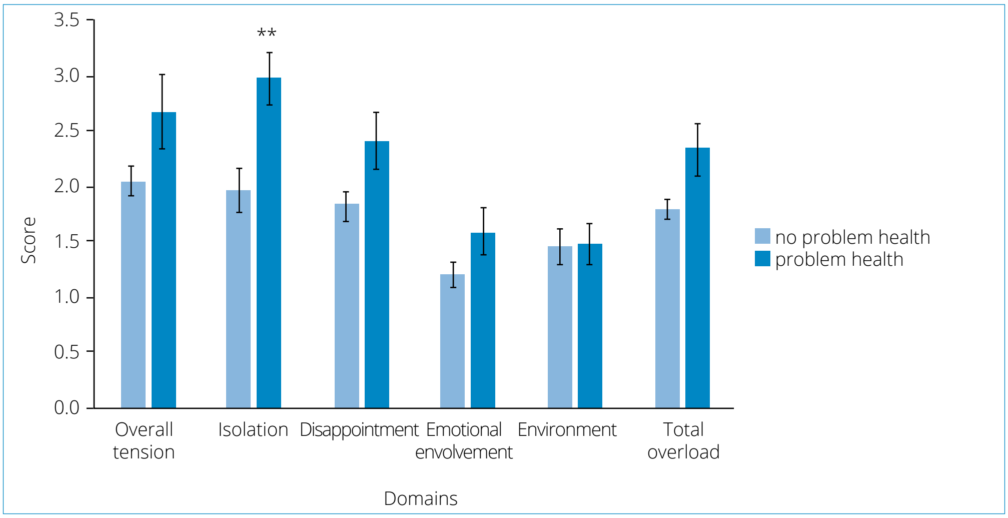

Figure 1. Distribution of care burden scale (CBScale) domains compared to caregivers' self-reported health problems. Campinas (SP), Brasil, 2019*.

* Mann-Whitney test; **p < 0,05.

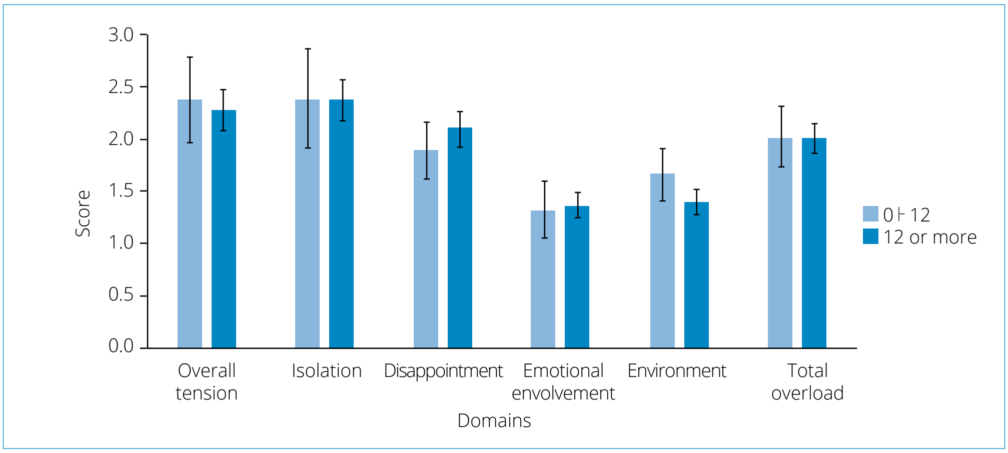

Figure 2. Comparison between the care burden scale (CBScale) scores, by domain and total, as a function of the time spent with daily care by informal caregivers. Campinas (SP), Brasil, 2019.

DISCUSSION

The profile of people participating in this study corroborates that of other studies of similar scope that highlight elderly men with predominantly female caregivers (daughters or wives) as the population most affected by PI.[8,11]. The predominance of elderly people can be justified by population aging, and advanced age is considered a risk factor for forming PI due to reduced physical mobility, greater dependence and skin fragility.

The study data reveal a predominance of people with only one PI, mainly in the sacral region. However, despite having a single lesion, people with PI require prolonged treatment for complete healing, requiring daily attention from the caregiver, which can promote care overload[17].

It is noteworthy that caring for a family member, friend or neighbor with a wound that is difficult to heal has been recognized as a source of overload that involves physical, psychological, emotional and social challenges. Furthermore, most of the time, the informal caregiver of people with PI performs an even more complex function since they are only sometimes qualified to prevent and/or care for injuries. Guidance for family caregivers is occasionally limited and vague, which leads to reduced capacity in care[18].

Informal caregivers participating in this study showed care overload in all domains evaluated. A meta-synthesis of qualitative studies about the patient's and caregiver's experience living with PI identified a high burden associated with care. Despite the burden, family members understood themselves obliged to provide this care[19].

The total burden of care was heavier for caregivers of people with PI and dementia, orthopedic problems and neurological sequelae. This finding may be related to these health problems reducing physical mobility or making patients bedridden, increasing caregiver dependency.

Caregivers with self-reported health problems had a more significant care burden, corroborating a study on the physical, emotional and social burden of informal caregivers of the elderly, in which caregivers with comorbidities experienced a greater burden[20].

The study's findings reveal higher mean CBScale scores in isolation, overall tension and disappointment. Caregivers' dedication to assisting people with PI involves considerable daily effort, requiring them to adapt their personal, family and professional lives. Their routine affects life habits, promotes changes in family dynamics, and impacts caregivers' leisure time, in addition to causing changes and absence from work, due to the weekly hours dedicated to care. These adaptations can generate isolation, feelings of tension and disappointment[8].

Danish researchers have shown that informal caregivers can spend 4 to 13 hours weekly on informal care[21]. Another consulted study revealed that informal caregivers dedicated themselves to home care five days a week, averaging 20 hours (± 7) daily. The minimum time was 6 hours/day, and the maximum was 24 hours/day[22]. In the present study, the mean scores for general tension, isolation and disappointment were higher for caregivers who dedicated 12 hours or more to care.

Evidence showed that the longer the time and number of injuries, the greater the burden on the caregiver. The reason may be that the time spent on care generally increases with the progression of the disease and the number of lesions. A study carried out with caregivers of people with PI in Goiânia (GO) identified that most caregivers are the spouse who lives in the same household, which increases the hours of care and, over time, leads to overload and negative psychic manifestations, such as anxiety, sadness and fragility[23].

This finding serves as a reference for health professionals who assist in-home care to pay attention to the application of standardized care, adequately guide caregivers, identify the burden of care and seek interventions that can help the patient's quality of life and that of the patient's caregiver[24].

The analysis of the overload of informal caregivers presents relevant subsidies for nursing practice, with the possibility of providing improvements regarding the planning of home care services for assisted people and their family members/caregivers, through support measures and strategies, formal preparation and adequate training of the caregiver, to reduce the possibility of negative repercussions inherent to the care provided[25].

Thus, to improve the assistance provided, it is necessary to create a bond between the informal caregiver and the support network, from preparing for hospital discharge to delivering the transition from care to the home environment safely and securely, with fewer difficulties for caregivers.

Limitations of this study include the reduced sample size and the delimitation of data collection in a given social and health scenario, not multicentric, as well as the absence of measurements of caregiver burden at different time intervals, which compromises the generalization of results.

New research on the subject is essential to expand knowledge about the overload in caring for people with PI, considering that prevention and management of PI can produce physical and psychological repercussions on informal caregivers, given the need for constant mobilization and specific care with the injury.

CONCLUSION

Informal caregivers of people with PI have subjective impacts measured by the burden scale, mainly in the domains of isolation, general tension and disappointment, as a consequence of involvement because the person with PI is a family member. Understanding the overload experience of care overload can contribute to developing care strategies for family members/informal caregivers to reduce the risk of burnout and illness.

It is up to the professionals who work directly in the home care scenario to consider the caregiver as a subject in the care process and who has individual needs that must be taken into account in addition to the role played as a caregiver to improve the individual and caregiver dyad, regarding the preparation of safe and quality care, with support for the caregiver in their limitations and difficulties experienced in the process, which can minimize the burden of care.

AUTHORS' CONTRIBUTION

Substantive scientific and intellectual contributions to the study: Fernandes AM and Rabeh SAN; **Conception and design:** Fernandes AM and Rabeh SAN; **Collection, analysis and interpretation of data:** Fernandes AM and Rabeh SAN; **Article writing:** Fernandes AM, Brandão MGSA, Teodoro ML, Vianna PC, Pereira MCA, Nogueira PC and Rabeh SAN; **Critical review:** Fernandes AM, Brandão MGSA, Teodoro ML, Vianna PC, Pereira MCA, Nogueira PC and Rabeh SAN; **Final approval:** Fernandes AM, Brandão MGSA, Teodoro ML, Vianna PC, Pereira MCA, Nogueira PC and Rabeh SAN.

DATA STATEMENT AVAILABILITY

All research data are available at the *Biblioteca de Dissertações e Teses da Universidade de São Paulo* (Dissertation and Theses Library of the University of São Paulo) (https://doi.org/10.11606/D.22.2020.tde-20112019-170926).

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REFERENCES

1. Mondragon N, Zito PM. Pressure Injury [Internet]. Treasure Island: StatPearls; 2022 [acessado em 22 jan. 2022]. Available at: https://www.ncbi.nlm.nih.gov/books/NBK557868/
2. Cicceri G, Vita F, Bruneo D, Merlino G, Puliafito A. A deep learning approach for pressure ulcer prevention using wearable computing. Hum Cent Comput Inf Sci. 2020;10:5. https://doi.org/10.1186/s13673-020-0211-8
3. Cascão TRV, Rasche AS, Piero KCD. Incidência e fatores de risco para lesão por pressão em unidade de terapia intensiva: Incidence and risk factors for pressure injury in intensive care unit. Rev Enferm Atual In Derme. 2019;87(25):1-8. https://doi.org/10.31011/reaid-2019-v.87-n.25-art.204
4. Lima Melo DP, Silva de Moura SR, Silva Rocha GM. A prevalência de lesão por pressão em um hospital escola. Recien. 2021;11(33):27-34. https://doi.org/10.24276/rrecien2021.11.33.27-34
5. Silva LL de O, Felix LG, Negreiros RV de, Abreu RA de. Prevalência e incidência de lesão por pressão em pacientes internados em unidades de clínica médica. Braz J Develop. 2022;8(3):16138-49. https://doi.org/10.34117/bjdv8n3-042
6. Santos SJ, Oliveira JC, Almeida CP, Magalhães FB, Pinheiro FGMS, Vieira RCA, Vasconcellos GMT, Jesus VMC, Santos ES. Occurrence of pressure injury in patients admitted to the intensive care unit. Rev Min Enferm. 2021;25:e-1367. https://doi.org/10.5935/1415.2762.20210015
7. Gama BG, Mola R, Fernandes FECV, Xavier SB. Prevalência e fatores associados à ocorrência de lesão por pressão em pacientes internados em unidade de terapia intensiva. Hu Rev. 2020;46(2):1-8. https://doi.org/10.34019/1982-8047.2020.v46.28248
8. García-Sánchez FJ, Martínez-Vizcaíno V, Rodríguez-Martín B. Barriers and facilitators for caregiver involvement in the home care of people with pressure injuries: A qualitative study. PLoS One. 2019;14(12):e0226359. https://doi.org/10.1371/journal.pone.0226359
9. Gonçalves JVRL, Vilabril F, Pereira M, Santos J. Cuidadores informais: um elemento fundamental na reabilitação. Rev SPMFR. 2019;33(1):1-7. https://doi.org/10.25759/spmfr.365

10. Rodrigues, AM, Ferreira PL, Ferré-Grau C. Providing informal home care for pressure ulcer patients: how it affects carers' quality of life and burden. J Clin Nurs. 2016;25(20):3026-35. https://doi.org/10.1111/jocn.13356

11. Ramos P, Borges C, Azevedo I, Almeida P, Soares A, Alves P, Magalhães A. Burden of informal caregivers of patients with pressure ulcers in a primary care setting. J Wound Care. 2022;31(10):864-71. https://doi.org/10.12968/jowc.2022.31.10.864

12. Mena LS, Zillmer JGV, Borges SF, Genz N, Soares ER, Barcellos CRB. Prevenção de lesão por pressão no domicílio: revisão integrativa. Braz J Hea Rev. 2020;3(4):8806-20. https://doi.org/10.34119/bjhrv3n4-126

13. Burston A, Miles SJ, Fulbrook P. Patient and carer experience of living with a pressure injury: A meta-synthesis of qualitative studies. J Clin Nurs. 2022;32(13-14):3233-47. https://doi.org/10.1111/jocn.16431

14. European Pressure Ulcer Advisory Panel, National Pressure Injury Advisory Panel and Pan Pacific Pressure Injury Alliance. Prevenção e tratamento de úlceras/lesões por pressão: guia de consulta rápida [Internet]. EPUAP/NPIAP/PPPIA; 2019 [acessado em 15 jan. 2022]. Available at: https://www.epuap.org/wp-content/uploads/2020/11/qrg-2020-brazilian-portuguese.pdf

15. Nogueira PC, Rabeh SAN, Caliri MHL, Dantas RAS, Haas VJ. Sobrecarga do cuidado e impacto na qualidade de vida relacionada à saúde de cuidadores de indivíduos com lesão medular. Rev Latino-Am Enfermagem. 2012;20(6):1048-56. https://doi.org/10.1590/S0104-11692012000600006

16. Medeiros MMC, Ferraz MB, Quaresma MR, Menezes AP. Adaptation and validation of the caregiver burden scale to Brazilian cultural milieu. Rev Bras Reumatol. 1998;38(4):193-9.

17. Boyko TV, Longaker MT, Yang GP. Review of the Current Management of Pressure Ulcers. Adv Wound Care. 2018;7(2):57-67. https://doi.org/10.1089/wound.2016.0697

18. Rafiei H, Vanaki Z, Mohammadi E, Hosseinzadeh K. The Role of Family Caregivers in Pressure Injury Prevention Guidelines: A Scoping Review. Home Healthc Now. 2021;39(5):253-60. https://doi.org/10.1097/NHH.0000000000001000

19. Burston A, Miles SJ, Fulbrook P. Patient and carer experience of living with a pressure injury: A meta-synthesis of qualitative studies. J Clin Nurs. 2023;32(13-14):3233-47. https://doi.org/10.1111/jocn.16431

20. Mendes PN, Figueiredo ML, Santos AM, Fernandes MA, Fonseca RS. Sobrecargas física, emocional e social dos cuidadores informais de idosos. Acta Paul Enferm. 2019;32(1):87-94. https://doi.org/10.1590/1982-0194201900012

21. Doser K, Norup A. Caregiver burden in Danish family members of patients with severe brain injury: The chronic phase. Brain Inj. 2016;30(3):334-42. https://doi.org/10.3109/02699052.2015.1114143

22. Santos DJ, Oliveira Limeira FN, Braz de Oliveira Alves V. Percepção do cuidador diante da lesão por pressão de pacientes atendidos na atenção domiciliar. Rev Enferm Atual In Derme. 2022;96(37):e021196. https://doi.org/10.31011/reaid-2022-v.96-n.37-art.1281

23. Galvin M, Corr B, Madden C, Mays I, McQuillan R, Timonen V, et al. Caregiving in ALS - a mixed methods approach to the study of Burden. BMC Palliat Care. 2016;15(1):81. https://doi.org/10.1186/s12904-016-0153-0

24. Shiferaw WS, Akalu TY, Mulugeta H, Aynalem YA. The global burden of pressure ulcers among patients with spinal cord injury: a systematic review and meta-analysis. BMC Musculoskelet Disord. 2020;21:334. https://doi.org/10.1186/s12891-020-03369-0

25. Aires M, Mocellin D, Fengler FL, Rosset I, Santos NO, Oliveira Machado D, Paskulin LMG. Associação entre responsabilidade filial no cuidado aos pais e sobrecarga dos cuidadores. Rev Bras Enferm. 2017;70(4):767-74. https://doi.org/10.1590/0034-7167-2017-0133